

*If I knew what would happen
I would have kept it to myself...*GENDER VIOLENCE
& HIV

Gender violence as both a cause and effect of HIV has long been recognised. It is also well-documented that high levels of sexual and gender violence exacerbate women's risks and vulnerabilities to HIV exposure and transmission, while a positive HIV status exacerbates women's risks and vulnerabilities to violence, abuse and other rights violations.

GENDER VIOLENCE AND HIV

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 need to address gender violence in its various forms as a key strategy for effective responses to women and HIV is widely recognised both at a national and global level. Violence needs to be *'dealt with as an integral part of multisectoral responses'*, and

...much greater investment should be made to address the intersection between HIV vulnerability, gender inequality and violence against women and girls.¹

The protection of women's rights, including women's sexual and reproductive rights, as well as the protection of rights of people living with, and vulnerable to HIV, are fully enshrined in South Africa's legislative and policy framework. The promotion and protection of rights are also the premise for the national response to women and HIV. In reality, however, women experience multiple layers, and a continuum, of violence and other rights abuses – ranging from interpersonal to structural to institutional – based on their 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 project intended to assess and document positive women's realities and experiences of gender violence based on and in the context of HIV; as well as to build an evidence and knowledge base on HIV-related violence and other rights abuses – so as to enhance women's access to, and benefit from available HIV prevention, testing, treatment, care and support services without fear of discrimination, abuse and other rights violations.²

The study took place in four areas, namely in New Brighton (Eastern Cape), Illovo (KwaZulu Natal) and Beacon Valley and Tafelsig (Western Cape). In total, 2354 community questionnaires were administered; six focus group discussions

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with women living with HIV, as well as service providers, were facilitated; 41 women were interviewed; and 80 incident forms were collated between April and September 2012.

The study design is based on the principled understanding that positive women's experiences of violence and other rights abuses are intrinsically linked to their communities' perceptions of the realities, rights and needs of women living with HIV. Thus, the study aimed to document women's experiences of violence, as well as communities' perceptions of violence against women living with HIV.

The study is further premised on a broad understanding of violence, incorporating structural, institutional and systemic violence as key aspects of violence experienced by women living with HIV. Within this context, violence is recognised as achieving and asserting power and control over others, and thus perpetuating and further manifesting the gendered and unequal context of society. This understanding of violence also implies that violence is, to an extent, accepted and condoned as part of normal social structures.

MAIN FINDINGS

...I must not be seen as a woman who is HIV positive, but as a woman who is a human being...³

The study clearly highlights the various forms and prevalence of violence against women living with HIV, and illustrates the multiple risks associated with women's HIV status disclosure. Women's experiences undoubtedly give evidence to the multiple forms and the continuum of abuse and violence in all aspects of their lives, perpetrated by partners, families, friends, communities and service providers alike.

Although indicating some levels of awareness and understanding among communities of violence perpetrated against women living with HIV, the study also demonstrates high levels of prejudice, stigma and discrimination prevalent against women living with HIV.

The findings further seem to suggest a degree of disconnect between women's realities upon HIV status disclosure and communities' perceptions of women's experiences as and when their HIV positive diagnosis becomes known.

Communities' perceptions of women's HIV disclosure consequences

...it depends, the ones who have knowledge about HIV they will support her, others will call her names and stigmatise her... [Woman, 30s]

The study shows community members' levels of awareness of the risks associated with women's HIV disclosure. Responses, however, also reveal that community members are more likely to perceive families and healthcare centres as sources of support for women living with HIV, as compared to communities and workplaces, which are seen as rejecting and discriminating environments.

Contrary to women's experiences of HIV disclosure, more than a third of community members participating in the study believed that women living with HIV would get 'support' and 'love' from family and household members, and more than half (65%) 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'.

The number of community members who felt that women would be 'rejected', 'treated badly', and 'discriminated against' as and when their HIV positive status becomes known varied greatly. While only 10% of participants believed that women would be at risk of ill-treatment and abuse based on their HIV positive status within healthcare provision, close to 60% highlighted the risk of rejection, abuse, and discrimination upon women's HIV disclosure at a community level.

