

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

GENDER VIOLENCE & 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

Johanna Kehler, Sethembiso Mthembu,
Thembisile Ngubane-Zungu, Silungile Mtambo

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EXECUTIVE SUMMARY

***...I must not be seen as a woman who is HIV positive,
but as a woman who is a human being...¹***

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.

Although the protection and advancement 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 the legislative and policy framework and are the premise for the national response to women and HIV, women living with HIV continue to be subjected to a continuum of violence, abuse and discrimination based on their HIV positive diagnosis. Similarly, whilst recognising the various causalities and links between gender violence and HIV, as well as designing and implementing various programmes and interventions to address the very same, gender violence against women prevails to be as much a cause of women's greater risks to HIV exposure and transmission, as an effect of women's HIV positive status.

THE STUDY

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.

In order to achieve the aim of the study, project activities included a literature review, as well as information and data collection through various means, including questionnaire and interview administration, facilitated focus group discussions, and collation of incidence data forms. As such, various research tools were developed, tested and administered.

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 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.

RESEARCH FINDINGS

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 and assess 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

EXECUTIVE SUMMARY

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.

Communities' perceptions of women's HIV disclosure consequences

The data clearly highlights that community members are well aware of the risks associated with women's HIV disclosure within their families and households, at a community level, within healthcare provision, and at the workplace. However, the data also suggests generally lower levels of awareness of the occurrence of HIV-related stigma, discrimination and other rights abuses in families and healthcare settings, as compared to rights abuses and violence against women living with HIV prevalent at the community level and the workplace.

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

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.

Women's experiences of access to healthcare

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 limit women's access to quality healthcare free of fear, stigma and discrimination, but also deter women from accessing healthcare.

Service providers' perceptions

Service providers' perceptions 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.

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

The data clearly indicates that communities to a certain extent are 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. The data, however, also highlights the

vastly different degrees of awareness and knowledge levels between samples, hence the need for awareness raising and rights education.

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

Women's experiences are a clear illustration of both the barriers to accessing legal redress, and the 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.

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 court structures.

Communities' knowledge of rights protection for women living with HIV

While the data undoubtedly indicates persistent levels of stigma, discrimination, and prejudice 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.

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

Although the data indicates some levels of understanding among community members 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 further seems to suggest a general lack of understanding among community members of their role in perpetrating and perpetuating violence and abuse against women living with HIV.

Service providers' perceptions of women's risks of HIV-related violence

The data clearly reflects NGO and community-based service providers' high levels awareness and understanding of the multiple risks of violence and abuse for women living with HIV, which arguably also gives an indication of service providers' potential to adequately respond to women's realities and needs.

Women's experiences of HIV-related violence

Women's experiences of living with HIV are a clear illustration of multiple forms of abuse and violence in all spheres of their lives, perpetrated by partners, families, friends, communities and service providers alike. Upon disclosure of women's HIV positive status, irrespective of whether or not women themselves decided the time of and manner in which their HIV status became known, women's lives change, due to fear and the continuum of violence and abuse perpetrated against them, based on their positive HIV status.

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
- Education and information on HIV and women's rights
- Safe places for women living with HIV
- Access to healthcare and quality services
- Integration of services
- Access to justice and redress

What do communities 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 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

CHAPTER ONE

GENDER VIOLENCE & HIV¹

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.²

The need to address gender violence in its various forms is similarly acknowledged as a key strategy for effective responses to women and HIV, 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.³

INTRODUCTION AND OVERVIEW

It is well-evidenced that women are at greater risk of HIV transmission and violence, including violence based on and in the context of HIV.⁴ Moreover, the effects of gender violence in its various forms on women are widely recognised and well-documented.

The evidence clearly indicates that violence and/or the fear of violence 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.⁵ Research also shows that violence

in its various forms impacts on decisions as to whether or not and when to access services, including HIV prevention and testing; as well as whether or not and to whom to disclose an HIV positive diagnosis.⁶

Prevailing high levels of violence and other rights abuses against people living with HIV was also confirmed in a recent study on HIV-related human rights violations in the Eastern Cape, South Africa.⁷ The study revealed not only the various layers of violence and rights abuses people are subjected to, ranging from physical violence to rape and refusal of treatment, but also the gendered nature of HIV-related violence and other rights abuses (74% of people who reported rights abuses were women). In addition, findings of this study further suggest that violence based on and in the context of HIV is an ongoing process of violations, as compared to a 'single' incident, and that these violations mostly occur within families and households (58% of cases), within communities (24% of cases), and within healthcare provision (11% of cases).⁸

High prevalence of HIV-related stigma and discrimination further leads to a situation in which especially women living with HIV are further subjected to violence and other rights abuses within their relationships, families, households, communities and service provision, as and when their HIV positive status becomes known. A study by Amnesty International, involving rural women from KwaZulu Natal, South Africa, concluded that women continue to live 'in a general environment of high levels of sexual and other forms of gender-based violence'⁹, which, among other effects, impedes on women's access to services.

Within healthcare provision, women living with HIV are often exposed to prejudices and discriminatory attitudes

and practices by healthcare providers, and as a result, often experience limited, delayed and/or denied access to services. There is also growing evidence that women are subjected to 'coercive' practices, especially in the context of sexual and reproductive healthcare, most notably 'coerced' termination of pregnancy and sterilisation without consent.¹⁰ Prevailing rights violation and abuse against women living with HIV within service provision not only has an adverse impact on women's access to services, including the potential to deter women from accessing services, but also seems to impede effectiveness of responses to women and HIV.

Many women living with HIV are unable to access services, because they fear stigma and discrimination if their HIV status is disclosed. Violence against women, which has been defined as a form of gender-based discrimination, also created barriers for women living with HIV who may fear the consequences of accessing HIV testing and medication. They risk violence, abandonment and poverty if their HIV status is discovered by their partners and families.¹¹

Within the context of HIV testing, including HIV testing during pregnancy, women and women's rights are frequently compromised and violated, as women find themselves often 'coerced' and/or 'forced' to test for HIV as a pre-requisite for accessing antenatal care and other sexual and reproductive health services.¹² Based on women's experiences, research suggests that HIV testing during pregnancy has 'become another form of gender violence in women's lives',¹³ whilst simultaneously increasing women's risks to gender violence at a family, household and community level. A study, conducted in the Western Cape and KwaZulu Natal, for instance revealed that in reality there seems to be little to no option for pregnant women to voluntarily decide whether or not to test for HIV. The study also showed that pregnant women are afforded limited access to adequate information and time to make an informed choice, free of coercion and fear of repercussions whether or not to test for HIV. Resulting from a general lack of confidentiality within healthcare provision, both due to healthcare workers' attitudes and the structural separation of

services, women were often exposed to further violence and abuse by family and community members subsequent to their HIV positive diagnosis.¹⁴

A recent report on violence in the lives of women living with HIV¹⁵ clearly highlights the many 'hidden forms of violence' and their effects on women's lives. Women's experiences

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illustrate how

...abuse extends beyond the family cycle to public health institutions and police stations. Even if there is no physical violence, women are subjected to various kinds of structural violence.¹⁶

Research also shows that access to justice and redress for women who have been abused and violated is severely limited for a variety of reasons, including inadequate investigations of cases by the police and insufficient sentencing of perpetrators of violence, as well as women's fear of secondary victimisation and further abuse while pursuing legal actions.¹⁷

The risks and consequences of HIV status disclosure, particularly within healthcare provision, combined with a lack of adequate access to justice and redress for women who have been violated and abused upon their HIV status disclosure, often create a situation in which women experience multiple layers, and a continuum, of violence and other rights abuses, ranging from interpersonal to structural to institutional. Recognising both the gendered nature of HIV risks and the pervasiveness of gendered violence based

on and within the context of HIV, arguably underscore the need for effective rights-based responses to women, HIV and gender violence.

LEGAL AND POLICY FRAMEWORK

In South Africa, the right to equality and non-discrimination, the right to dignity and respect, the right to privacy, the right to autonomy and consent, and the right to be free from all forms of violence, both in public and private spheres, are constitutionally guaranteed¹⁸, with numerous laws and policies giving effect to these provisions.

Laws and policies most relevant in the context of gender violence and HIV include legislation addressing various forms of violence (such as the Domestic Violence Act¹⁹ and the Sexual Offences Act²⁰), laws and policies regulating the provision of health services (such as the National Health Act²¹ and the National HIV Counselling and Testing Policy Guidelines²²), and legislation promoting equality and prohibiting discrimination (such as the Equality Act²³). In addition, South Africa's national response to women, HIV and gender violence is guided by the National Strategic Plan on HIV, STIs and TB, 2012 – 2016 (NSP)²⁴.

Both the Domestic Violence Act and the Sexual Offences Act are purposed to afford women who have been sexually or otherwise violated and abused the right to lay a charge against the perpetrator(s). However, prevailing implementation challenges and a general lack of knowledge about the applicability of these laws in the context of HIV, among women and service providers alike, impact on the extent to which these laws provide redress to women who experienced HIV-related violence and abuse. Similarly, while the Equality Act affords women the possibility of redress for HIV-related violence and other rights abuses, a general lack of knowledge about its applicability in the context of HIV severely limits women's access to justice.²⁵

In addition, provisions in the National Health Act clearly

outline the protection of rights in the context of healthcare provision, particularly with regard to the right to autonomy and informed consent, the right to privacy and confidentiality, and the right to equality and non-discrimination. The National Health Act also provides for redress mechanisms as and when rights violations occur within healthcare settings. In reality, however, evidence shows that these rights protections are often compromised and violated in the provision of services, especially in the provision of HIV-related services. Various studies of women's experiences of accessing healthcare, including experiences of women living with HIV, evidenced the risks and occurrences of rights violations in the provision of services, despite the rights protections afforded by the law.

...women living with HIV are further subjected to violence and other rights abuses within their relationships, families, households, communities and service provision...

The National HIV Counselling and Testing Policy Guidelines have been at the centre of debate and critique from rights advocates for some time, specifically highlighting the inherent risks for rights violations based on the provider-initiated HIV testing approach, as well as the gender biased and discriminatory nature of both the policy and its implementation. Most notably, women's rights to equality, non-discrimination, consent, confidentiality, counselling and to be free from all forms of violence, including coercion, are persistently violated in the context of HIV testing during pregnancy.²⁶

CHAPTER ONE: GENDER VIOLENCE & HIV

In the context of addressing the links between gender violence and HIV, the National Strategic Plan on HIV, STIs and TB, 2012 – 2016 (NSP) is the guiding strategic document for the design and implementation of interventions and programmes at a community, provincial and national level. While affirming its commitment to the protection of rights in the context of HIV, the NSP also identifies as one of its principles that the response to HIV

...must be rooted firmly in the promotion and protection of human and legal rights, including prioritising gender equality and gender rights.²⁷

The national response to women and HIV is undoubtedly informed by an analysis of the various risks and vulnerabilities of women to HIV transmission and related violence and other rights abuses. Based on its contextual analysis, the NSP recognises both 'gender roles and norms' and 'sexual abuse and intimate partner violence' as structural determinants of HIV, and thus proposes to

...implement interventions to prevent gender-based violence, as well as intimate partner violence, and educate men about women's rights.²⁸

Further noting the impact of gender roles on the risk of HIV exposure and transmission, the NSP emphasises the need for 'social interventions' to include 'efforts to change cultural and social norms', as these norms may promote discrimination and 'condone gender violence', which also impact on women's access to services, including redress mechanisms as and when their rights have been violated.²⁹

...women experience multiple layers, and a continuum, of violence and other rights abuses, ranging from interpersonal to structural to institutional...

It is within this context that the NSP includes various objectives and interventions aimed at changing social and cultural norms and practices that define and perpetuate especially women's risks of HIV exposure, transmission and related violence and rights abuses. Thus, the NSP includes provisions to address gender inequalities and gender-based violence (Objective 1.3), to implement a comprehensive national social and behavioural change communications strategy (Objective 2.4), and to provide training to prevent unfair discrimination in access to services (Objective 4.3).

Recognising the barriers to accessing services, the NSP also emphasises the need to ensure that rights are not violated in the implementation of programmes and interventions (Objective 4.1), and that 'access needs of particular groups' and 'barriers to accessing services' are taken into account when planning and implementing interventions.³⁰ Although commendable that the barriers to service access and the need to ensure rights protection within service provision are recognised, it is the effective translation of this commitment into interventions and programmes that carries the potential to ultimately enhance women's access to services. Within the context of gender violence and HIV it is further argued that gender violence in all its forms has to be recognised and addressed as a *barrier for women*, both within and *outside* service provision, so as to guarantee that women are in the position to exercise their rights and to access services free of fear, coercion, discrimination, violence and other rights abuses.

A further analysis of the NSP objectives however also reveals a rather narrow approach and/or understanding of the various causes, forms and effects of gender violence based on and in the context of HIV.³¹ Interventions meant to address 'gender-based violence' seem to mainly focus on 'sexual violence', rather than 'gender violence' in its entirety – thus restricting the potential impact these interventions could have on women's realities, risks and needs.

Similarly, in the context of violence as an effect to women's HIV positive status, the NSP, although specifically referencing the violations of women's '*sexual and reproductive health rights, especially the desire to have children*'³², fails to recognise the many layers and forms of violence women experience based on their HIV positive status.

South Africa has, undoubtedly, an enabling and supportive legal environment premised on the recognition, promotion, protection and realisation of human rights and freedoms of all people. In the context of women and HIV, further specific legislative and policy provisions are in place, which recognise and protect women's rights.

Nonetheless, an enabling legal and policy environment does not automatically translate into a social environment in which rights and freedoms, as well as the protections of the law, are equally accessible to and realisable for women in South Africa. Creating an enabling and supportive social environment for women in the context of HIV risks and vulnerabilities would entail addressing (and ultimately transforming) the societal context determining the very same, most notably gendered inequalities, power relations, patriarchal systems, gender violence and discrimination. Hence, effective responses to women and HIV are to take into account (and address) women's realities, risks and needs, as well as the societal context in which '*choices*' are made and services are accessed.

WOMEN'S REALITIES AND NEEDS

Women's HIV risks and vulnerabilities are well recognised, with data confirming that women are at disproportionate risk of HIV exposure and transmission, and are more likely to be subjected to stigma, discrimination, violence and other rights violations based on and in the context of HIV.³³

Data indicates that an estimated 5.63 million adults and children are living with HIV in South Africa, 3.3 million (59%) of whom are women. Furthermore, young women (aged 15

to 24 years) are four times more likely to be living with HIV, as compared to their male counterparts of the same age, and HIV risks are further exacerbated for pregnant women and survivors of physical and/or intimate partner violence in this age group.³⁴ In addition, the 2010 Antenatal Survey published by the Department of Health in 2011, calculated the national prevalence among antenatal women aged 15 to 49 years at 30.2%, with the highest recorded provincial prevalence of 39.4% in KwaZulu Natal. Although below the national prevalence, both Eastern Cape and Western Cape showed an increase in prevalence in 2010, to 29% and 20.2% respectively. According to latest data, the peak of HIV prevalence now occurs in women between the ages of 30 to 34 years, with a prevalence rate of 42.6% in this age group.³⁵

Data also confirms that women's HIV risks and vulnerabilities are further exacerbated by high levels of sexual and gender violence.³⁶ According to UNAIDS, experiencing violence

*...the need to ensure that
rights are not violated in the
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and interventions...*

increases the risk of HIV transmission by a factor of three³⁷, and women are more likely to experience violence and abuse based on their positive HIV diagnosis³⁸.

In South Africa, cases of sexual assault and rape remain to be highly under-reported, with data from Gauteng indicating that only one out of every 25 rapes is reported to the police³⁹,

due to self-blame, fear of not being believed, trauma, and fear of secondary victimisation⁴⁰. According to the South African Police Services (SAPS), 64 514 cases of sexual assault, including rape, have been reported between April 2011 and March 2012, with the highest number of reported cases (12 419) in Gauteng, followed by KwaZulu Natal (12 288), Eastern Cape (9 239) and Western Cape (9 153).⁴¹

However, despite all the evidence and recognition of women's realities and needs based on and in the context of HIV, as well as the commitments (globally and nationally) to address

*...when gender violence
is recognised in its multiplicity
and as a continuum...*

these, responses to women and HIV continue to be mostly inadequate and ineffective in addressing (and transforming) women's risks and vulnerabilities to HIV and related rights abuses. Similarly, gender inequality, patriarchal systems, violence, as well as social and cultural norms maintaining and condoning the very same, are well-recognised as 'drivers' of especially women's HIV risks and vulnerabilities. Yet, there are very few 'successful' programmes and interventions addressing the gendered societal context that defines 'who' is at higher risk of HIV exposure and transmission, and 'who' is more likely to experience violence, abuse and other rights violations.

Although the protection and advancement 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 the legislative and policy framework and are the premise for the national response to women and HIV, women living with HIV continue to be subjected to a

continuum of violence, abuse and discrimination based on their HIV positive diagnosis. Similarly, whilst recognising the various causalities and links between gender violence and HIV, as well as designing and implementing various programmes and interventions to address the very same, gender violence against women prevails to be as much a cause of women's greater risks to HIV exposure and transmission, as an effect of women's HIV positive status.

Women's rights protections, especially women's right to make free and informed decisions about all aspects of their lives are critical aspects of effective responses to women and HIV. However, a societal context filled with gendered norms and expectations around sex and sexuality severely limits women's access to and enjoyment of sexual rights and choices, while at the same time, societal expectations of motherhood, compromise women's rights to make informed reproductive choices. The extent to which women living with HIV are in the position to claim and exercise their right to choose is further limited due to societal prejudices and discriminatory attitudes against women living with HIV, including common societal assumptions that women seem to lose their right to decide whether or not and when to engage in sex, have children or get married upon an HIV positive diagnosis.

