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.

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 New Brighton, 791 community questionnaires were administered; two focus group discussions with women living with HIV were facilitated; 11 women were interviewed; and 30 incident forms were collated.

MAIN FINDINGS: NEW BRIGHTON, EASTERN CAPE

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

Communities’ perceptions of women’s HIV disclosure consequences

Contrary to women’s experiences of HIV disclosure in New Brighton, more than a third of community members participating in the study (36%) believed that women living with HIV would get ‘support’ and ‘love’ from family and household members, and almost 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’. 

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, 58% highlighted the risk of rejection, abuse, and discrimination upon women’s HIV disclosure at a community level, and 18% thought that women would be ‘treated badly’ by their families. Women in New Brighton were more likely to believe in the risk of women’s HIV disclosure at a community level (60%), as compared to men (55%), while more men thought that women would be at risk of ill-treatment within healthcare centres (20%, as compared to 16% of women).

…they are really cruel, that’s why people living with HIV are so stressed…the community is going to isolate her…

[Woman, 20s]

Despite these levels of awareness of the risks associated with women’s HIV disclosure, the majority of community members (80%) felt strongly that women need to disclose their HIV positive status. The data further shows that women in New Brighton were far more likely to believe in disclosing to families (33%), than to partners (12%); while more men expressed the need for women to disclose to their partners (25%), as compared to disclosing to their families (21%).

…some families will accept her, but most families will reject her and ask why she is bringing HIV to the home…

[Woman, 50s]

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.

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

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 tried to be upright, though I felt very hurt…

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.

…that’s how most people find out that you are HIV positive, when they see you at the clinic…

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.

…when they come to the clinic they will see their neighbours and someone they know…then they will run away from the clinic without taking their treatment…

Communities’ awareness of redress mechanisms
The data indicates that New Brighton community members are well 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 half of community members participating in New
Brighton believed that women should take ‘legal actions’ against the person (or persons) who discloses their HIV status without their consent (55%), and against people who discriminate against women living with HIV (51%).

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

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.

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

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.

...I thought they will try and talk to her and that will just make things worse for me...

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

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

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

A third of New Brighton participants (33%) 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 needs to address violence against women living with HIV.

...people gossip and undermine and ill-treat women living with HIV... [Woman, 40s]

Elaborating on their responses, 45% of New Brighton community members mentioned that women living with HIV are ‘abused’, ‘beaten by their partners’, ‘called names’, and ‘forced to have sex without a condom’, while an additional 29% made reference to women being ‘treated badly’ and ‘discriminated against’ because of their HIV positive status.

...some women are forced to have sex without condoms and are beaten, because he says I am the one who came with this thing... [Woman, 30s]

Recognising the high levels of violence and abuse, New Brighton community members’ recommendations for change stressed the need for ‘awareness and education’ (36%), and re-emphasised the need for women living with HIV to ‘take legal actions’ as and when they are abused and violated (16%).

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

RECOMMENDATIONS

What do women in New Brighton 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 New Brighton 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:

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 New Brighton, Eastern Cape.