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

PERCEPTIONS AND EXPERIENCES OF VIOLENCE AGAINST WOMEN LIVING WITH HIV IN TAFELSIG AND BEACON VALLEY, WESTERN CAPE

ender 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 the Western Cape, 836 community questionnaires were administered (429 in Tafelsig and 407 in Beacon Valley); two focus group discussions with women living with HIV were facilitated; 20 women were interviewed; and 22 incident forms were collated.

MAIN FINDINGS: TAFELSIG AND BEACON VALLEY, WESTERN CAPE

...if I knew what would happen, I would have kept it to myself...²

Communities' perceptions of women's HIV disclosure consequences

Contrary to women's experiences of HIV disclosure in Tafelsig and Beacon Valley, 27% of community members participating in the study believed that women living with HIV would get 'support' and 'love' from family and household members, and about two-thirds (63%) 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'.

Beliefs that women would be 'rejected', 'treated badly', and 'discriminated against' as and when their HIV positive status becomes known varied. While only 8% of participants in both areas believed that women would be at risk of ill-treatment and abuse based on their HIV positive status within healthcare

FACT SHEET: GENDER VIOLENCE & HIV: WESTERN CAPE

provision, 62% highlighted the risk of rejection, abuse, and discrimination upon women's HIV disclosure at a community level, and 26% thought that women would be '*treated badly*' by their families. Women in Tafelsig were far more likely to believe in the risk of ill-treatment within healthcare centres (11%), as compared to men in this area (4%), and as compared to women in Beacon Valley (6%).

...they will treat her differently; it will be unsafe for her... [Woman, 40s]

Despite these levels of awareness of the risks associated with women's HIV disclosure, the majority of community members felt strongly that women need to disclose their HIV positive status (78% in Tafelsig and 71% in Beacon Valley). The data further shows that women in Tafelsig were more likely to believe in disclosing to families (21%), than to partners (17%); while more than twice as many men expressed the need for women to disclose to their partners (32%), as compared to disclosing to their families (13%). To the contrary, women in Beacon Valley expressed a greater need for partner disclosure (24%), than disclosing to families (17%).

...if the family is educated, they will help her maintain a healthy lifestyle and support her...if not, there will be stigma and discrimination... [Woman, 30s]

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 in Tafelsig and Beacon Valley also spoke about leaving their homes and moving away, due to the abuse and violence.

...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 manner in which, their HIV status became known to families, friends and community members.

... it is no longer the same... I don't feel safe anymore...

Women's experiences of access to healthcare

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.

... I always feel uncomfortable when it's time for me to go to the hospital, because you can be seen by someone who knows you...

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.

... I don't like people being rude to me over and over again, when I need help...so, I have not been back to the clinic...

Communities' awareness of redress mechanisms

The data indicates that Tafelsig and Beacon Valley community members are, to some extent, 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.

More than a third of community members participating in these areas believed that women should take '*legal actions*' against the person (or persons) who disclose their HIV status without their consent (35% in both areas). A significant higher number of people in Tafelsig thought that '*legal actions*' should also be taken against people who discriminate against women living with HIV (49%), as compared to Beacon Valley (41%).

...she must take steps against these people... [Woman, 20s]

In the context of HIV status disclosure without consent, men in Beacon Valley seem to be more aware of women's right to take '*legal actions*' (39%), as compared to women in this area (33%). In Tafelsig, however, far more women are aware and knowledgeable about available redress for unlawful HIV status disclosure (38%), than men (29%). These responses not only suggest different levels of access to information, but also imply a greater assumed HIV disclosure need among women in Beacon Valley.

Women's experiences of seeking redress

The data highlights that women, although aware of their right to take legal actions, are more likely to decide not to lay charges, for reasons of fear of further abuse and humiliation, as well as feelings of shame, embarrassment, and 'not wanting to deal with it'.

... 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...

Women, who sought legal redress, spoke generally of their disappointment with the lack of support received, as well as 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.

> ...nothing happened with the case, because the docket got lost...

Communities' knowledge of rights protection for women living with HIV

The data underscores the prevailing 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 engage in sex and have children upon an HIV positive diagnosis. While 37% of participants in Tafelsig and 28% in Beacon Valley thought that women should not engage in sex, close to half of community members in these areas believed that women living with HIV should not have children (49% in Tafelsig and 47% in Beacon Valley). Further qualifying their responses, the majority of community members in both areas made reference to the *'risk of transmission'* during sex (72%), and during pregnancy and childbirth (90%), while some also conveyed that women living with HIV are *'not supposed to'* engage in sex (12% in Tafelsig and 9% in Beacon Valley).

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

Similarly, persisting stigma, prejudices and discrimination against women living with HIV is also undoubtedly evidenced with half of community members affirming that women, because of their HIV positive diagnosis, 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]

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

About half of Tafelsig and Beacon Valley participants (51%) agreed that women living with HIV are at greater risk of violence and abuse, thus indicating some levels of community members' awareness of women's greater risks of violence and abuse based on their HIV positive status, and the need to address violence against women living with HIV.

...we, as women, should stand together and stop gender violence... [Woman, 40s]

Elaborating on their responses, more than a third of community members in both areas mentioned that women living with HIV are 'abused', 'beaten by their partners', 'called names', and 'forced to have sex without a condom' (36% in Tafelsig and 37% in Beacon Valley), while an additional 38% in Tafelsig and 31% in Beacon Valley made reference to women being 'treated badly' and 'discriminated against' because of their HIV positive status.

...most people will discriminate you, push you away...because they are scared you're going to infect them... [Woman, 30s]

Recognising the high levels of violence and abuse, community members' recommendations for change stressed the need for 'awareness and education' (19% in Tafelsig and 29% in Beacon Valley), and re-emphasised the need for women living with HIV to 'take legal actions' as and when they are abused and violated (22% in Tafelsig and 24% in Beacon Valley).

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

FACT SHEET: GENDER VIOLENCE & HIV: WESTERN CAPE

RECOMMENDATIONS

What do women in Tafelsig and Beacon Valley 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
- Integration of healthcare services
- Access to justice and redress

What do Tafelsig and Beacon Valley community members recommend?

- Education and awareness raising
- Women to speak up and claim their rights
- Actions to stop violence against women

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 Tafelsig and Beacon Valley, Western Cape.