It is this very same societal context that not only largely determines women's risks to HIV-related violence and abuse, but also perpetuates and to an extent condones the prevalence and occurrence of violence against women living with HIV. Moreover, women's access to services and access to quality of care will arguably remain limited accordingly. In summary, HIV-related violence and other rights abuses against women living with HIV can only be adequately addressed as and when the societal context is challenged and transformed, and when gender violence is recognised in its multiplicity and as a continuum.

FOOTNOTES:

1. This chapter is in part based on prior publications by the author. Kehler, J. 2012. *Are women at the centre? A critical review of the new NSP response to women's sexual and reproductive rights*. Cape Town, AIDS Legal Network; Kehler, J. 2012. 'Effective rights-based responses: The NSP response to gender violence'. In: *ALQ*, March/April 2012, pp1-10.
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CHAPTER TWO

BACKGROUND & METHODOLOGY

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.

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 and assess 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'¹. As such, violence defined as

...any act, structure or process in which power is asserted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.²

RESEARCH METHODOLOGY

The study on perceptions and experiences of violence and other rights abuses against women living with HIV took place in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa, from February to October 2012.

In order to achieve the aim of the study, project activities included a literature review, as well as information and data collection through various means, including questionnaire and interview administration, facilitated focus group discussions, and collation of incidence data forms. As such, various research tools were developed, tested and administered.

The 20-item (5-page) questionnaire, including both quantitative and qualitative questions, was designed to assess respondents' perceptions of risk and occurrence of HIV-related violence and other rights abuses against women living with HIV; levels of awareness of redress mechanisms as and when rights violations occur; and levels of knowledge and understanding of rights protections for women living with HIV.

Data of incidences of HIV-related violence and other rights abuses against women living with HIV were gathered through narrative interviews and incident forms. The interview guide was designed to assess positive women's experiences of HIV-related violence and other rights abuses not only at a family, household and community level, but also within healthcare provision.

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The incident forms gathered further information on rights violations in the context of HIV, including whether or not redress mechanisms were accessed and redress had been received.

The questions guiding the facilitated focus group discussions sought to gain a deeper understanding of HIV-related rights abuses both as experienced by women living with HIV and as perceived by service providers, as well as the barriers to service provision as experienced by women living with HIV and as perceived by service providers. The focus group discussions further focused on women's recommendations for change so as to effectively address HIV-related rights violations and to enhance access to services without fear of violence and other rights abuses.

STUDY SAMPLE AND PROCESS

The project was conducted in four areas, namely New Brighton (Eastern Cape), Illovo (KwaZulu Natal) and Beacon Valley and Tafelsig (Western Cape). While Illovo could be described as a semi-rural area, New Brighton, Beacon Valley and Tafelsig are developing townships.

New Brighton forms part of the Nelson Mandela Bay Municipality in Port Elizabeth, Eastern Cape, and Beacon Valley and Tafelsig, are part of Mitchell's Plain on the Cape Flats, situated approximately 30km from the City of Cape Town (Western Cape). Tafelsig, the most densely populated and low income area of Mitchell's Plain, and Beacon Valley, a low to middle income area, experience high levels of violent crimes, gang-related violence, and substance abuse. Illovo, forms part of the eThekweni municipality in KwaZulu Natal (situated approximately 35 kilometres south of Durban), and as a semi-rural area faces many challenges in accessing inadequate access to basic services, including healthcare.

Characteristic to all areas are high levels of unemployment, gender violence, and HIV prevalence.

Moreover, all the areas are located in provinces which have shown an increase in HIV prevalence from 2009 to 2010. According to latest available statistics published by the Department of Health, HIV prevalence among antenatal women in the study areas were estimated to be 41.1% in Illovo (eThekweni District), 29% in New Brighton (Nelson Mandela Metro District), and 20.2% in Tafelsig and Beacon Valley (Cape Town Metro District).³

During the research phase of this project, the AIDS Legal Network (ALN) closely collaborated with women's groups and networks in these areas, namely the South Africa Positive Women's Ambassadors (SAPWA) in KwaZulu Natal, the Mitchell's Plain Network Opposing Abuse in the Western Cape, and Her Rights Initiative (HRI) and South Africa Partners in the Eastern Cape. Partners assisted in the development and validation of the various research tools, in the administration of the community questionnaires, and with the analysis and interpretation of the data. The process of data collection was closely linked to knowledge transfer and capacity building on both the broad understanding of violence against women living with HIV, as well as on research ethics and methodology. As such, the ALN, prior to the questionnaire administration, facilitated capacity building sessions in each of the respective areas.⁴

The data collection focused on women living with HIV, their communities and service providers. Thus, the primary research participants were women living with HIV in the respective communities. Community members participating in the respective areas were informed about the purpose of the study and asked whether or not they would like to participate. All participants were informed about the anonymity and confidentiality of the collected data.

As for the narrative interviews and focus group discussions, women were given information about the purpose of the study, asked to volunteer to share their experiences, were informed of their rights, ensured confidentiality, as well as anonymity, and consented to participate in the study.

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The questionnaire data, as well as the information collated through the incident report forms, was entered, coded and analysed using Excel. The interviews and focus group discussions were transcribed and coded.

In total, 2354 community questionnaires were administered; six focus group discussions 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.

FOOTNOTES:

1. Hale, F. & Vazquez, MJ. 2011. *Violence against women living with HIV/AIDS: A background paper*. Development Connections and the International Community of Women living with HIV/AIDS (ICW Global), with the support of UN Women, pp7-13 [www.dvcn.org/content/hiv_violence_against_women]; see also Hale, F. & Vazquez, MJ. 2011. 'Addressed as a continuum: Violence against women living with HIV'. In: *Mujeres Adelante* IAS 2011 Rome Edition, pp12-14.
2. Hale, F. & Vazquez, MJ. 2011. 'Addressed as a continuum: Violence against women living with HIV'. In: *Mujeres Adelante* IAS 2011 Rome Edition, p12.
3. Department of Health. 2011. National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa, 2010. Pretoria, Department of Health, p43.
4. These sessions took place on 28 – 29 March 2012 in KwaZulu Natal, 07 – 08 May 2012 in the Western Cape, and on 20 – 21 August 2012 in the Eastern Cape.

CHAPTER THREE

Experiences of violence and other rights abuses against women living with HIV were documented and assessed by various means, namely narrative interviews, incident report forms and focus group discussions.

SOCIO-DEMOGRAPHIC BACKGROUND OF PARTICIPANTS

A total of 2354 community members (1429 women, 925 men) participated in the research by responding to the structured questionnaire. Of these participants, 791 were from New Brighton, Eastern Cape, (447 women, 344 men), 727 from Illovo, KwaZulu Natal, (422 women, 305 men), 429 from Tafelsig (311 women, 118 men), and 407 from Beacon Valley (249 women, 158 men), both in the Western Cape.

The majority of respondents (1657, 70%) were between 21 and 49 years old, with the highest number of respondents (785, 33%) between the ages of 20 to 29 years.

In total, 121 women (aged between 25 and 53 years) shared their experiences of HIV-related violence and abuse through narrative interviews and incident reports (41 women in New Brighton, 38 in Illovo, 13 in Tafelsig, and 29 in Beacon Valley); and 82 women participated in six facilitated focus group discussions (2 in New Brighton, 2 in Illovo, 1 in Tafelsig and 1 in Beacon Valley). All women were between the ages of 25 and 53 years old.

In addition, 50 community-based service providers' perceptions and experiences were assessed through three

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facilitated focus group discussions (2 in New Brighton and 1 in Beacon Valley), and two interviews (1 in Tafelsig and 1 in Illovo). Except for two people, all the service providers participating were women, the majority of whom were in their 30s and 40s.

COMMUNITIES' PERCEPTIONS OF WOMEN'S HIV DISCLOSURE CONSEQUENCES

The questionnaire included a number of questions designed to assess communities' perceived need for women living with HIV to disclose their HIV status; as well as perceptions of consequences and risks as and when women's positive HIV diagnosis becomes known; and perceived consequences for women not disclosing their HIV status.

Perceived need for women's HIV disclosure

To assess communities' perceptions of the need for disclosing one's HIV status, respondents were asked whether or not they believed that women should disclose their HIV positive status, as well as '*whom*' they believed women should disclose to and '*why*'.

The majority of respondents (1843, 78%) affirmed that women need to disclose their HIV positive status, 17% of respondents (403) disagreed, and 5% (108) were unsure. The response rates differed between the samples, ranging from 71% in Beacon Valley to 81% of respondents in Illovo affirming the need for disclosure. Of all the respondents, women in their 20s in the Beacon Valley sample (55%) were least likely to agree with the need for HIV disclosure.

Respondents who agreed that women need to disclose their HIV positive diagnosis were further asked '*whom*' they thought

*...women are more aware of
and knowledgeable about the
potential negative consequences
associated with partner
disclosure...*

women should disclose to and 'why'. Most of the respondents (62%) believed that women should disclose to 'partners' (417, 23%), to 'family' (400, 22%), to 'partner and family' (176, 10%), and to 'family and friends' (146, 8%). An additional 12% of respondents (212) thought that women should disclose to 'people they trust' (106, 6%) and 'people close to them' (106, 6%). The data shows significant differences between women and men, between the samples, and between age groups.

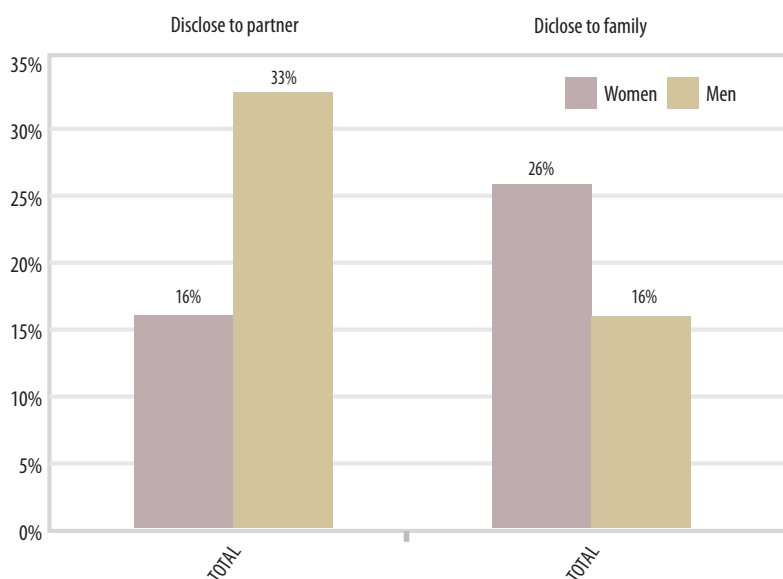
For example, the data shows that women were far more likely to believe in disclosing to family (287, 26%), than to partners (16%, 175). To the contrary, twice as many men expressed the need for women to disclose to their partners (242, 33%), as compared to disclosing to their families (113, 16%).

While women in their 20s least believed in disclosing to partners (11%), 21% of women in their 30s, and 19% of women in their 40s indicated the need to disclose to the partner. Men responding were far more likely to believe that women need to disclose to their partners across all age groups, ranging from 32% of men in their 20s to 41% of men in their 30s.

Overall, both women and men in their 30s seemed most inclined to believe that women should disclose their HIV status to their partners (21% of women and 41% of men), as compared to respondents in their 20s (11% of women and 32% of men) and in their 40s (19% of women and 30% of men).

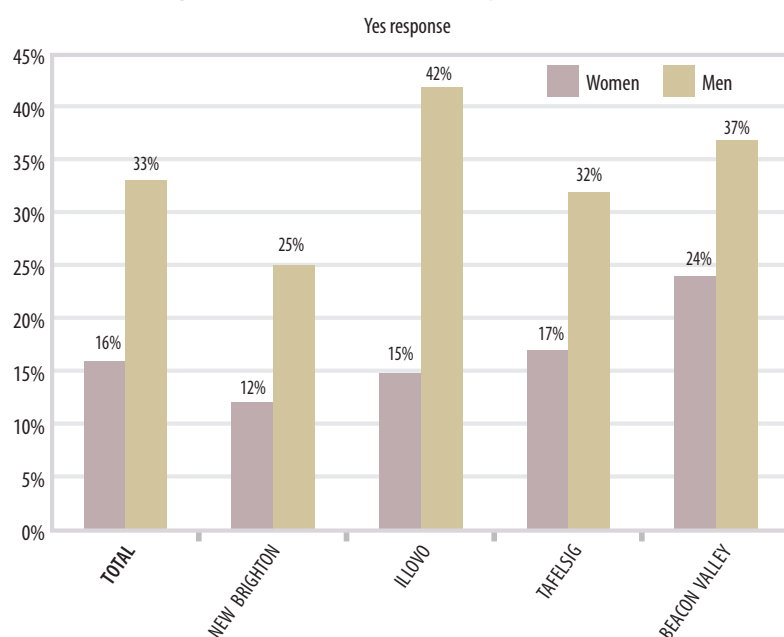
The data also shows a marked difference in the responses between the four areas. While 23% of the total sample (417) believed that women should disclose to their partner, the responses ranged from 17% in New Brighton, to 29% in Beacon Valley. Women believing in the need for partner disclosure ranged from 12% of women in New Brighton to 24% in Beacon Valley. The difference in perceptions as to whom women need to disclose to is most significant in the Illovo sample, with almost three times as many men (42%) believing in women's partner disclosure, as compared to 15% of women in Illovo.

Figure 1: Perceived need for women's HIV disclosure to partner and family



*...women are
more aware and
knowledgeable of the
right to choose whether
or not to disclose one's
HIV status...*

Figure 2: Perceived need for women's partner disclosure



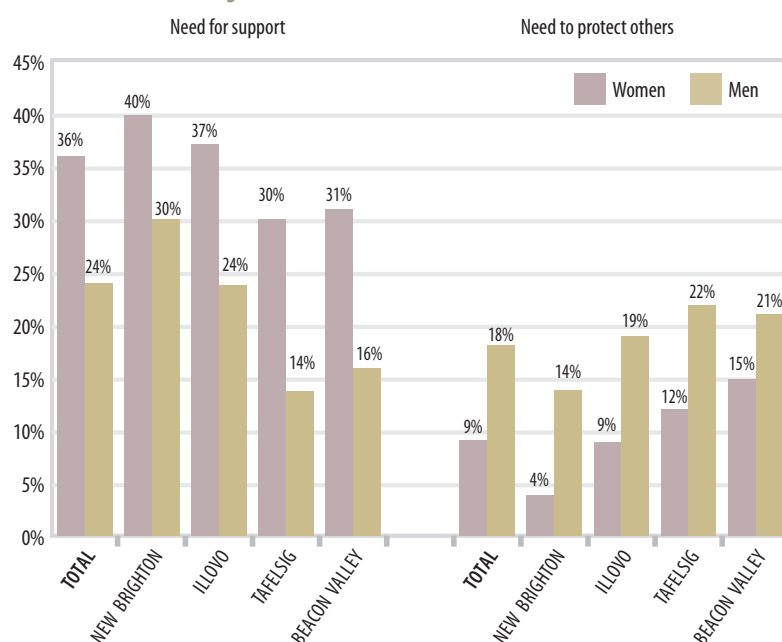
...she needs to disclose to someone she trusts,
because she needs all the support she can get...
it's not easy getting used to living with HIV...
[Woman, 30s]¹

...you need to disclose to your partner,
because if you don't tell him and he
finds out from other people,
your marriage will be over...
[Women, 40s]²

Responses varied greatly between women and men in relation to the need for 'support' (36% of women, 24% of men) and the need 'to protect others' (9% of women, 18% of men).

Figure 3: Reasons for women's HIV disclosure

The data arguably reflects that women not only see a greater need for HIV disclosure to their families, as compared to partners, but also seems to indicate that women are more aware of and knowledgeable about the potential negative consequences associated with partner disclosure. Men, however, are far more likely to believe in the need for partner disclosure, which, among other, confirms the common assumptions that it is women's responsibility to disclose to their partners – although women may fear the consequences of such disclosure – and that it is the responsibility of the person knowing to be living with HIV to 'protect' the partner, as compared to both partners being responsible for the prevention of HIV.



The data, indicating that women are more likely to believe that the 'need for support' is the reason as to why women should disclose their HIV status, clearly reflects not only the gendered nature of providing 'support' to people living with HIV, as it is mostly women who carry the responsibility for caregiving and support, but also the gender dimensions of 'who' is likely to 'know first' of an HIV positive diagnosis, and thus, has the responsibility 'to protect others'.

Perceived reasons for women's HIV disclosure

Explaining further as to 'why' respondents believed that women need to disclose their HIV status, most respondents indicated 'support' (569, 31%), 'to protect others' (231, 13%), the 'need to know' (236, 13%), and that disclosure is 'better for women's health' (194, 11%) as reasons for HIV disclosure.

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Although affirming that women should disclose their HIV status, respondents also cautioned about the risks associated with women's disclosure of HIV their status, and thus, emphasised the need to be 'careful' of whom to disclose to – indicating that there is a general awareness and knowledge of the risks associated with HIV disclosure, albeit the belief that women should disclose their HIV positive status.

...but there is this stigma... just tell family, so if anything happens, they can be ready... [Woman, 40s]³

...only family, no others can she tell, because you can't trust anyone with your status...
[Man, 20s]⁴

Respondents who did not believe that women need to disclose their HIV positive status (403, 17%), mainly qualified their response with reference to 'the right to choose whether or not to disclose' (216, 54%) and the 'fear of stigma, discrimination and abuse' (115, 29%). A higher percentage of respondents in the Illovo and Tafelsig samples (33% and 34%, respectively) believed that it would be better for women not to disclose for reasons of fear of negative consequences.