...they will treat her differently; it will be unsafe for her...

[Woman, 40s]

In addition, the data indicates varying degrees of levels

of awareness of HIV disclosure consequences between the different areas, as well as between women and men participating in the study. For example, more than twice as many women participating in Illovo thought that women living with HIV would be at risk of 'ill-treatment' within healthcare provision, as compared to women in Beacon Valley. In the context of perceived reactions by families and communities to women's HIV status disclosure, the study shows that while men seem more aware of women's risks of violence and abuse within families, women are more aware of HIV-related stigma, discrimination and other rights abuses against women living with HIV at a community level.

Despite these levels of awareness of the risks associated with women's HIV disclosure within families and households, at a community level, within healthcare, and at the workplace, the majority of community members (78%) felt strongly that women need to disclose their HIV positive status. The data further shows that women were far more likely to believe in disclosing to families (26%), than to partners (16%). Contrary, twice as many men expressed the need for women to disclose to their partners (33%), as compared to disclosing to their families (16%).

...she needs to disclose to someone she trusts, because she needs all the support she can get... it's not easy getting used to living with HIV...

[Woman, 30s]

Recognising both communities' awareness of the risks for women to be subjected to HIV-related violence and rights abuses, and communities' perceived need for women to disclose their HIV status, the data seems to highlight a strong disconnect between beliefs that women's HIV disclosure is essential and the awareness and knowledge about the risks associated with women's HIV disclosure. As such, communities feel strongly that women need to disclose their HIV positive status, whilst knowing of women's potential risks of rejection, abuse and violence upon disclosure.

Women's experiences of HIV disclosure

...if I knew what would happen, I would have kept it to myself...

Women's experiences of HIV disclosure illustrate not only the multiple risks associated with women's HIV status disclosure, but also that women seem to encounter similar experiences, irrespective of their HIV status disclosure being voluntary or involuntary. Women's accounts also highlight as much a continuum of violence and abuse upon disclosure of their HIV positive status, as a continuum of people violating and abusing women living with HIV.

The majority of women participating 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.

...I was never abused before in my marriage, until I started asking for condoms during sex...

While some women, particularly in the Illovo sample, shared experiences of being chased away and asked to leave the family home after their HIV positive status became known, other women gave accounts of leaving their homes and moving away, due to the abuse and violence.

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

...this upset me so much and it became so unbearable that I moved away from that area...here, I don't tell anyone about my status and we are happy here...

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

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manner in which, their HIV status became known to families, friends and community members. However, even in situations whereby women decided when and how to disclose their HIV status to members of the community, most women did not receive the support they expected.

...although I was ready to disclose my status, the community was not ready to accept me...

Women's experiences of access to healthcare

...that's how people find out that you are HIV positive, when they see you at the clinic...

Women's experiences within healthcare provision undoubtedly account for the many barriers, including the fear and occurrence of disclosure, abuse, and ill-treatment, to not only access to healthcare, but also access to quality healthcare. Moreover, women's accounts also illustrate that healthcare provision is but one of the elements in the continuum of abuse and rights violations against women living with HIV.

The experiences of women arguably also indicate the extent to which especially healthcare providers' attitudes and prejudices against women living with HIV not only limits women's access to quality healthcare free of fear, stigma and discrimination, but also deters women from accessing healthcare.

Many women recalled 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...

Service providers' perceptions

...in my opinion, each person at the clinic must be treated equally... [Service providers]

Service providers' perceptions, especially among NGOs providing services to women living with HIV, indicate high levels of awareness and knowledge not only about women's challenges while accessing healthcare services, but also the seemingly inherent rights violations against women, due to the infrastructure of healthcare centres, as well as healthcare workers' attitude and prejudices against women living with HIV.

...if you look at the infrastructure of a health facility, you would very easily be able to identify why a person is at the clinic, which I think has huge consequences for women...
[Service providers]

...clerks and nurses at the clinic must change their attitude and try to be professional when addressing issues of women living with HIV... [Service providers]

Acknowledging the risks of rights violations within clinics and hospitals, the data further seems to suggest that services provided for women living with HIV by NGOs and community-based organisations are better positioned to respond to the realities, rights and needs of women and thus, highlighting the dire need for interventions aimed at enhancing women's access to healthcare services free of stigma, discrimination and other rights violations.