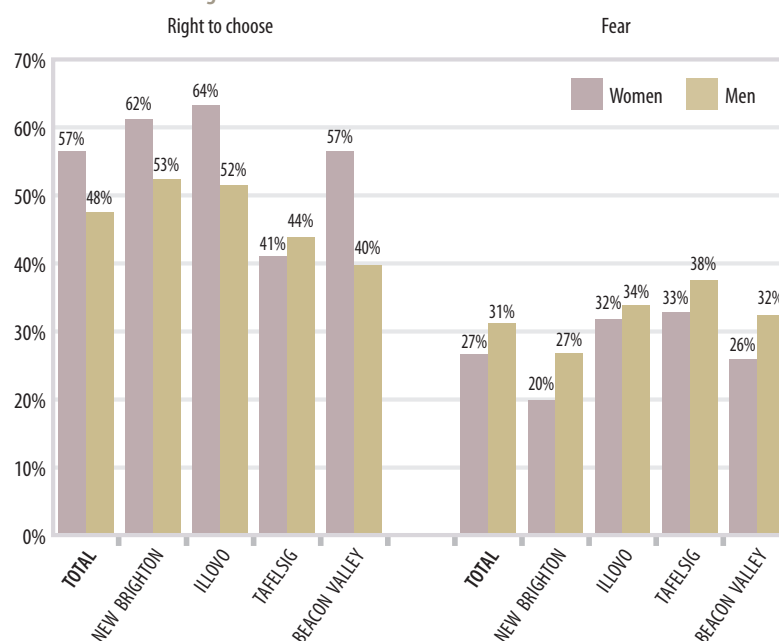
Across all the samples, a higher percentage of men (31%, 49; as compared to 27% of women, 66) believed 'fear of stigma, discrimination and abuse' to be the reason as to why women should not disclose their HIV status. In the Beacon Valley sample, twice as many men in their 20s (33%, as compared to 16% of women in this age group) qualified their response with the risk of negative consequences as and when women disclose their HIV status.

...especially for us as women it is so unsafe to disclose, because our boyfriends they beat us... how much worse will it get if we disclose... [Woman, 30s]⁵

...it depends if there's a support system then she can tell, but if the environment is risky then she must not disclose...
[Man, 30s]⁶

Except for Tafelsig, the data also shows that women across all samples are far more likely to refer to women's right to choose whether or not to disclose their HIV status (140, 57%), as compared to men (76, 48%). These varying response patterns are most markedly in the Beacon Valley sample with 17% more women than men referencing women's right to choose. Tafelsig is the only sample, in which more men than women (44% of men, as compared to 41% of women) stated women's right to choose as the reason why women should not disclose their HIV positive status.

Figure 4: Reasons for women's HIV non-disclosure



The data seems to indicate that women are more aware and knowledgeable of the right to choose whether or not to disclose one's HIV status, as compared to men who seem more inclined to believe that women should not disclose their HIV status, due to the risks associated with women's HIV disclosure. At the same time, the data arguably reflects

...men are far more likely to believe in the need for partner disclosure...

...more than two thirds of respondents believed that women who do not disclose to their partners would be responsible for their partner's HIV acquisition...

gendered assumptions that women are more 'vulnerable' and 'at risk', as compared to being rights bearers and decision makers in the context of HIV disclosure.

Perceptions of non-disclosure consequences

Further assessing perceived consequences of non-disclosure of HIV status, respondents were asked who they thought would be responsible and what they believed should happen if a woman living with HIV is not disclosing her HIV status, and her partner subsequently acquires HIV.

More than two-thirds of all respondents (1913, 69%) believed that women who do not disclose to their partners would be responsible for their partner's HIV acquisition, and an additional 20% (461) thought that both partners would be equally responsible. Response rates varied greatly between the samples, ranging from 55% (402) of respondents in Illovo indicating that women would be responsible for their partner's HIV acquisition to 82% (353) in Tafelsig. The data shows a similar response pattern among respondents who believed that both partners would be responsible, ranging from 9% of respondents in Tafelsig to 27% of respondents in Illovo.

...we were supposed to use a condom, knowing or not knowing her status... [Man, 20s]⁷

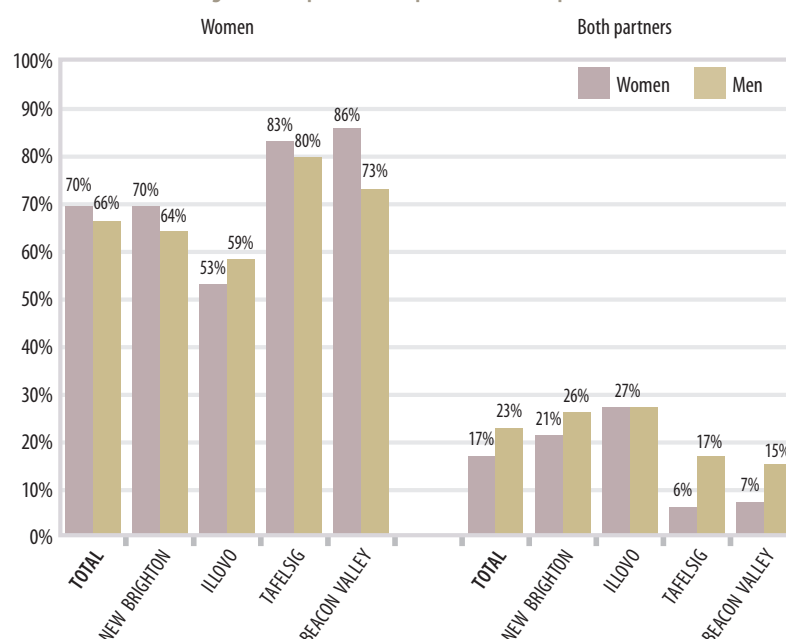
...it is our responsibility...no one can blame anyone...

[Woman, 40s]⁸

Of all respondents, a higher percentage of women (70%, 1005) believed that women would be responsible for their partner's HIV acquisition, as compared to 66% of men (608); while a higher percentage of men believed that both partners would be responsible (23%, 215), as compared to 17% of women (246). Respondents in their 20s were most inclined to believe that both partners are responsible (21% of women and 29% of men).

Except in the Illovo sample, the data also shows significant differences between women and men believing that both partners are responsible across the samples, ranging from 6% of women and 17% of men in Tafelsig to 21% of women and 26% of men in New Brighton.

Figure 5: Responsible for partner's HIV acquisition



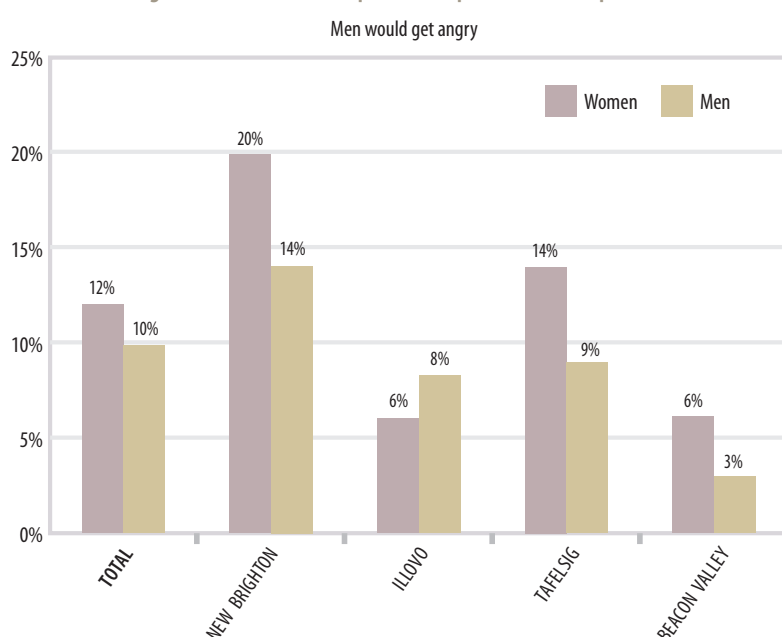
Asked what respondents thought should happen if a woman does not disclose her HIV status to her partner and the partner acquires HIV, a third of respondents (33%, 768) indicated that both need to get 'support', including 275 participants (12%) specifically referring to 'counselling' and 223 (9%) to 'treatment'. An additional 269 participants (11%) believed that both partners have to 'sort it out', without further qualifying as to how, and 11% of respondents (259) believed that 'men would get angry' and 'make problems for women'.

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...in our culture, my husband would be furious and he would divorce me... [Woman, 50s]⁹

With regards to respondents believing that 'men would get angry', there were significant differences in response patterns between the samples and between women and men. While only 5% of respondents in the Beacon Valley sample thought that 'men would get angry' (6% of women and 3% of men responding), in the New Brighton sample, 17% of participants responded to this effect (20% of women and 14% of men). Illovo is the only sample in which fewer women (6%) than men (8%) believed 'men getting angry' to be a potential consequence.

Figure 6: Perceived consequences for partner's HIV acquisition



Recognising high levels of violence and abuse against women, particularly against women living with HIV, in both Illovo and Beacon Valley, the response rates in these areas are arguably an indication of not only community members' lower levels of awareness of the prevalence of HIV-related violence and abuse, but also of possible levels of acceptance that men respond with abuse and violence to women's HIV disclosure.

Perceptions of HIV disclosure consequences

To further explore perceived consequences of HIV status

disclosure, respondents were asked what they believed are potential consequences for women as and when their positive HIV status becomes known within the household and family, at a community level, within healthcare provision, and at the workplace.

Families and households

Asked about potential consequences for women when their HIV positive status becomes known to family and household members, 33% of respondents (783) thought that women would get 'support' from family and household members, and 23% of respondents (538) believed that women would be 'rejected', 'treated differently', and 'discriminated against'. While women and men equally believed that women would receive

'support' (33% among both women and men), a slightly higher percentage of men (24%, as compared to 22% of women) indicated that women would be 'rejected' as a result of their HIV status becoming known to family and household members.

...the family will support her with her HIV status... [Woman, 40s]¹⁰

...if they love you and don't want you to be hurt, they will give you comfort... [Man, 50s]¹¹

Some of the respondents also made reference to the fact that the way women will be treated will 'depend' on the particular family (217, 9%), as well as that some family members will treat her 'well', while others will treat her 'badly' (173, 7%).

...it depends what knowledge the people you tell have... some people have wrong beliefs... [Woman, 40s]¹²

...I think 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]¹³

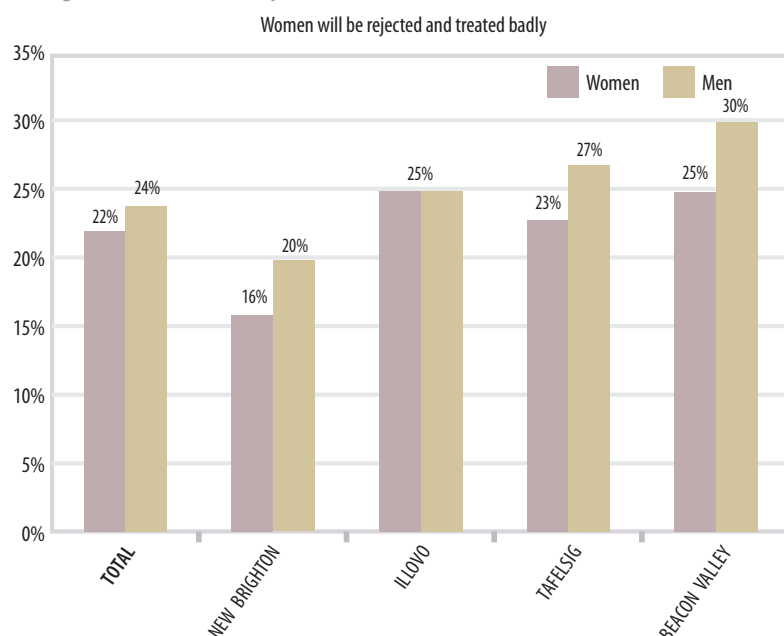
...in some families, they become supportive, yet in some families they will ask her not to cook... as if she is going to infect them... [Man, 40s]¹⁴

The response patterns of participants believing that women will be 'rejected' and 'treated badly' within their families and households, due to their HIV positive status, varied greatly between the samples. For example, only 18% of respondents in the New Brighton sample (16% of women and 20% of men) believed that women would be 'rejected', as compared to 27% of respondents in Beacon Valley (25% of women and 30% of men).

...I know my mom can chase me away, she can think I can spread HIV to them... [Woman, 20s]¹⁵

...some families will accept her, but most families will reject her and ask why she is bringing HIV to the home... [Woman, 50s]¹⁶

Figure 7: Perceived consequences of HIV disclosure within families and households



The questionnaire data seems to suggest that men are more aware and knowledgeable about the risks for women disclosing their HIV status to family and household members, than women. However, the data is arguably also a reflection of men's perceptions of what the consequences for women

whose HIV positive status becomes known within the family and household would be; taking into account that many times it is the male partner who would violate and abuse women living with HIV.

At the same time, women's lower levels of perceived risks of negative consequences of HIV disclosure to family and household members (as indicated by the questionnaire data) is possibly also indicative of women's levels of understanding of what constitutes 'ill-treatment' of women within families and households, as well as a certain degree of acceptance that there will be negative consequences for women upon HIV disclosure.

Communities

When asked about potential consequences for women as and when their HIV positive status becomes known in their communities, more than half of all respondents (1400, 59%) indicated that women would be 'rejected', 'treated badly', and 'discriminated against'. Of these, 497 respondents (36%) made specific reference to community members 'gossiping' and 'talking bad' about women living with HIV. Only 10% of the total sample (228) thought that women would be 'supported' at a community level. Similar to the response pattern regarding perceived consequences within families and households, some participants indicated that communities' responses to women living with HIV 'depend' on 'how educated communities are' (5%, 16), and that some 'will support her' and some 'will treat her badly' (8%, 195).

...it depends, the ones who have knowledge about HIV they will support her, others will call her names and stigmatise her... [Woman, 30s]¹⁷

While an equal percentage of women and men thought that women would receive 'support' from their communities (10% of women and 10% of men), a higher percentage of women

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responding (61%, 872, as compared to 57% of men) believed that women would be 'rejected' and 'treated badly'. The data shows that women in the Beacon Valley and Tafelsig samples (63% in both samples) were more likely to believe that women would have negative experiences, as compared to women in Illovo and New Brighton (60% and 59%, respectively).

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

[Woman, 40s]¹⁸

...she will lose respect and not be considered as a person...

[Man, 20s]¹⁹

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

...it's just bad...maybe in another lifetime it will work without stigma...not in this one... [Man, 20s]²¹

Healthcare

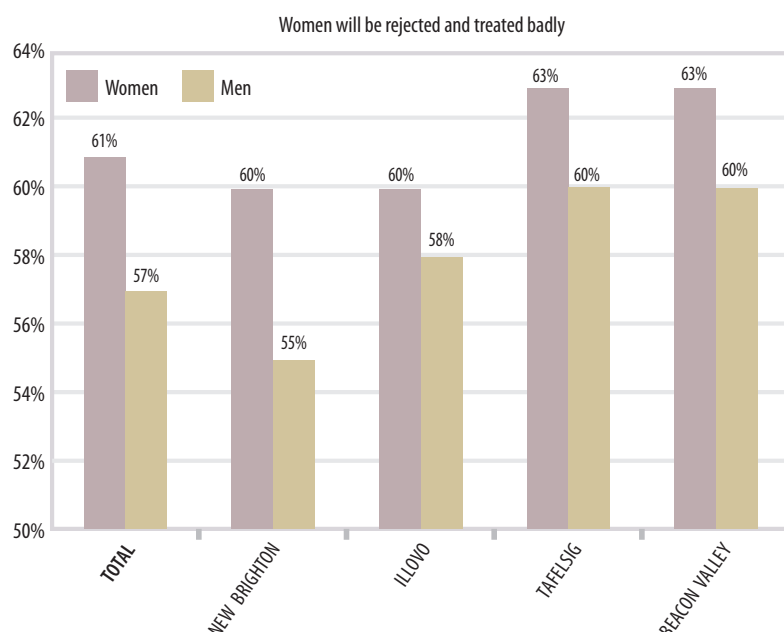
Asked about potential consequences within healthcare provision, most of the respondents (1527, 65%) indicated that women living with HIV would be treated 'well' and 'with respect' at clinics and hospitals, as it is 'their job to treat and support women'. Responses varied between the samples, ranging from 59% of respondents in Tafelsig (254) to 68% of respondents in Illovo (491) believing that women living with HIV are treated 'well and with respect' within healthcare provision.

...doctors will support her, it's their job... [Woman, 20s]²²

...they are educated, they know very well how to deal with this situation about HIV and AIDS...if there is a nurse that mistreats you, she must be fired... [Woman, 20s]²³

...I don't think they have a choice; they have to help her... [Woman, 50s]²⁴

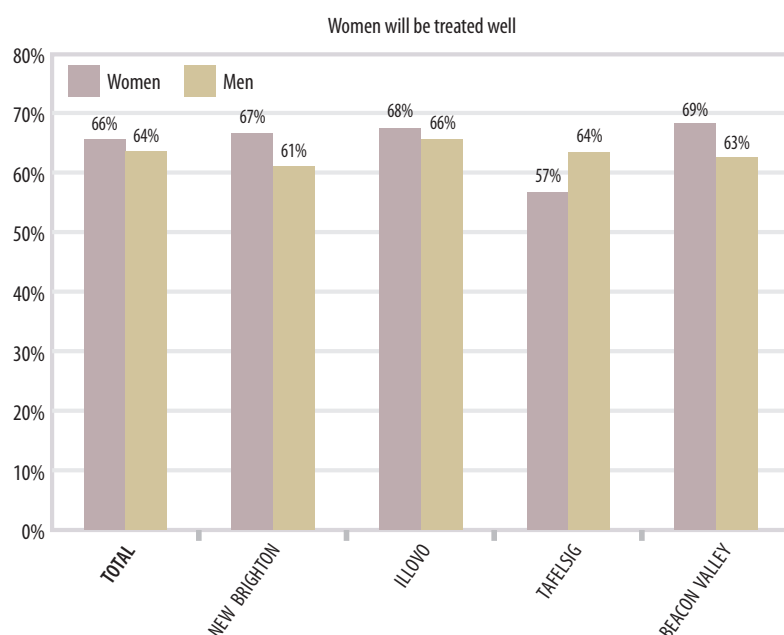
Figure 8: Perceived consequences of HIV disclosure at a community level



*...an indication...
of possible levels of
acceptance
that men respond with
abuse and violence
to women's HIV
disclosure...*

The data clearly indicates high levels of awareness about and prevalence of HIV-related stigma, discrimination and other rights violations in communities against women living with HIV, as well as knowledge about the risks associated with women's HIV disclosure.

Figure 9: Perceived consequences of HIV disclosure within healthcare



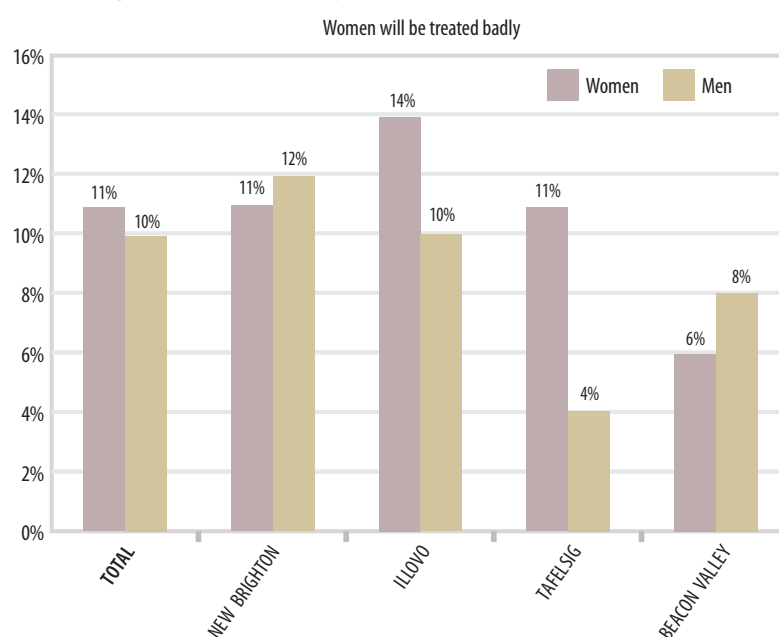
...indicative of women's levels of understanding of what constitutes 'ill-treatment' of women within families and households...

The data highlights low levels of awareness among community members about the prevalence of HIV-related stigma, discrimination and other rights abuses against women living with HIV within healthcare provision.

Of all respondents, 10% (11% of women and 10% of men) also thought that women would be 'treated badly' within healthcare provision, due to their HIV positive status. The data

shows that a far lower percentage of women in Beacon Valley (6%) believed that women would have negative experiences at the clinic, as compared to women in Illovo and New Brighton (14% and 11%, respectively).

Figure 10: Perceived consequences of HIV disclosure within healthcare



...communities' responses to women living with HIV 'depend' on 'how educated communities' are...

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...pulling faces and making remarks like 'no, don't worry about her, she has AIDS', that's what nurses will say...she will be last to be treated... [Woman, 30s]²⁵

...people with HIV are not treated with respect; they are separated from other patients... [Woman, 40s]²⁶

...the nurses have a bad attitude towards women living with HIV...even if you have an eye problem, they will not assist you...they will say it's because you are positive... [Woman, 50s]²⁷

...some nurses are treating us very badly... [Woman, 40s]²⁸

Respondents also made specific reference as to how the infrastructure of healthcare settings, including the separation of services, impacts negatively on women living with HIV, and often leads to involuntary disclosure of women's HIV status within healthcare provision.

...I don't like the style of the clinics...they have a special room for HIV and when you go there there's no confidentiality, no pre-test counselling...everybody knows if one is tested HIV positive... [Woman, 50s]²⁹

...when you fetch your treatment, you have your own place...so everyone will know your status... [Woman, 40s]³⁰

...clinics are not the same...in the New Brighton clinic, they don't treat HIV positive people well...the folders go lost and people are forced to disclose...and ARVs are counted and people walk up and down... [Woman, 20s]³¹

Workplace

Respondents were also asked to indicate what they believed are the potential consequences for women in the workplace as and when their HIV positive status becomes known. Of all respondents, 44% (1026, 45% of women and 42% of men) believed that women living with HIV would be 'rejected', 'treated differently', and 'discriminated against' in the workplace, as and when their HIV status becomes known to co-workers and management. Amongst these respondents,

17% (180, 20% of women and 14% of men) indicated that women 'would be fired' and 'lose their job' as a result of their HIV positive status becoming known. A higher percentage of women in the Illovo and Tafelsig samples (27% and 22%, respectively) believed that women would 'lose their job', as compared to women in Beacon Valley and New Brighton (13% and 14%, respectively).

...it will depend on what kind of job...if a domestic worker or nanny, they will fire you...but also, it depends on the employers... [Woman, 20s]³²

...they will fire me and talk about me in the whole town... [Woman, 20s]³³

An additional 15% of all respondents (351, 16% of women and 14% of men) thought that women would be 'supported' by co-workers and management, while 8% (187, 7% of women and 9% of men) believed that women's experiences at the workplace will 'depend' on levels of knowledge about HIV, as well as existing policies and programmes at the place of work.

...not all jobs have things for HIV, so I think most bosses will dismiss her, because colleagues won't want to work with her and they will complain... [Woman, 20s]³⁴

...they can be supportive depending on what kind of people she works with... [Woman, 30s]³⁵

...I think she can be victimised or lose her job, if there is no proper information, because the disease is very much stigmatised... [Woman, 40s]³⁶

...it depends on the levels of HIV information amongst her colleagues, but I think they will support her and treat her well... [Woman, 20s]³⁷

The perceived risks for women living with HIV to be 'discriminated against' in the workplace differed between the samples, ranging from 39% in the New Brighton sample to

51% in the Beacon Valley sample. The data also shows different response patterns between women and men, in that a higher percentage of women in the New Brighton and Illovo samples (as compared to men in these samples) believed that women would be 'discriminated against', while a higher percentage of men in the Tafelsig and Beacon Valley samples thought that women living with HIV would be 'discriminated against' in the workplace (as compared to women in these samples).

...from my experiences at my workplace, they stand away from one as you are a separate person, discriminate and have bad attitude against you, which is not supposed to happen at work, they supposed to support you, not destroy you... [Woman, 30s]³⁸

...people will become distant, but it's normal... [Woman, 50s]³⁹

...they discriminate you...even if you deserve a promotion, you won't get it... [Woman, 20s]⁴⁰

...people don't put their status on top of the agendas, because stigma is there at work and discrimination also...
[Woman, 40s]⁴¹

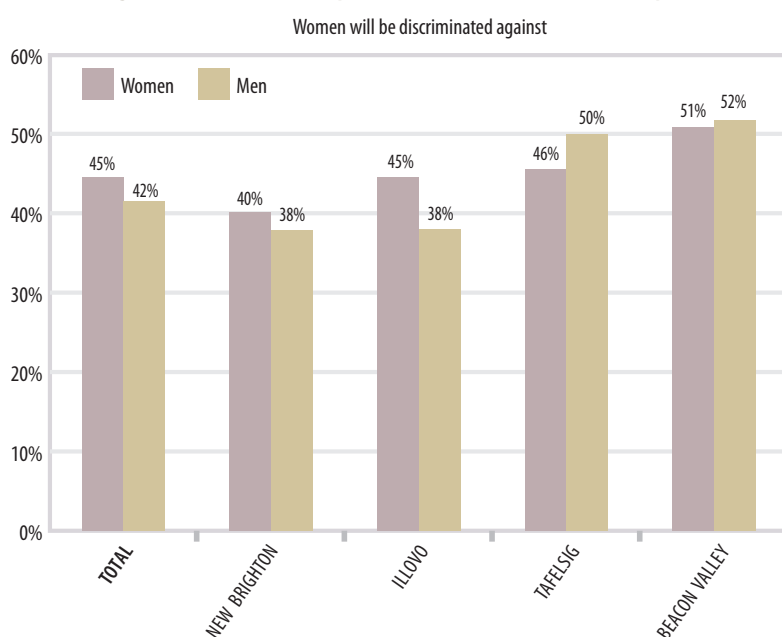
The data indicates high levels of awareness and knowledge about the potential risks for women as and when their HIV positive status becomes known at their places of employment. The data also seems to suggest greater awareness and knowledge about HIV-related stigma, discrimination and rights abuses at the workplace among community members in the Western Cape samples, as compared to the samples in the Eastern Cape and KwaZulu Natal, which is arguably indicative of variances in the unemployment rates of these communities.⁴²

Higher levels of perceived risks of HIV disclosure among women, as indicated by the data, could also point to the fact that since women are more likely to be employed in the domestic service sector and the informal sector of employment, women living with HIV are at greater risk of HIV-related stigma, discrimination and other rights abuses by co-workers and management, including being dismissed from work.

Discussion

The data clearly highlights that community members are well aware of the risks associated with women's HIV disclosure within their families and households, at a community level, within healthcare provision, and at the workplace.

Figure 11: Perceived consequences of HIV disclosure at the workplace



However, the data also suggests generally lower levels of awareness of the occurrence of HIV-related stigma, discrimination and other rights abuses in families and healthcare settings, as compared to rights abuses and violence against women living with HIV prevalent at a community level and the workplace.

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

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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

...firstly, it is not easy to disclose, and then if you do disclose you must commit yourself to the process that you're in this position.

*Like myself, I am having my friends, they're HIV positive too; talking with the same language, and we see things through the same eyes. But you can't just trust anyone, because there is a lot of rejection. If you just have an ordinary friend, don't even think of telling that person, don't even think about that. Otherwise you lose your friendship, because people they still don't understand. I don't agree with telling someone who is negative; tell someone who is just like you...*⁴³

Women's experiences, as collated through narrative interviews and incident forms, clearly illustrate the multiple risks and layers, as well as the continuum, of violence and abuse in all aspects of their lives upon disclosure of their HIV positive status. Women living with HIV shared accounts of being rejected and blamed, insulted, sworn and shouted at, called names, and gossiped about by family and community members alike. Women also spoke about being threatened, beaten, and stabbed, as well as forced to have sex without a condom.

Two of the women participating gave an account of being evicted from their rented accommodation as a result of their HIV positive status becoming known to the owners of the property, due to the unlawful disclosure of their HIV status by people they trusted.

While most women participating experienced multiple forms of abuse as a consequence of family members and friends

disclosing their HIV status, women who themselves disclosed their HIV positive status shared similar experiences of violence and abuse subsequent to their 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.

*...my mother asked me what was wrong, because I was continuously sick and going to the clinic. I then told my mother and I thought she was going to give me support; but she said it can't happen in this family, she doesn't have a family like that, and she started swearing at me and saying she can't have someone like this at her house and that is when she called my father's family... I have never seen my mother like that in my entire life, she was very angry at me... when family members asked about the purpose of the meeting, my mother just stood up and pointed at me and said: 'this bitch here goes and sleeps around and now she brought bad luck and sickness to the family. If her father was alive, he was definitely going to kill her'... that is where they decided they cannot accept me in the family, because I was going to infect other family members. They said I must go and stay with my children...*⁴⁴

*...when I tested HIV positive, I told my father. We went for counselling and then he decided to tell the whole family that I am HIV positive... the treatment changed. I had my own plate, spoon, my own blanket. I was sleeping under the table in the kitchen... my stepsister called me names and gossiped about me to people in the street...*⁴⁵

*...my daughters words were: 'mommy forgets that mommy is already in a nasty fix'... if these things are said, then it is in moments when one is angry. You don't expect these things to come out, but then at the end of the day, it still comes out. And if it comes from someone from outside, then it won't hurt me so much, but like I said, it comes from my child, and it really hurts...*⁴⁶

...he beat me for bringing HIV into his home. I couldn't even touch my face, I was so swollen... he locked me inside the house

*and refused to take me to the hospital; he bought Deep Heat and other painkillers from the pharmacy... that's when I regretted that I agreed to do the stupid HIV test...*⁴⁷

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... when I gave my husband my test results, he said 'I am so sorry my wife, I didn't tell you before that I am HIV positive'... it was a week after I tested positive that the husband wanted sex without a condom and that same week the beating started. I was afraid to have sex with him because of my HIV status. He told me 'you are not going to tell me you're not going to have sex with me. I'm your husband and we are supposed to have sex, because we have done it before'. I told him if I had known he was HIV positive, I would not have taken the risk of sex without condoms... the social workers put me into an outreach centre for abused women and children and I divorced my husband...*⁴⁸

...multiple risks and layers, as well as the continuum, of violence and abuse...

While some women, particularly in Illovo, 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 endured.

...the relationship started deteriorating. My brothers didn't want to eat the food that I cooked and finally one of my brothers took the decision that I should go and stay with the child's father, so

*that the father can take care of me and the kids, as they were not prepared to stay with sick people...*⁴⁹

*...it was in 2008, when I was sick, I didn't know what was wrong. My husband requested that we both do an HIV test and unfortunately, the results came back positive... the in-laws blamed me and they chased me out of my husband's house while I was sick. I went back to my parent's house where my mom took good care of me until I recovered... even today, I still feel the pain and hear their voices swearing at me and blaming me for everything...*⁵⁰

*...my friends were not informed by me that I am HIV positive, they just knew that I was sickly... this didn't stop them from preventing me from using their cups that they use for themselves when I visited them. They had no shame in telling me that I can't use their toilets either and they started telling their children that they can't play with my children... I had problems with my husband too... this upset me so much and it became so unbearable that I moved away from that area to where I am staying now... here I don't tell anyone about my status and we are happy here...*⁵¹

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 positive status became known to families, friends, and community members.

*...when I got back from the clinic after testing HIV positive, I told my best friend whom I took as a sister. She was the first person I told... after I told her, she went home and told the people in her house... it started when another neighbour talked about that I have AIDS. The houses are close together and news spreads like fire here... I tried to be upright, though I felt very hurt...*⁵²

...I told my best friend that I was tested HIV positive. I trusted

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her so much; I believed that she will be able to keep my secret.

*Little did I know that she was not the person I thought she was...without my permission, she told my partner that I was HIV positive. My partner blamed me for bringing HIV into our relationship and not being faithful. He started to beat me up, especially when he was drunk. He blamed me and forced me to have unprotected sex for many years, until I decided to leave him...*⁵³

*...people will know now, because he shouts at me in the streets... it hurts me very much, I don't even want to walk down the road anymore...they [neighbours] were ok with me, liked me a lot, laughed and talked to me a lot. But now, it is no longer the same...I don't feel safe anymore...*⁵⁴

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. Instead, women experienced blame and rejection, as well as various forms of verbal abuse, from being called names to being gossiped about.

*...although I was ready to disclose my status, the community was not ready to accept me...*⁵⁵

Women also shared how these experiences of violence and abuse effect their lives, mostly making references to being scared of leaving the house, feeling unsafe, and the effects of the ongoing abuse on their health and overall well-being.

*...I remember it was in July when one of my neighbours shouted at me saying that I'm spreading HIV, that's why people don't buy from me anymore. I was so shocked, because I didn't tell anyone about my HIV status. 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...*⁵⁶

...these constant comments all got too much for me. And when I discovered that she told everyone in church that I've got AIDS, it

*was just too much...my health suffered tremendously because of this treatment from my grandmother...*⁵⁷

Based on their experiences of HIV disclosure, both voluntary and involuntary, some women underscored the need of being careful to whom and when to disclose one's HIV positive status, while others shared that they chose not to disclose their HIV positive status any more, after they moved to different areas.

*...it is risky...you need to think carefully about disclosing and that's why I keep mine a secret...*⁵⁸

*...in the community, you can't tell someone you're HIV positive, not even your neighbour...it's not safe, they will always reject you...you can laugh, talk and sing with them, but keep it quiet, because they always will point fingers...*⁵⁹

...women were not the ones deciding on the time of, or the manner in which, their HIV positive status became known...

*...things still break my heart when people say things about HIV positive people, even if it's not about me...honestly, I don't think we should disclose in the communities we stay in, not with the way things are. People are too uneducated in my opinion...just be careful about who you disclose to, because just when you think you trust this person, then they go and spread the news that you are HIV positive...*⁶⁰

*...if I knew what would happen, I would have kept it for myself...*⁶¹

Summary

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.

Especially in the context of families and households, women's accounts of HIV status disclosure further seem to indicate that communities' perceptions as to how women living with HIV are treated is very different to the realities of women living with HIV in these communities, as women's experiences account for high levels of HIV-related violence and rights abuses within their families and households.

WOMEN'S EXPERIENCES OF ACCESS TO HEALTHCARE

*...that's how most people find out that you are HIV positive, when they see you at the clinic...*⁶²

The experiences of women living with HIV gave an account of the ill-treatment, abuse and rights violations endured at clinics and hospitals, including healthcare providers' discriminatory attitudes and remarks. 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 appointment. One woman shared being threatened with arrest by a doctor for not coming to the clinic at the time of the appointment.