Communities' awareness of redress mechanisms

**...you don't have the right to discuss my private life
with anyone...** [Woman, 20s]

The data clearly indicates that communities are, to a certain extent, aware of and knowledgeable about 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.

Close to half of the community members participating in the study believed that women should take 'legal actions' against the person (or persons) who discloses their HIV status without their consent (41%), and against people who discriminate against women living with HIV (43%).

...it's against the law; she would have to go to the police...
[Woman, 40s]

Levels of perceptions of what redress is available to women living with HIV vastly differed between samples, highlighting among others the need for intensified awareness raising and rights education, especially in the communities of Illovo, Tafelsig and Beacon Valley. While, for example, only 32% of community members in Illovo thought that women should take 'legal actions' in cases of unlawful HIV disclosure, in New Brighton, 55% of respondents knew of women's rights to take legal actions.

...she must stand up and fight for her rights... [Woman, 20s]

However, a significant number of community members also thought that there is 'nothing women can do' in cases of unlawful HIV status disclosure (14%) and HIV-related discrimination (17%), as women 'should just ignore and go on with their lives', almost half of whom were from Illovo. In addition, several references were made, especially in Illovo and New Brighton, that women should 'move away' as response to their rights being violated.

**...she can move to another place, where they don't know
her...** [Woman, 30s]

The data also seems to suggest greater levels of awareness and knowledge about redress mechanisms in the context of women being discriminated against based on their HIV positive status, as compared to women's HIV status being disclosed without their consent. While these response patterns arguably illustrate that women's HIV disclosure without consent is not necessarily understood by community members as a form of discrimination, they also, to an extent, point to the common assumption at a community level that women need to disclose their HIV status.

Women's experiences of seeking redress

**...the community will keep on talking...at the end of the
month, how many people are you going to report...**

Women's experiences are a clear illustration of both the barriers to accessing legal redress, as well as the many challenges when pursuing legal actions against the perpetrators. The data further 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, especially in Illovo.

Fear of further abuse and humiliation, as well as feeling 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.

**...no, I don't want her to be arrested, at the end of the day,
we are family...**

Women, who sought legal redress, spoke generally of their disappointment with the lack of support received, including insufficient sentences as and when cases go to court. Women also spoke about being ridiculed by the police when trying to open a case; the lack of confidentiality at the police station; and the failure of police to adequately follow-up on cases or refusing to open cases.

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*...it was at the front desk, we were told not to open a case...
because she should just accept her HIV status...*

In women's accounts, the potential risks associated with taking legal actions combined with the failure of the police and courts to provide adequate recourse outweigh possible benefits from seeking redress. Subsequently, the fear of further abuse and humiliation by perpetrators; reluctance to lay charges against family members; and feelings of shame and embarrassment are as much deterrents to women's access to justice, as the risks of further HIV disclosure, and inadequate responses by police and the court structures.

*...I don't think you have the energy to go through that...
I think at the end of the day you do more harm to yourself...*

Communities' knowledge of rights protection for women living with HIV

*...what are the odds that they will have long and healthy lives
with children growing up... [Woman, 30s]*

While the data clearly indicates 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, the data also seems to suggest that women are more likely to believe that women's rights to make sexual and reproductive choices are limited by default, due to their HIV positive status. Furthermore the data seems to underscore the notion of blaming women for living with HIV, thus to an extent justifying the denial of sexual and reproductive rights and choices.

Community members' general lack of knowledge of women's rights is most evident with regard to communities' perceptions about women's right to engage in sex and have children upon an HIV positive diagnosis. While 17% of participants believed that women living with HIV should not engage in sex, a third of participating community members (33%) stressed that women living with HIV should not have children – for reasons of 'risk of transmission', and because women living with HIV are 'not supposed to' engage in sex and 'shouldn't get pregnant, because of their health'.

*...it's not right to have sex, when you have HIV...
[Woman, 50s]*

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

Similarly, prevailing stigma, prejudices and discrimination against women living with HIV is undoubtedly evidenced in almost a third of community members affirming that women, because of their HIV positive status should be encouraged to be sterilised (30%).