...in July this year, I missed my appointment to collect my ARVs, because I had to go to work that day...when I went to the clinic three days later to get a new appointment, the nurse shouted at

*me to leave and come back when I don't have a job to go to...I asked if I can't get a new date, but she told me that I didn't think of the date when I missed my appointment...I begged her for a new date, but she refused...*⁶³

*...in late 2010, I went on holiday...I missed my and my child's dates and I also didn't inform the doctor that I'll not make my appointment for medication. The medication for me and my child were not finished yet, so I was not worried...when I returned from holiday, I went to the hospital. The doctor was very furious and upset, because I dared miss the appointment of the child...so the doctor said he would take me to the police station because I missed the appointment for my child. They are not so much worried about us, but they are worried about the kids. The children are more important, because they are children and if you don't look after them properly, then they will die quickly, you understand, that's why they are very strict on children...I begged and pleaded so that they did not take me to the police station, but the doctor said that it is my last warning...I even had to go get an affidavit to state where I was and I had to beg and plea that they should not take me in...*⁶⁴

Many women also 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 setup of the clinics, and the separation of services.

*...in December last year I went to the clinic for my CD4 test result. When the nurses called for all who came for CD4 results, I didn't stand up, because I was scared that my neighbours who were there will know about my HIV status. I sat there waiting for my turn to get inside the nurse's room. When I got in, I told the nurse that I was here for my CD4 test results. She then started shouting at me saying that why do I still hide my status, because everybody is living with HIV...do I think I am special and more important than others. Before I left the clinic, everybody knew that I am living with HIV...this was the saddest day of my life. I decided to go to another clinic...*⁶⁵

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...we come from the back with our file...now people aren't stupid anymore, they know by now that that side is the HIV clinic...and now perhaps there's someone that you know [at the clinic] and don't even know you have this sickness, and now you come from the back...⁶⁶

...some people don't want to go, because they know some people would know they're HIV positive...by sitting there everyone knows that I am HIV positive, so let me not go sit there... if they can mix us, then maybe also the death rate of people living with HIV and AIDS will be decreased...⁶⁷

Women, recognising the risks of potential HIV status disclosure, as well as other violations, in clinics and hospitals, made reference to how these challenges impact on their and other women's access to healthcare, particularly access to ARV treatment.

...some people they're hiding themselves, they don't want to be seen taking ARVs at the clinic and they will end up defaulting the treatment, because 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...⁶⁸

...something bad happened to me at the clinic. It was bad for me. It was not the nurse, but the lady sitting at the computer...I missed my date, so I went the day after...she was very rude and telling me I am a day late. She didn't wait for an explanation, she was just rude...luckily there was no one at the clinic when this happened...I never went back to that clinic again, because I don't like people being rude with me over and over again, when I need help, so I have not been back to the clinic...I want to still find out about another clinic that I can go to, because I don't want to go to this clinic any longer...⁶⁹

Women who participated in the focus group discussions shared similar experiences of ill-treatment by healthcare workers, and involuntary disclosure of their HIV status, due to the way services are provided in clinics and hospitals. Women also spoke in depth about women avoiding going to the clinic

and subsequently defaulting on their treatment, as a result of healthcare providers' attitude.

...I just want to talk about the nurses' negative attitude... sometimes they are the ones who make people afraid to come to the clinic. The nurses are very cheeky, when you ask questions, their response is like they are doing you a favour, and that's why people don't want to come to the clinic. Also the way they give information, it's not done in the right way, they just scream at you that 'you must use condoms, otherwise you will die'...the nurses at the clinic really need an ongoing training, especially focussing on their attitude...nurses need to change their attitude...⁷⁰

...sometimes you go to the clinic and you get ill-treated by the nurses or counsellors; you might be scared to go back to the clinic because you are scared of what will happen to you...sometimes you can end-up defaulting...⁷¹

...the lack of assured confidentiality...and the risks of involuntary disclosure...

Summary

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 limit women's access to quality healthcare free of fear, stigma and discrimination, but also deter women from accessing healthcare.

SERVICE PROVIDERS' PERCEPTIONS

Service providers' perceptions of women's experiences of access to healthcare, and treatment within healthcare settings, underscored the many barriers to women's access to quality care. Service providers participating made reference to the lack of confidentiality and the impact of the structural setup of healthcare centres on the risks of unintended disclosure of women's HIV positive status.

...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...⁷²

...there is a separate room that every person knows that the said room is for people living with HIV. People's HIV status is disclosed publicly in that room, it doesn't matter who or how many people are in that room. The settings at the clinic is wrong, because even community members know that once you are in a certain room, it simply means that you are HIV positive. I wish there can be a place away from the clinic that serve people living with HIV...⁷³

Service providers also spoke about the ill-treatment and abuse women have to endure as and when they miss their clinic appointment, as well as the general lack of sensitivity towards women.

...there is no privacy at the clinic, because the nurses and sisters will just check your file and start shouting at you if you skipped your appointment. Instead of calling you into the room and asking you politely why didn't you honour your appointment, they prefer to shout at you in front of patients and colleagues...⁷⁴

...the way healthcare workers hand over the news [of an HIV positive test result] to women is also sometimes traumatising

for the fact that they will break the news insensitively and without any consideration of women's fears or pains...⁷⁵

To enhance women's access to healthcare services and to ensure that health services are provided in an environment that is free of stigma, discrimination and other rights abuses, service providers made various suggestions for change. Service providers' recommendations included education and training of service providers and community members; change in service providers' attitude towards women living with HIV; and building bridges between community-based service providers and healthcare providers at clinics and hospitals.

...clerks and nurses at the clinic must change their attitude and try to be professional when addressing issues of women living with HIV...⁷⁶

...in my opinion, each person at the clinic must be treated equally, they must be treated like human beings, there must be no discrimination based on HIV status...we, as the community and the health sector should work together hand in hand so that we can move forward...as long as we work past each other, women living with HIV will be treated badly and discriminated against...⁷⁷

Discussion

Service providers' perceptions 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.

As such, the data arguably shows a far greater understanding among community-based service providers of women's risks of ill-treatment, abuse and other rights violations within healthcare provision, as compared to community members in the respective areas.

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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

Measuring the levels of knowledge and awareness of redress mechanisms available to women living with HIV, respondents were asked what they thought women can do if their HIV status has been disclosed without their consent; and if they experienced discrimination based on their HIV positive status.

Perceived redress for HIV status disclosure without consent

Asked what steps women can take as and when their HIV positive status has been disclosed without their consent, 41% of respondents (958, 41% of women and 40% of men) indicated that women have to take 'legal actions' against the person. An additional 8% of the total sample (198, 8% of women and 9% of men) thought that women must 'do something', without further qualifying their responses, while 11% (260, 11% of women and 11% of men) indicated that they do not know what women could do in such a situation.

...I'll throw out a peace order. You don't have the right to discuss my private life with anyone... [Woman, 20s]⁷⁸

...I'm going to the police station to open a case, because it's not their status, it's mine... [Woman, 30s]⁷⁹

...it's against the law; she would have to go to the police...
[Woman, 40s]⁸⁰

...definitely seek legal advice, because sometimes you aren't ready psychologically for the people to know...you should seek

legal and psychological help, because it has a lot of implications if you aren't ready... [Woman, 40s]⁸¹

However, 14% of all respondents (331) thought there was 'nothing women could do', as women should 'just ignore and go on with their lives', and because 'going to the police' would not change anything. Almost half of these respondents (150) were from the Illovo sample (21% of women and 20% of men).

...there are also risks associated with taking legal actions...

...she should just ignore, because taking them to the police station or getting them arrested would not help or change anything... [Woman, 20s]⁸²

...she must stay calm and pretend as if it never happened...
[Woman, 20s]⁸³

...people should not listen to what people say...if you know your HIV status, just ignore them... [Woman, 20s]⁸⁴

...we can't go to the police, because they won't help you they will laugh at you... [Woman, 50s]⁸⁵

Respondents' levels of awareness about what redress is available to women greatly varied between the samples, in that only 32% of respondents in Illovo (229, 34% of women and 28% of men) thought that women should take 'legal actions', as compared to 55% of respondents in New Brighton (435, 56% of women and 54% of men). While across all samples women were more likely to believe that 'legal actions' should be taken, Beacon Valley is the only sample in which a higher percentage of men (39%, as compared to 33% of women) indicated the need for 'legal actions'.

Figure 12: Perceived redress for HIV disclosure without consent



The data not only reflects relatively high levels of awareness and knowledge about rights protections in the context of HIV, but also indicates that communities are aware of and knowledgeable about redress mechanisms available to women whose HIV positive status has been disclosed without their consent. The data, however, also suggests great variances in the levels of awareness and knowledge between the areas, highlighting, among others, the need for intensified awareness raising and rights education, especially in the communities of Illovo, Tafelsig and Beacon Valley.

The data also shows that more women in their 30s (47%) believed that legal actions need to be taken against the person(s) disclosing a woman's HIV positive status without her consent, as compared to women in their 20s (42%), and in their 40s (41%). Similarly, data shows different response patterns amongst men responding, with 40% of men in their 40s believing that women need to take legal actions, as compared to 38% of men in their 20s and 30s. These responses are arguably also an indicator of different levels of access to information between women and men in different age groups. However, the data seems to suggest that women and men in their 20s across samples have the least access to information about rights

protections, as well as redress mechanisms, which seems to further suggest a general lack of rights education and awareness programmes focusing on women and men in their 20s.

Perceived redress for HIV-related discrimination

When further asked what steps women can take if they have been discriminated against based on their HIV positive status, a slightly higher percentage of respondents (43%, 1003) indicated that women need to take 'legal actions' when they have been discriminated against, as compared to 'taking legal actions' against disclosure without consent (41%,

958). An additional 10% of respondents (247) indicated that they do not know what women could do, while 6% (136) thought that women have to 'do something', without qualifying their responses.

...she must stand up and fight for her rights... [Woman, 20s]⁸⁶

...go to the police and lay a charge...everyone has their democratic rights... [Woman, 40s]⁸⁷

...she can take steps and actions...if she doesn't it will only get worse and bring her further down... [Woman, 30s]⁸⁸

...well, that's wrong, that's so wrong...she must take steps against these people... [Women, 20s]⁸⁹

Some respondents highlighted that although women have the right to go to the police and open a case, there are also risks associated with taking legal actions, as some people may respond with violence if a case has been opened against them. In addition, respondents mentioned the risks of further disclosures as a potential negative side effect of opening a case.

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...she must go to the police, if she is ready for the whole community to know that she is HIV positive...

[Woman, 40s]⁹⁰

Similar to respondents' perceptions with regard to HIV disclosure without women's consent, 17% (405) thought there is 'nothing women could do', as women should 'just ignore and go on with their lives'. Of these, 44% (179) were from the Illovo sample (24% women and 25% of men).

...to be discriminated takes away pride and respect, it's very hurtful...she must just stay strong... [Woman, 50s]⁹¹

...there is nothing you can do, because people are ignorant... [Woman, 20s]⁹²

...pretend as if nothing happened...move on with your life, because people will only destroy you... [Woman, 40s]⁹³

...she can't do anything, except to hide in shame... [Woman, 20s]⁹⁴

Respondents, especially from the Illovo and New Brighton, also made several references to 'women moving away' as a response to incidences of HIV-related discrimination.

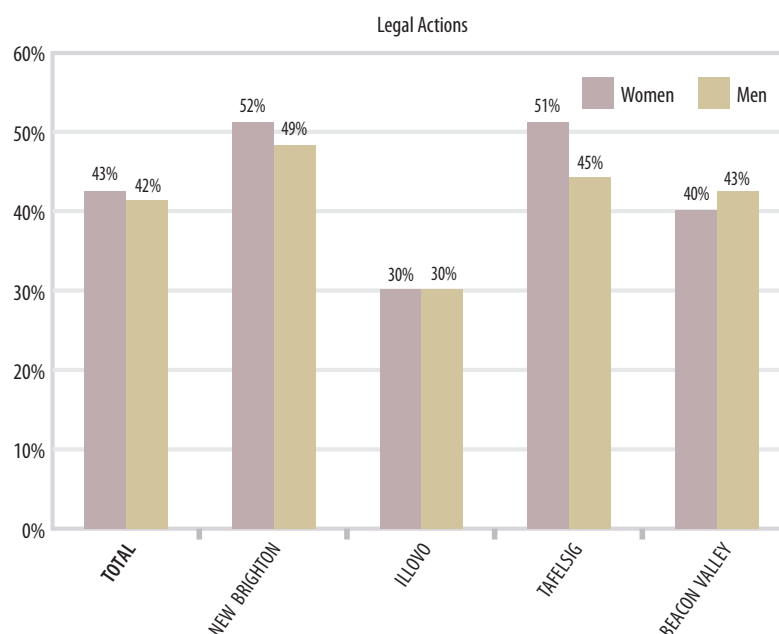
...she can move to another place, where they don't know her...

[Woman, 30s]⁹⁵

While there is no difference in the response pattern between women and men in the Illovo sample (30% of women and men, respectively), a higher percentage of women in the Tafelsig and New Brighton samples thought that women have to take 'legal actions' (51% and 52%, respectively), as compared to men in these samples (45% and 49%, respectively). In the Beacon Valley sample, the response patterns are very different in that more men (43%) than women (41%) believed that 'legal actions' need to be taken.

Respondents' perceptions as to whether or not women living with HIV should take 'legal actions' vary greatly between age groups, with 51% of respondents in their 40s indicating that 'legal actions' need to be taken, as compared to 39% in their 20s, and 41% in their 30s.

Figure 13: Perceived redress for HIV-related discrimination



Again, the data shows fairly high levels of awareness and knowledge of available redress mechanisms for women who have been discriminated against due to their HIV positive status. The data also shows significantly varying degrees of awareness levels between the samples, arguably underscoring the need for intensified awareness raising and rights education, especially in Illovo.

Discussion

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. The data, however, also highlights the vastly different degrees of awareness and knowledge levels between samples.

The data further 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.

Recognising the prevalence of rights violations and abuse against women living with HIV, the data also seems to confirm that the knowledge about redress mechanisms, including taking legal actions against a person who is violating the rights of a woman living with HIV, does not necessarily deter community members from unlawfully disclosing women's HIV status or from discriminating against women living with HIV. In addition, experiences of delayed, insensitive and/or no responses by the police further impact on the potential effect of available redress mechanisms as both a deterrent to discrimination against and violation of women living with HIV, as well as a recourse to women who have been violated and abused based on their HIV positive status.

WOMEN'S EXPERIENCES OF SEEKING REDRESS

*...the community will keep on talking. What can we do? On the other hand you will just be stressed further. So you're going to report one person today, another one tomorrow and somebody else the next day. At the end of the month, how many people are you going to report? Just prove to the community that I am the same person I was before. I am still human, I live with it, I love with it. There is nothing wrong with me. Just prove a point, that's all...*⁹⁶

The majority of women participating knew of their right to take legal actions against the person(s) for the unlawful

disclosure of their HIV status, and other forms of abuse and violence committed against them, due to their HIV status. However, most women did not seek any form of legal redress for the abuse and violence committed against them; instead they sought support and advice from family members and friends. Some women also spoke of going to social workers and counsellors to get advice.

*...she has the right to go to the police station to report it, because that is what the law says, no one has a right to tell...you share in confidence your problem with someone and then that someone creates just a bigger problem for you by telling the next person, who spreads it to two, three other people, and then your problem ends up being a much bigger problem...which is the case for many positive women...she has the right to report to the police and then the law must take its course...*⁹⁷

Fears 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...*⁹⁸

*...I thought that they will try and talk to her and that will just make things worse for me...*⁹⁹

*...no, I don't want her to be arrested, at the end of the day, we are family...*¹⁰⁰

*...I am not the talking type, I was too embarrassed...*¹⁰¹

*...I didn't want people to laugh at me...*¹⁰²

Women from New Brighton, Beacon Valley and Tafelsig, who sought legal redress, spoke generally of their disappointment with the lack of support they received, including insufficient sentences as and when cases went to court.¹⁰³

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*...I went to the police station and they told me I should go to the social worker, they don't deal with such cases...*¹⁰⁴

*...I went to make a case, but nothing happens with the case, because the docket got lost...my suspicion is that the docket got lost because a relative [of the accused] works at SAPS...*¹⁰⁵

*...the court gave a letter to warn her not to repeat her name calling in 30 days...she was quiet for a month or so and then, last night, she did it again...*¹⁰⁶

*...two days after the incident, I reported the case to the police and all of us, including witnesses had to go and testify in court... they just gave them a warning...*¹⁰⁷

Women also spoke about being ridiculed by police when trying to open a case; the lack of confidentiality at the police station; and police failing 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...*¹⁰⁸

*...there is no privacy at the police station...they talk like for everyone to hear. You stand in the queue and then they call you one by one to the counter...then I say, I am here to lay a charge of discrimination and he says, 'so, Misses, now what did they do to you, did you tell them that you have AIDS?...'and then it's like the whole police station is staring at you...when you come out of there you feel a great deal worse than before you went to the police station...this is not on, they have to get more privacy for people who want to come lay charges...*¹⁰⁹

Sharing their experiences of attempting to open a case at the police station, women in the focus group discussions talked about the emotional trauma caused by going to the police station, and needing to repeat, and in so doing relive, the incident several times in the process of opening a case. Recognising the impact of going to the police station and laying a charge, some women felt it might be better not to

open a case, because 'at the end of the day, you do more harm to yourself.

*...it's not easy to go to the police station...you hurt, you so hurt you can't express yourself, you can't even explain...and then you have to tell another person and another person and another person, and you never know who's sitting in the police station listening...*¹¹⁰

*...you must just go in your house and cry your heart out, there's nothing you can do...it's wrong, it's very wrong...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...*¹¹¹

Asked about the change they would want to see, women referenced the need for education and awareness raising for the police, and called for stricter sentences, as and when cases do go to court, as this would build confidence among women and create an enabling environment for women to take legal actions and receive adequate recourse in future.

*...I think the police must be more informed about the charges to be laid and how to deal with people like us when they come to the police station. They would have to go deeper into this issue to study and realise that there are cases like that...if one or two cases are being made and the police takes on those cases, then, I believe, that more will fall out of the closets to lay charges, because there are many people who do not know what to do with people who shout at them or shout about their illness in the streets...*¹¹²

*...I think they must make an example and maybe throw them in jail for a very long time if people call you names. My brother did six months, but because he is my brother, he did six months outside. It was going to be a six months inside Pollsmoor, but then they said, because he was my brother, they're going to give him a lighter sentence...*¹¹³

Summary

Women's experiences illustrate both the barriers to accessing legal redress, and the 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.

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.

COMMUNITIES' KNOWLEDGE OF RIGHTS PROTECTIONS FOR WOMEN LIVING WITH HIV

To explore respondents' knowledge and understanding of rights protections, the questionnaire included a series of questions asking whether or not women living with HIV should have sex; should get pregnant; and should get married. Respondents were also asked whether or not they believed that women living with HIV should be encouraged not to have (more) children; to have a termination of pregnancy, and to be sterilised.

The questionnaire also contained a few questions to assess levels of knowledge and understanding of women's right to choose whether or not, and when, to test for HIV. To this effect, respondents were asked if they believed that pregnant women should take an HIV test; and women have the right to refuse an HIV test during pregnancy. In addition, the questionnaire assessed perceived consequences of women's refusal to test for HIV during pregnancy.

Sex, pregnancy and marriage

When asked whether or not women living with HIV should have the right to have sex, 78% of the total sample agreed

(1836, 77% of women and 80% of men), 17% disagreed (410, 19% of women and 15% of men), and 108 respondents (5%) were unsure. Responses varied greatly between the samples, ranging from 55% of respondents who agreed that women living with HIV have the right to engage in sex in Tafelsig to 88% in New Brighton and Illovo.

Of all the respondents who agreed, 32% (452) qualified their response by adding that women living with HIV should only engage in sex if they use condoms (31% of women and 25% of men). A higher percentage of women in their 40s (33%) indicated that women living with HIV have to use a condom, as compared to women in their 20s (29%) and women in their 30s (32%).

With regard to women's right to choose whether or not to have children, 61% of the total sample agreed that women living with HIV should have the right to get pregnant (1435, 61% of both women and men), while 33% disagreed (778, 34% of women and 32% of men), and 6% of respondents were unsure (141, 5% of women and 7% of men). Less than half of the respondents from Tafelsig and Beacon Valley (42% and 47%, respectively) believed that women living with HIV should get pregnant, as compared to 66% of the Illovo sample and 74% of the New Brighton sample.

*...high levels of prejudices
against women living with HIV
leading to abuse and violations
of women's rights to make
informed choices...*

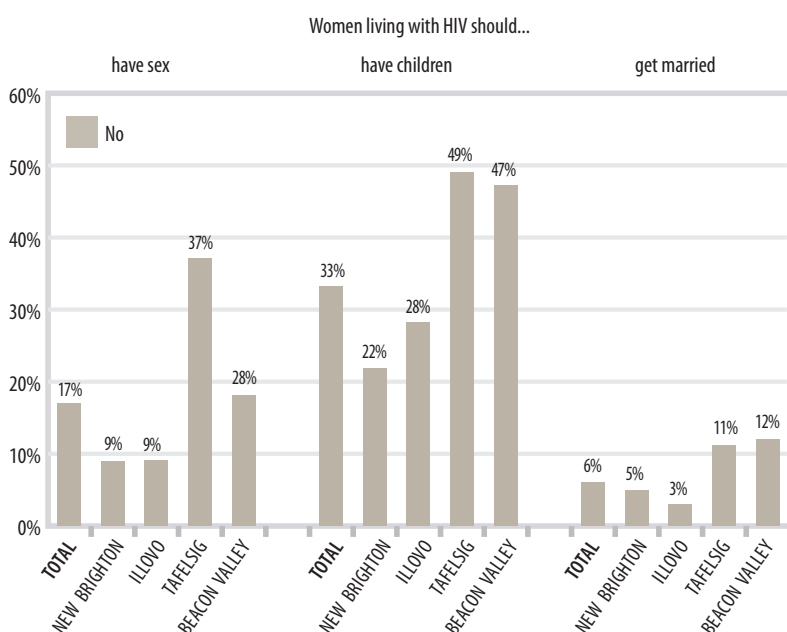
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The vast majority of all respondents (2135, 91%) agreed that women living with HIV should have the right to get married, 6% disagreed (153), and 3% (66) were unsure. Again, the two samples in the Western Cape were least likely to agree (84% of both the Tafelsig and Beacon Valley samples), as compared to the respondents in the Illovo and New Brighton samples (95% and 94%, respectively).

Beacon Valley) seem to suggest far lower levels of awareness and knowledge about women's rights, and thus implying that women living with HIV in these areas are at far greater risk of abuse and rights violations.

Acknowledging the links between levels of knowledge and prevalence of discriminatory attitudes and beliefs against women living with HIV, the data seems to indicate that women's limited access to information about rights protections in the context of HIV manifests itself in greater levels of HIV-related stigma and discrimination against women living with HIV.

Figure 14: Perceptions of rights of women living with HIV

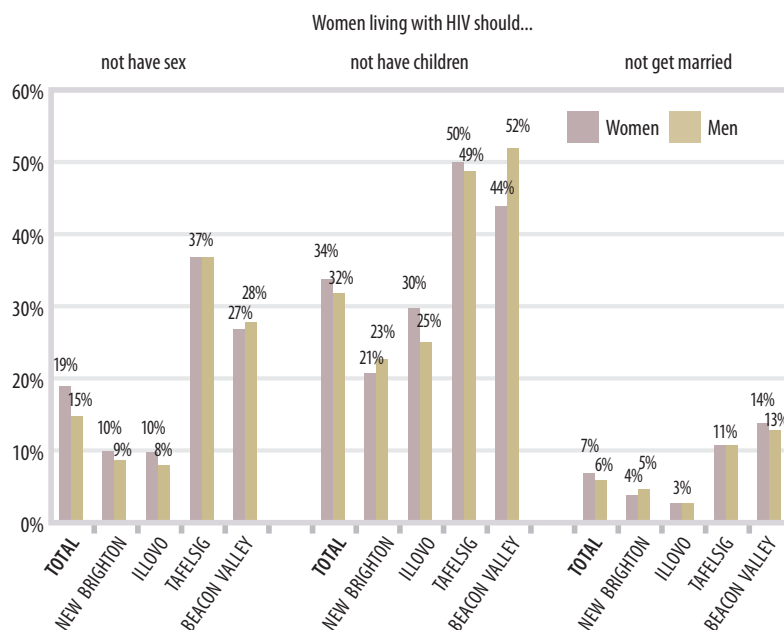


...women's sexual and reproductive rights are severely limited upon an HIV positive diagnosis...

The data undoubtedly reflects the prevailing levels of HIV-related stigma and discrimination against women living with HIV, and mirrors common assumptions at a community level that women's sexual and reproductive realities, rights and needs are severely limited upon an HIV positive diagnosis.

While the data highlights a general lack of knowledge about women's rights to engage in sex, have children and get married across all samples, there are significant differences between the various areas participating in the study. The responses from participants in the two areas in the Western Cape (Tafelsig and

Figure 15: Perceptions of rights of women living with HIV



Respondents who disagreed with women's right to engage in sex, have children, and be married were further asked to qualify their responses.

Of the respondents who did not agree that women living with HIV should engage in sex (410, 17% of total sample), more than two thirds (67%, 276) qualified their response with the risk of 'infecting the partner' and 'spreading the virus' (66% of women and 70% of men), while an additional 18% (74) indicated that women living with HIV are 'not supposed to' engage in sex, as they are 'sick' and should 'abstain' from sex (18% of both women and men).

...it's not right to have sex when you have HIV... [Woman, 50s]¹¹⁴

...because there are so many chances of becoming sick and die, it is better to abstain... [Woman, 20s]¹¹⁵

The 'risk of HIV transmission' was also the main reason mentioned by respondents across all samples as to why women living with HIV should not get pregnant. Of all respondents who disagreed (778, 33% of total sample), 72% (562) referred to the 'risk of transmission' (71% of women and 74% of men) as the reason why women living with HIV should not have children. An additional 18% of respondents believed that women living with HIV 'shouldn't get pregnant, because of their health' (139, 19% of women and 16% of men).

...what are the odds that they will have long and healthy lives with children growing up...who will look after the child... [Woman, 30s]¹¹⁶

...you're sick, why get pregnant... [Woman, 20s]¹¹⁷

...because it is a high risk for the baby and what I have seen in babies with HIV is very painful...it's not good for them... [Woman, 40s]¹¹⁸

With regard to the right of women living with HIV to get married, half of the respondents who disagreed thought that

it would be 'wrong', as women are 'sick and will die soon' (77, 48% of women and 30% of men). The 'risk of HIV transmission' as the reason why women living with HIV should not get married was mentioned by 22% of the respondents (22% of women and 21% of men), while 14% felt that women shouldn't get married, because they would not be 'treated right' by their partners and families (14% of women and 13% of men).

...there is no need, the purpose of getting married is to get babies and have nice sex, which she can't... [Woman, 40s]¹¹⁹

...the in-laws want babies and will treat her bad if she doesn't get pregnant... [Woman, 20s]¹²⁰

Termination of pregnancy and sterilisation

Respondents were asked whether or not they thought that women living with HIV should be encouraged not to have (more) children, to terminate a pregnancy, and to be sterilised.

Of all respondents, 32% believed that women should be encouraged not to have children (757, 34% of women and 29% of men); 12% indicated that women living with HIV should be encouraged to undergo a termination of pregnancy as and when they are pregnant (275, 12% of women and 11% of men); and 30% of all respondents thought that women should be encouraged to be sterilised (710, 33% of women and 26% of men).

Similar to the response patterns with regard to women's rights to engage in sex, have children and get married, a greater percentage of respondents in the Tafelsig and Beacon Valley samples believed that women living with HIV should be encouraged not to have children, to terminate a pregnancy, and to be sterilised, as compared to respondents in the Illovo and New Brighton samples. For example, almost twice as many respondents in the Tafelsig sample (47%) indicated that women should be encouraged not to have children, as compared to respondents in New

...women's sexual and reproductive rights are severely limited upon an HIV positive diagnosis...

Brighton (24%). The data shows similar marked differences regarding whether or not women should be encouraged to be sterilised, with 47% of respondents in Beacon Valley agreeing that women should be encouraged to be sterilised, due to their HIV positive status as compared to 20% of respondents in the Illovo sample.

In addition, the data also indicates that women across samples and across age groups are more likely to believe that women living with HIV should be encouraged to be sterilised.

Again, the data obviously highlights high levels of prejudices against women living with HIV leading to abuse and violations of women's right to make informed choices as to whether or not to have (more) children, to terminate a pregnancy, and to be sterilised. At the same time, the data strongly underscores common assumptions that women living with HIV should not have children and to this effect should be 'encouraged, forced or coerced' to be sterilised, a belief which; as indicated by the data, is more common among women than men in these areas.

Figure 17: Perceptions of women's right to choose

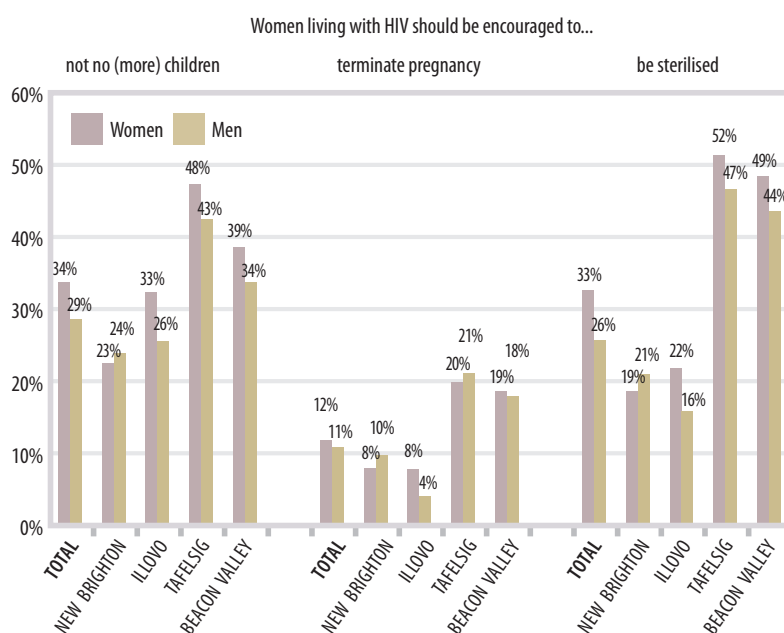
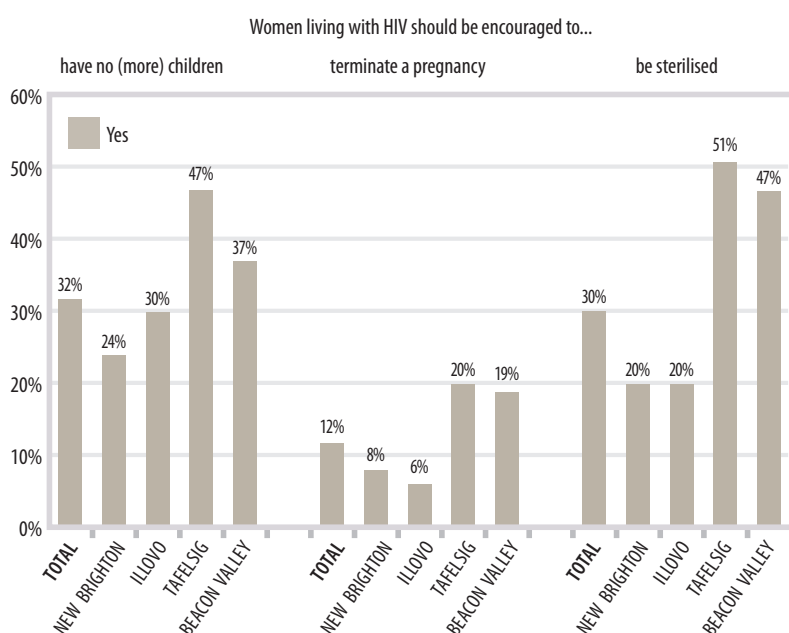


Figure 16: Perceptions of women's right to choose



Asked to qualify their responses, participants referenced the 'risk of HIV transmission' as the reason why they thought women should be encouraged not to have children (38%, 37% of women and 41% of men); and be encouraged to terminate the pregnancy (30% among both women and men). Similarly, respondents emphasised that it would be 'best for the child', as the 'child would suffer', as a reason why women living with HIV should be encouraged not to have children (16%, 18% of women and 12% of men), and encouraged to terminate a pregnancy (19%, 18% of women and 20% of men).

...it's about the children's lives...people with discriminate against the kids, and their lives will be miserable... [Woman, 20s]¹²¹

...they should be encouraged to make sure they don't get children...for their own sake... [Woman, 30s]¹²²

In addition, some respondents also underscored that women should only be 'encouraged, not forced' to have no more children (13%, 12% of women and 15% of men), to terminate a pregnancy (13%, 10% of women and 17% of men), and to be sterilised (6%, 6% of women and 7% of men), as it is women's right to make such decisions.

...it's up to the person living with HIV to decide what she wants to do... [Woman, 40s]¹²³

...may be encouraged, but not forced or coerced... [Woman, 20s]¹²⁴

Of all respondents who thought that women living with HIV should be encouraged to be sterilised (710, 33% of total sample), 38% indicated that it would be 'best for women not to have children' (268, 40% of women and 34% of men), with responses ranging from 34% in the New Brighton sample to 40% in the Tafelsig sample.

...it's to help her not to get children; she doesn't need them and she is unable to help, when she is sick... [Woman, 30s]¹²⁵

...if they want to have sex, they should be sterilised, so that they don't get more children...she's human, she also wants to have sex... [Woman, 20s]¹²⁶

...because then, they can enjoy their sex life... [Woman, 40s]¹²⁷

Discussion

While the data clearly indicates persistent levels of stigma 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.

The data on communities' perceptions about the realities and rights of women living with HIV pertaining to sexual and reproductive choices arguably confirms 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.

Recognising the availability of, and access to, services preventing the vertical transmission of HIV, the data further raises the question as to the impact of the knowledge of, and access to prevention of vertical transmission programmes, on the levels of awareness amongst community members about the risks of HIV transmission during pregnancy and childbirth, and the right of women living with HIV to decide whether or not to have children.

And finally the data suggests the dire need to raise levels of awareness and knowledge about sexual and reproductive rights of women living with HIV, and about the fundamental rights of women to freely make informed choices about sex and reproduction without fear of repercussions, coercion, discrimination and violence.