Responses from community members in the two areas of the Western Cape (Tafelsig and Beacon Valley) seem to suggest far lower levels of awareness, and thus implying that women living with HIV in these areas are at much greater risk of abuse and rights violations. For example, almost half of the respondents in these areas believed that women living with HIV should not have the right to have children (49% in Tafelsig and 47% in Beacon Valley), and should be encouraged to be sterilised (51% in Tafelsig and 47% in Beacon Valley).

*...they should be encouraged to make sure they don't get
children...for their own sake... [Woman, 30s]*

The data on communities' perceptions about the realities and rights of women living with HIV pertaining to sexual and reproductive choices also seems to confirm the realities of women living with HIV who experience abuse and violations, when they claim their sexual and reproductive rights to choose to have (more) children.

Communities' perceptions of women's risks 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]*

The study revealed some degree of 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. However, the data also shows the varying degrees of awareness and knowledge in the respective areas.

Almost half of participants (45%) agreed that women living with HIV are at greater risk of violence and abuse, with a higher percentage of women (47%), as compared to men (42%), believing that women are at risk of violence based on and in the context of HIV. Perceptions of women's risk differed greatly between the samples. While only 33% of community members in New Brighton believed in women's risks of HIV-related violence, 52% of participants in both Tafelsig and Beacon Valley affirmed that women living with HIV are at greater risk of violence and abuse.

Further explaining their responses, 36% of community members made reference to women being '*treated badly*' and '*discriminated against*' because of their HIV positive status, while an additional 36% also mentioned that women living with HIV are '*abused*', '*beaten by their partners*', '*called names*', and '*forced to have sex without a condom*'.

...women are beaten up, others gossip about her and others don't want to eat with her... [Woman, 40s]

Community members' recommendations for change mostly stressed the need for '*awareness and education*' (37%), while 15% re-emphasised the need for women living with HIV to '*take legal actions*' as and when they are abused and violated.

...women living with HIV must report these incidences to the police, so that people will learn and stop... [Woman, 40s]

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

In summary, while community members' responses indicate some levels of understanding of the various forms of violence and abuse, the data also seems to suggest a general lack of understanding of the multiple actors perpetrating the violence and abuse against women living with HIV, most notably with regard to healthcare providers. Similarly, communities' call for more women living with HIV to take legal actions as and when they have been violated and abused, is arguably

an indicator of communities' lack of awareness and understanding of the many challenges women encounter when attempting to seek legal redress. Moreover, the data seems to suggest a general lack of understanding among community members of their own role in perpetrating and perpetuating violence and abuse against women living with HIV.

RECOMMENDATIONS

While women's experiences imply a general lack of adequate programmes and interventions effectively responding to the realities, risks and needs of women living with HIV, communities' perceptions indicate a general lack of rights awareness and knowledge, and service providers' responses underscore the dire need for interventions to enhance women's access to healthcare services.

The study concludes with recommendations made by women and community members, as well as advocacy responses drawn from the findings of this study.

What do women recommend?

- Equal treatment and respect

...we are part of the community, you should accept us...

- Education and information on HIV and women's rights
- ...if people are informed, they treat women differently...so, something needs to be done to educate people...***

- Safe places for women living with HIV

...there should be safe places where women who experience all this could go and talk freely without any fear...

- Access to healthcare and quality services
- ...I would like to see government employing people who are passionate, people who really care about people living with HIV...***

- Integration of services

...if government can mix the patients, so that we cannot differ

from other patients...we must not have special rooms, special nurses and special administration...

- Access to justice and redress

...the police must be informed about the charges to be laid and how to deal with people like us when they come to the police station...

What do communities recommend?

- Education and awareness raising

...make sure everybody is educated about HIV transmission, highlighting that women are not there to spread the virus...

[Woman, 20s]

- Women to speak up and claim their rights

...women who are abused must speak up and stand up for their rights... [Woman, 30s]

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. UNAIDS. 2010. Getting to Zero, 2011 – 2015 Strategy, p7.
2. 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.
3. 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.



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