HIV TESTING DURING PREGNANCY

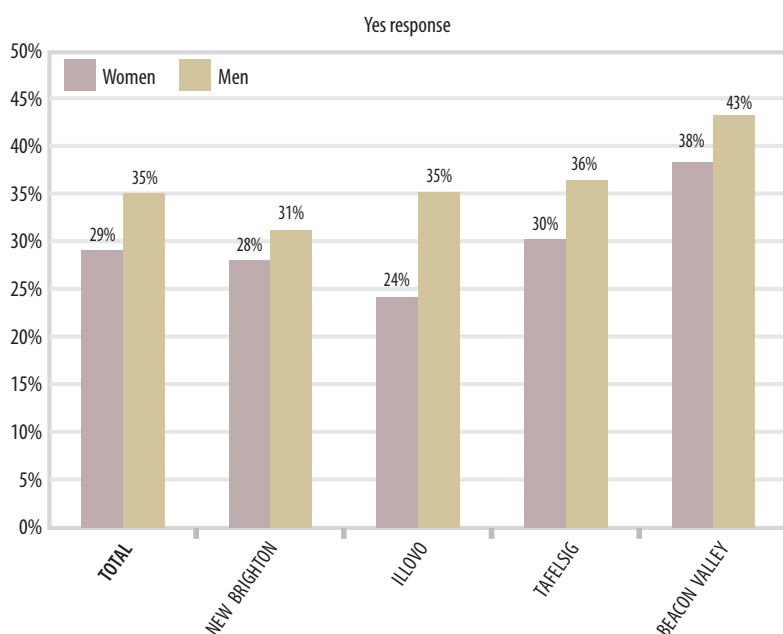
When asked whether or not respondents believed that women should get tested during pregnancy, the vast majority of respondents affirmed that pregnant women should get tested for HIV (97%), 2% disagreed, and 1% indicated that they are unsure.

Further asked if respondents believed that pregnant women should have the right to refuse to get tested for HIV, 31% of

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respondents agreed (736, 29% of women and 35% of men), 64% disagreed (1508, 67% of women and 59% of men), and 5% were unsure (110, 4% of women and 6% of men). The responses greatly differed between the samples, ranging from 28% of respondents in the Illovo sample who thought that women have the right to refuse an HIV test during pregnancy, to 40% of respondents in the Beacon Valley sample.

Figure 18: Women's right to refuse HIV testing during pregnancy



While the data undoubtedly indicates greater levels of awareness among men about pregnant women's right to refuse an HIV test, the data also seems to confirm the common assumption that it is women's responsibility and duty to test for HIV during pregnancy in order to protect the unborn child.

Further elaborating as to why respondents thought that women need to test for HIV during pregnancy and should not have the right to refuse, more than half of the respondents (782) expressed that women need to test for HIV 'for the sake of the child' (52%, 53% of women and 49% of men), and because 'women need to know' their HIV status, since they are pregnant (15%, 16% among women and 12% among men). An additional 12% of respondents indicated that women 'must' test, without further specifying as to why (12%, 11% of women and 14% of men).

...because if you are thinking about the health of the baby, wouldn't you like to know if you're HIV positive...
[Woman, 40s]¹²⁸

...in clinics, we are told that we are doing it for our babies, to save our unborn babies... [Woman, 40s]¹²⁹

...everybody should do the test for the baby... if they don't care about their own health, its fine, but it's for the protection of the child, so they should be forced... [Woman, 20s]¹³⁰

...because if she is educated, she will know that it's best for the unborn child... [Woman, 30s]¹³¹

Of the respondents who believed that women have the right to refuse HIV testing during pregnancy (736, 31% of total sample), 69% made reference to the women's 'right to decide' whether or not to test for HIV (509). Of these, 10% – although affirming that women have the right to choose – believed that it would still be 'best for pregnant women' to test for HIV. An additional 14% of respondents indicated 'fear of knowing', 'fear of consequences', and the potential 'harm to women' when tested positive for HIV, as the reason why women should have the right to refuse HIV testing during pregnancy.

...she can be afraid of knowing her status; it's not that she wants to hurt the baby... [Woman, 30s]¹³²

...they are scared of what the next person is going to say...
[Woman, 30s]¹³³

...it's her right; no one can test her without her permission...
[Woman, 40s]¹³⁴

The responses varied greatly between women and men and between the samples. While, for example, 15% more men

than women highlighted pregnant women's right to choose whether or not to test for HIV (78%, as compared to 62% of women), a higher percentage of women believed that 'fear of negative consequences' as and when pregnant women test positive for HIV is the reason why women should have the right to refuse the test (16%, as compared to 11% of men). The data also shows that respondents in the Tafelsig sample were least inclined to mention women's right to choose (61%, 52% of women and 81% of men), and a far higher percentage of respondents in New Brighton made reference to women's right to decide whether or not to test for HIV during pregnancy (77%, 72% of women and 81% of men).

Respondents also remarked on the risks for women claiming their rights, because women have the right to choose whether or not and when to test for HIV, this right seems to be taken away based on her pregnancy.

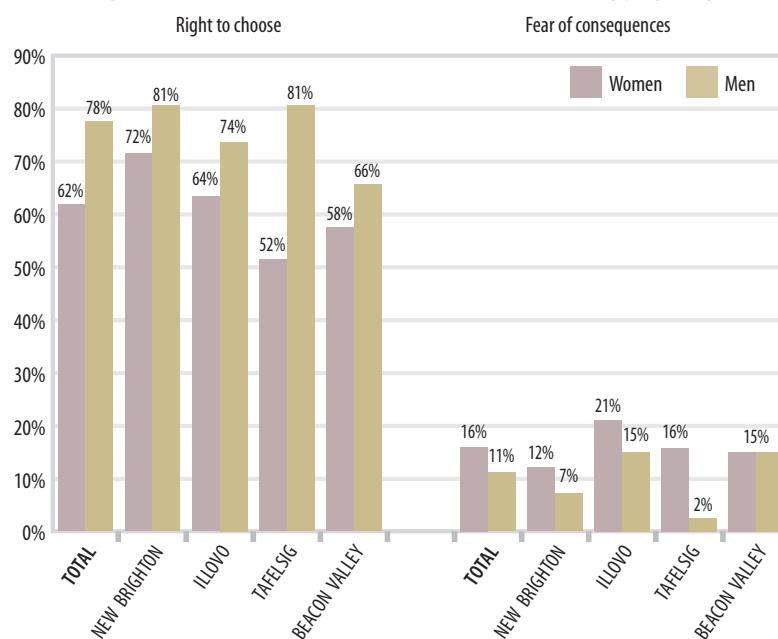
...at the end of the day, the doctor will not help her giving birth, if she has refused to test... [Woman, 30s]¹³⁵

...but they don't give you a choice, they tell you to do the test...
[Woman, 20s]¹³⁶

...pregnant women's responsibilities to protect the unborn child prevail over the knowledge of women's right to choose whether or not and when to test for HIV...

...you can't force anyone, but they test you, because they want to protect the baby... [Woman, 20s]¹³⁷

Figure 19: Perceived reasons for refusal to test for HIV during pregnancy



The data clearly highlights not only high levels of rights awareness, but also general levels of understanding of potential risks and consequences of women testing for HIV during pregnancy. In addition, the data shows that women are more likely to explain women's right to refuse HIV testing during pregnancy with the fear of negative consequences, as compared to men, who are more inclined to refer to women's right to choose.

These response patterns are arguably a reflection of women's greater knowledge, and possible experiences, of the adverse consequences of HIV testing during pregnancy, despite the knowledge of rights protections for women to decide whether or not and when to test for HIV. The data also possibly reflects women's experiences of HIV testing during pregnancy, and thus, the limited ability of women to decide whether or not to test for HIV, due to the pressure of HIV testing placed on pregnant women.

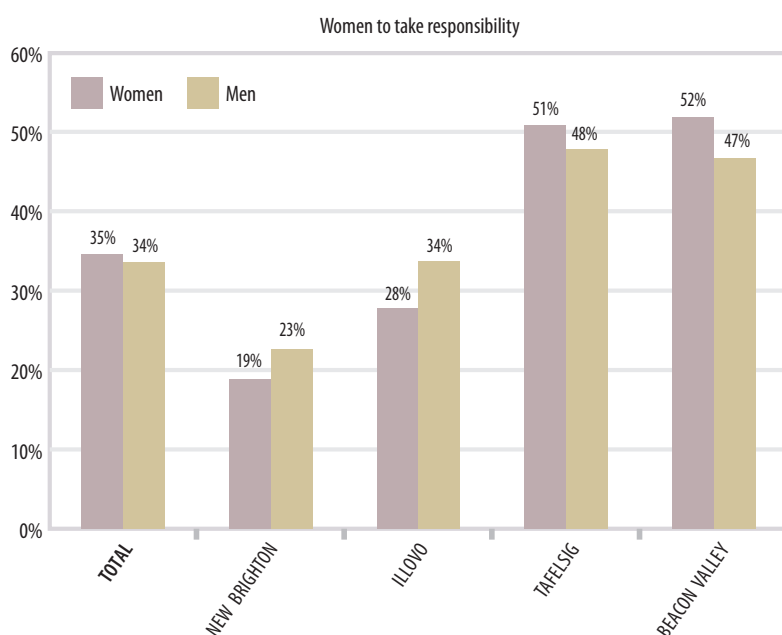
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Consequences of women's refusal to test for HIV during pregnancy

Respondents were also asked to explain what they thought would be the consequences for women who refused to test for HIV during pregnancy, and whose child later tests positive for HIV.

About a third of all respondents (34%) indicated that women need to 'be blamed' and 'take responsibility' for their actions (811, 35% of women and 34% of men). Of these, 10% made specific reference to 'legal actions' that should be taken against women (110, 8% of women and 12% of men). Respondents' beliefs that women need to 'be blamed' significantly differed between the samples, ranging from 21% of respondents in the New Brighton sample to more than twice as many respondents in the Tafelsig and Beacon Valley samples (51% and 50%, respectively).

Figure 20: Perceived consequences for women deciding not to test for HIV during pregnancy



...she must be held responsible for infecting the child, because if she did the test when pregnant then the child could have been born HIV negative... [Woman, 30s]¹³⁸

...the hospital should make a case against her, because she should have protected the baby... [Woman, 20s]¹³⁹

...the woman should be blamed...the nurses should shout at her for being selfish... [Woman, 20s]¹⁴⁰

...she will live with the guilt, because she refused...if she had tested, they could have done something about it...
[Woman, 40s]¹⁴¹

An additional 18% of respondents thought that both the woman and the child need to have access to 'medicines' (434, 18% amongst both women and men), and 14% indicated that women need to 'seek help and support' to deal with the situation, without further specifying their responses (333, 14% of women and 15% of men).

Discussion

The data, although demonstrating some levels of rights awareness, clearly reflects that communities' perceptions of pregnant women's responsibilities to protect the unborn child prevail over the knowledge of women's right to choose whether or not and when to test for HIV. Thus, as indicated by the responses, women who claim their right and decide not to test for HIV during pregnancy are to be 'blamed' and 'punished' if the child subsequently tests positive for HIV.

Hence, the data suggests that although there are some levels of awareness of both women's rights and women's risks pertaining to HIV testing during pregnancy, pregnant women are still expected to test for HIV, regardless, for the sake of the unborn child.

COMMUNITIES' PERCEPTIONS OF WOMEN'S RISKS OF HIV-RELATED VIOLENCE

Respondents were asked whether or not, and to what extent, they thought women living with HIV are at greater risk of

violence and other rights abuses, due to their HIV positive status, and what should be done to decrease women's risks to HIV-related violence.

Of the total sample, 45% of respondents agreed that women living with HIV are at risk of violence and abuse (1061, 47% of women and 42% of men), 43% disagreed (1020, 42% of women and 46% of men), and 12% indicated that they were unsure (273, 11% of women and 13% of men). The New Brighton sample showed a significant lower percentage of respondents believing that women are at risk of violence (33% among both women and men), as compared to 52% of respondents in both the Tafelsig and Beacon Valley samples (50% of women and 47% of men in Tafelsig; and 51% of women and 54% of men in Beacon Valley).

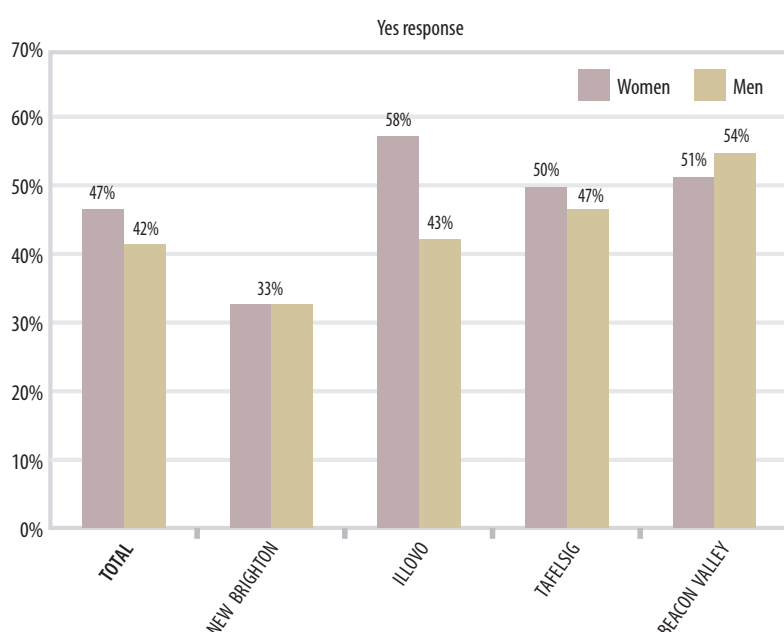
Furthermore, the data highlights greater levels of awareness and knowledge among women in communities, which arguably as much underscores women's knowledge, as it points to women's experiences of violence.

Respondents who indicated that women are at greater risk of violence and abuse, because of their HIV positive status, were asked to further elaborate on their response.

More than a third of respondents (36%) made reference to women being 'treated badly' and 'discriminated against', because of their HIV positive status, since people are 'ignorant' and 'have no education' about HIV (385, 37% of women and 34% of men).

...sometimes we don't even want to share anything with a woman living with HIV... [Woman, 50s]¹⁴²

Figure 21: Perceived risk of HIV-related violence against women



...if you have HIV, you must not tell people, because if you do, they will treat you like dirt... [Woman, 30s]¹⁴³

A further 36% respondents also indicated that women living with HIV would be 'abused', 'beaten by their partners', 'called names', and 'forced to have sex without a condom' and often subsequently experience a range of abuses, due to their HIV status (385, 36% of women and 37% of men).

...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]¹⁴⁴

While the data indicates undoubtedly the levels of awareness and knowledge of women's risks of violence and abuse based on their HIV positive status, the data also suggests the need for further awareness raising and education, especially in New Brighton.

...women are beaten up, others gossip about her and others don't want to eat with her... [Woman, 40s]¹⁴⁵

...people gossip and discuss everything behind a woman's back...even in the police station they'll make fun of her... [Woman, 30s]¹⁴⁶

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...like now, many women are abused, because they're blamed for bringing the disease home...so, we live in fear... [Woman, 20s]¹⁴⁷

Communities' recommendations for change

When asked what respondents thought should be done to address violence and abuse against women living with HIV, 37% of respondents thought that there is a need for 'awareness raising' and 'education' (392, 38% of women and 41% of men), and 10% highlighted that 'something needs to be done to stop the violence', without further qualifying their responses (11% among both women and men). The perceived need for 'awareness raising' and 'training' varied greatly between the samples. While only 19% of respondents in the Tafelsig sample thought that 'education' is needed to address violence against women living with HIV, more than twice as many participants in Illovo (52%) indicated that 'awareness' and 'education' are required to address the violence and abuse.

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

[Woman, 20s]¹⁴⁸

...we, as women, should stand together and stop gender violence... [Woman, 40s]¹⁴⁹

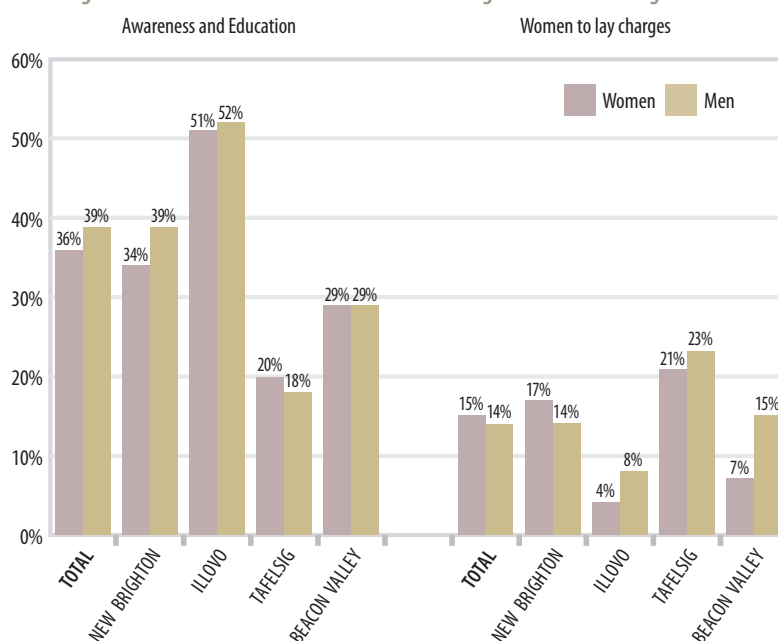
...government must do something about this and expose the rights of women living with HIV...there are too many laws, but little justice for this people... [Man, 40s]¹⁵⁰

...we need educational programmes which will enlighten peoples' minds and change their attitudes towards women in general... [Woman, 30s]¹⁵¹

In addition, 15% of respondents thought that women living with HIV have to 'lay charges' and take 'legal actions' against

the people who abuse and violate them (160, 15% of women and 14% men). Response rates significantly differed between the samples and between women and men, in that more than five times as many women respondents in the Tafelsig sample believed that women should 'lay charges' (21%), as compared to women in the Illovo sample (4%).

Figure 22: Perceived needs to address violence against women living with HIV



...women living with HIV must report these incidences to the police, so that people will learn and stop... [Woman, 40s]¹⁵²

...those women who are being abused must speak up and stand up for their rights... [Woman, 30s]¹⁵³

...women must break the silence and tell service providers of the abuse, so their dignity can be kept... [Woman, 30s]¹⁵⁴

Discussion

The data highlights some degree of communities' awareness of both women's greater risks of violence and abuse based on their HIV positive status and the needs to address violence and abuse against women living with HIV. However, the data also shows the varying degrees of awareness and knowledge in the respective areas, thus underscoring the need for

intensified awareness and education about the realities, rights and needs of women living with HIV.

Although the data indicates some levels of understanding among community members 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 role in perpetrating and perpetuating violence and abuse against women living with HIV.

Whilst recognising that almost half of the respondents were aware of women's risks of violence and abuse, the data also seems to suggest a certain degree of acceptance of HIV-related violence, abuse and other rights violations against women living with HIV, which is arguably a reflection of a societal context characterised by high levels of both HIV-related stigma, discrimination and other rights abuses, and high levels of violence against women.

...their role in perpetrating and perpetuating violence and abuse against women living with HIV...

SERVICE PROVIDERS' PERCEPTIONS OF WOMEN'S RISKS OF HIV-RELATED VIOLENCE

Service providers participating in the focus group discussions spoke about their perceptions and knowledge of women's risks of violence and abuse based on their HIV positive status. Many highlighted women's risks of rejection and other forms of abuse by partners and families, as well as the ill-treatment and humiliation women are faced with by community members and healthcare workers. Moreover, service providers spoke about the impact of women's disclosure, including the promotion of women's disclosure, on women's health and safety.

...in my areas there are many women living with HIV who are abused by their families...women will be told not to cook because no one will eat their food...she cannot touch anything...she will be called names and people will point fingers at her...¹⁵⁵

...women disclosing their status is still a very high risk, because of the abuse and violence...it is actually detrimental to their health...and now, you are promoting the importance of disclosing, but you can also see that it would not be of benefit for that woman to do this, because it might put her to the grave before she even can accept what is happening to her...¹⁵⁶

...the consequences HIV positive women face are basically due to the stigmatisation, discrimination and isolation, because there are still many taboos and misconceptions about HIV...even after all the awareness for the last ten to fifteen years, people still turn away from those who do disclose...so, yes women do run the risk of being discriminated against and isolated in terms of the illness...¹⁵⁷

Recognising the extremely high levels of violence against women in the communities, service providers also spoke in depth about women's exacerbated risks of violence and abuse in their relationships as and when their HIV positive status becomes known. Service providers also discussed the links between women insisting on condom

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use and the risks of violence, highlighting that the mere fact of women trying to introduce condom use in and of itself often causes various forms of abuse, ranging from accusations of being unfaithful and blaming women of not trusting their partners, to physical violence and forcing women to engage in sex without a condom. These risks will be heightened for women living with HIV, as women might feel the need to disclose to their partners because of fear of violence if women do not explain their HIV positive status to be the reason for requesting condom use, whilst at the same time risking more violence because of disclosing their HIV positive status to their partners.

*...surely, when you are abused and then you're coming back with a HIV positive result, the abuse will be more...*¹⁵⁸

*...if you are in an abusive relationship, it might make your risk higher simply because you don't have much to say about anything that goes on...so, you don't have a say whether you want to use condoms or don't want to use condoms...*¹⁵⁹

Discussion

The data clearly reflects NGO and community-based service providers' high levels of awareness and understanding of the multiple risks of violence and abuse for women living with HIV, which arguably also gives an indication of service providers' potential to adequately respond to women's realities and needs.

In addition, the data indicates that NGOs and community-based service providers are well aware and knowledgeable of the various links between, and causes of, violence against women in the context of HIV.

WOMEN'S EXPERIENCES OF HIV-RELATED VIOLENCE

*...here in our community men beat you once they know that you are HIV positive, and no one is really prepared to challenge that... the beatings of HIV positive women is very rife here...*¹⁶⁰

As reported earlier, women's experiences of living with HIV are a clear illustration of multiple forms of abuse and violence in all spheres of their lives, perpetrated by partners, families, friends, communities and service providers alike. Upon disclosure of women's HIV positive status, irrespective of whether or not women themselves decided the time of, and manner in which, their HIV status became known, women's lives change, due to fear and the continuum of violence and abuse perpetrated against them, based on their positive HIV status.

*...it's difficult, because if you don't disclose you are going to suffer and when you disclose you will be stigmatised...*¹⁶¹

Women participating in the focus group discussions also shared their experiences, talking about the rejection, humiliation, violence and abuse they endure, because they are living with HIV.

*...families are different, they have their own issues...you will be rejected and discriminated, just because you're HIV positive...that is why sometimes you will find people scared to tell their families that they are HIV positive, because they fear what will happen...*¹⁶²

*...once the community knows you are HIV positive, they will be pointing fingers at you and say that you are sick...they don't want to even touch you...*¹⁶³

*...you will be called names and you will be told that you're useless...you lose friends that you were close with, and when you lose friends you become lonely...and the rest of the community start pointing fingers...they do discriminate you, because of your status...people will define her as HIV positive and forget the person behind the HIV status...*¹⁶⁴

Speaking about the multiple layers of abuse, women participating in the focus group discussions particularly highlighted the impact of their HIV status disclosure on their relationships with partners, families and friends, as well as with neighbours and community members.

*...a general lack of
understanding of
the multiple actors
perpetrating the violence
and abuse against women
living with HIV...*

*...it was a very tragic experience for me to be rejected by my own family members...I had my own cup, my own saucer, everything of my own...when I was in hospital, she took my dirty clothes home and chucked them into the dustbin...I had to ask for clothes to wear from other people...*¹⁶⁵

*...it broke our family apart and ended my relationship, it messed up everything because of the blame... it's tough to deal with it...*¹⁶⁶

*...it still affects my relationship with my children's father to this day...when we argue, he will always bring it up and blame me...I don't know anymore how to deal with this...*¹⁶⁷

*...it was good before they [friends] knew I was HIV positive, but afterwards they changed...we were very close, but after they found out I was HIV positive, they started distancing themselves...*¹⁶⁸

Women also talked about the societal expectation that it is women's responsibility to protect their partners as one of the causes for violence, especially in situations in which women do not disclose their HIV positive status. Women felt strongly that given the risks of violence upon disclosure, that the responsibility of preventing HIV should equally be placed on both partners.

*...women are not responsible for the safety of their partners... everyone should know that they should use protection, whether the partner is HIV positive or negative...protection should be something you always use without knowing the HIV status of the woman you're with...*¹⁶⁹

Women's recommendations for change

*...we are all human beings; we just need to be treated the same...*¹⁷⁰

Women sharing their experiences of rejection, violence and abuse also shared their visions for positive change so as to ensure that women living with HIV are not violated and abused and that their rights are respected and protected in all aspects of their lives; that women living with HIV are treated equally, especially within healthcare provision; and that women who are violated and abused have access to adequate and quality services free of stigma and discrimination. Women also spoke of the need for safe places for women living with HIV who experienced violence and abuse, as well as services specifically designed to cater for the realities and needs of women living with HIV, such as women clinics¹⁷¹ and women-only support groups¹⁷².

*...there should be safe places where women who experience all this could go and talk freely without any fear...and where they will be helped...*¹⁷³

Based on the understanding that women's experiences of stigma, discrimination and other rights violations are closely linked to a lack of awareness and education about HIV and women's rights, women further emphasised the need for education, particularly rights education.

...people should be informed...I know if people are informed, they treat women differently...so, something needs to be done to educate people...it is not easy for women to speak out, because men don't listen to women...women must be educated about their rights, because when you have rights, you must exercise

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*them...I must not be seen as a woman who is HIV positive, but as a woman who is a human being...*¹⁷⁴

Recognising the multiple layers of abuse women experience within healthcare provision, women called mainly for training of healthcare workers so as to ensure professional attitude and access to quality services, as well as the need to assure confidentiality within healthcare provision, and integrated services.

*...I would like to see government employing people who are passionate about patients, people who really care for people living with HIV...*¹⁷⁵

*...I think if government can mix the patients so that we cannot differ from other patients, because we are not sick, we are just having this disease...we must not have special rooms, special nurses and special administration...*¹⁷⁶

Women also discussed the need to come together as women living with HIV and to collectively stand up for their rights, especially at a community level.

*...maybe we can call a meeting with the community and say it like it is: we are HIV positive and we are tired of you people looking down on us and discriminating us...we are part of the community, you should accept us...*¹⁷⁷

FOOTNOTES:

1. Illovo, 29 May 2012, Questionnaire 508.
2. New Brighton, 25 August 2012, Questionnaire 767.
3. New Brighton, 22 August 2012, Questionnaire 215.
4. New Brighton, 24 August 2012, Questionnaire 338.
5. Illovo, 12 May 2012, Questionnaire 253.
6. Tafelsig, 24 May 2012, Questionnaire 129.
7. Illovo, 11 April 2012, Questionnaire 131.
8. New Brighton, 23 August 2012, Questionnaire 480.
9. New Brighton, 22 August 2012, Questionnaire 246.
10. Illovo, 14 May 2012, Questionnaire 383.
11. New Brighton, 22 August 2012, Questionnaire 181.
12. Tafelsig, 22 May 2012, Questionnaire 34.
13. Beacon Valley, 21 May 2012, Questionnaire 387.
14. New Brighton, 21 August 2012, Questionnaire 59.
15. Illovo, 06 April 2012, Questionnaire 14.
16. New Brighton, 21 August 2012, Interview 35.
17. New Brighton, 21 August 2012, Questionnaire 113.
18. Tafelsig, 15 June 2012, Questionnaire 410.
19. New Brighton, 21 August 2012, Questionnaire 20.
20. Illovo, 13 April 2012, Questionnaire 207.
21. Beacon Valley, 15 May 2012, Questionnaire 298.
22. Tafelsig, 13 June 2012, Questionnaire 369.
23. Illovo, 12 April 2012, Questionnaire 144.
24. Beacon Valley, 17 May 2012, Questionnaire 377.
25. Tafelsig, 24 May 2012, Questionnaire 129.
26. New Brighton, 23 August 2012, Questionnaire 577.
27. Illovo, 30 May 2012, Questionnaire 624.
28. New Brighton, 23 August 2012, Questionnaire 464.
29. Tafelsig, 13 June 2012, Questionnaire 358.
30. Illovo, 28 May 2012, Questionnaire 414.
31. New Brighton, 23 August 2012, Questionnaire 469.
32. Illovo, 10 April 2012, Questionnaire 116.
33. Tafelsig, 15 June 2012, Questionnaire 420.
34. Tafelsig, 22 May 2012, Questionnaire 6.
35. New Brighton, 21 August 2012, Questionnaire 7.
36. Beacon Valley, 17 May 2012, Questionnaire 364.
37. Illovo, 31 May 2012, Questionnaire 663.
38. New Brighton, 22 August 2012, Questionnaire 302.
39. Tafelsig, 22 May 2012, Questionnaire 6.
40. Illovo, 12 April 2012, Questionnaire 168.
41. Tafelsig, 15 June 2012, Questionnaire 417.
42. South Africa's unemployment rate has been estimated to be 25.2% in 2012, with provincial unemployment rates of 28.3% in the Eastern Cape, 22.8% in the Western Cape, and 20.5% in KwaZulu Natal. [www.statssa.gov.za/publications/P0211/P02111stQuarter2012.pdf]
43. New Brighton, 24 August 2012, Interview 8.
44. Illovo, 27 August 2012, Interview 5.
45. New Brighton, 28 August 2012, Incident Report 23.
46. Tafelsig, 31 August 2012, Interview 2.
47. Illovo, 27 July 2012, Incident Report 12.
48. New Brighton, 29 August 2012, Incident Report 28.
49. Illovo, 29 August 2012, Interview 2.
50. Illovo, 27 July 2012, Incident Report 13.
51. Tafelsig, 29 September 2012, Incident Report 21.
52. New Brighton, 28 August 2012, Incident Report 15.
53. Illovo, 21 July 2012, Incident Report 3.
54. Beacon Valley, 30 August 2012, Interview 4.
55. Illovo, 29 August 2012, Interview 7.
56. Illovo, 25 July 2012, Incident 7.
57. New Brighton, 27 August 2012, Incident 14.
58. Beacon Valley, 29 September 2012, Interview 10.
59. New Brighton, 24 August 2012, Interview 8.
60. Beacon Valley, 28 September 2012, Interview 11.
61. Beacon Valley, 16 August 2012, Focus Group Discussion.
62. New Brighton, 23 August 2012, Focus Group Discussion 1.
63. New Brighton, 25 August 2012, Incident Form 5.
64. Tafelsig, 26 September 2012, Interview 5.
65. Illovo, 21 July 2012, Incident Report 4.
66. Beacon Valley, 28 September 2012, Interview 7.
67. New Brighton, 25 August 2012, Interview 7.
68. New Brighton, 29 August 2012, Interview 2.
69. Beacon Valley, 18 August 2012, Incident Report 1.
70. New Brighton, 28 August 2012, Focus Group Discussion 2.
71. Illovo, 29 August 2012, Focus Group Discussion 2.
72. Beacon Valley, 10 July 2012, Service Provider Focus Group Discussion.
73. Illovo, 24 August 2012, Service Provider Interview.
74. Illovo, 24 August 2012, Service Provider Interview.
75. Beacon Valley, 10 July 2012, Service Provider Focus Group Discussion.
76. Illovo, 24 August 2012, Service Provider Interview.
77. Beacon Valley, 17 August 2012, Service Provider Interview.
78. Tafelsig, 22 May 2012, Questionnaire 42.
79. New Brighton, 22 August 2012, Questionnaire 272.

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80. Illovo, 30 May 2012, Questionnaire 592.
81. Beacon Valley, 17 May 2012, Questionnaire 364.
82. New Brighton, 24 August 2012, Questionnaire 594.
83. Illovo, 08 April 2012, Questionnaire 63.
84. New Brighton, 22 August 2012, Questionnaire 292.
85. Tafelsig, 13 June 2012, Questionnaire 336.
86. New Brighton, 21 August 2012, Questionnaire 133.
87. Tafelsig, 30 May 2012, Questionnaire 137.
88. Beacon Valley, 21 May 2012, Questionnaire 384.
89. Tafelsig, 23 May 2012, Questionnaire 40.
90. Illovo, 13 April 2012, Questionnaire 255.
91. Tafelsig, 13 June 2012, Questionnaire 36.
92. New Brighton, 23 August 2012, Questionnaire 404.
93. Illovo, 13 April 2012, Questionnaire 254.
94. Beacon Valley, 09 May 2012, Questionnaire 69.
95. Illovo, 14 May 2012, Questionnaire 388.
96. New Brighton, 24 August 2012, Interview 8.
97. Tafelsig, 17 August 2012, Focus Group Discussion.
98. Illovo, 28 August 2012, Incident Report 23.
99. New Brighton, 27 August 2012, Incident Form 14.
100. Illovo, 29 August 2012, Incident Report 26.
101. Beacon Valley, 29 August 2012, Incident Report 20.
102. Illovo, 26 August 2012, Incident Report 20.
103. Only women from New Brighton, Beacon Valley and Tafelsig shared experiences of seeking legal redress, while women in Illovo shared mostly experiences of speaking to social workers and healthcare providers.
104. New Brighton, 29 August 2012, Incident Form 27.
105. Beacon Valley, 06 September 2012, Incident Report 10.
106. New Brighton, 28 August 2012, Incident Form 25.
107. Beacon Valley, 06 September 2012, Incident Report 9.
108. New Brighton, 22 August 2012, Incident Report 2.
109. Tafelsig, 31 August 2012, Interview 6.
110. Beacon Valley, 16 August 2012, Focus Group Discussion.
111. Beacon Valley, 16 August 2012, Focus Group Discussion.
112. Tafelsig, 31 August 2012, Interview 6.
113. Tafelsig, 18 August 2012, Interview 4.
114. Tafelsig, 30 May 2012, Questionnaire 147.
115. Illovo, 08 April 2012, Questionnaire 63.
116. Beacon Valley, 09 May 2012, Questionnaire 45.
117. Illovo, 23 August 2012, Questionnaire 458.
118. Tafelsig, 01 June 2012, Questionnaire 256.
119. Beacon Valley, 12 May 2012, Questionnaire 223.
120. Illovo, 16 April 2012, Questionnaire 309.
121. Tafelsig, 12 June 2012, Questionnaire 318.
122. Tafelsig, 22 May 2012, Questionnaire 17.
123. Beacon Valley, 09 May 2012, Questionnaire 70.
124. Tafelsig, 01 June 2012, Questionnaire 206.
125. Illovo, 17 April 2012, Questionnaire 344.
126. New Brighton, 21 August 2012, Questionnaire 71.
127. Tafelsig, 01 June 2012, Questionnaire 41.
128. Tafelsig, 22 May 2012, Questionnaire 32.
129. Illovo, 13 April 2012, Questionnaire 255.
130. New Brighton, 21 August 2012, Questionnaire 51.
131. Beacon Valley, 09 May 2012, Questionnaire 91.
132. Illovo, 17 April 2012, Questionnaire 331.
133. Tafelsig, 15 June 2012, Questionnaire 411.
134. New Brighton, 22 August 2012, Questionnaire 380.
135. Illovo, 14 April 2012, Questionnaire 384.
136. Tafelsig, 13 June 2012, Questionnaire 325.
137. Illovo, 13 April 2012, Questionnaire 243.
138. New Brighton, 21 August 2012, Questionnaire 113.
139. Tafelsig, 22 May 2012, Questionnaire 6.
140. Illovo, 10 April 2012, Questionnaire 116.
141. Beacon Valley, 10 May 2012, Questionnaire 160.
142. New Brighton, 21 August 2012, Questionnaire 65.
143. Illovo, 14 April 2012, Questionnaire 272.
144. New Brighton, 21 August 2012, Questionnaire 5.
145. Tafelsig, 23 May 2012, Questionnaire 82.
146. New Brighton, 21 August 2012, Questionnaire 73.
147. Tafelsig, 13 June 2012, Questionnaire 339.
148. Illovo, 10 April 2012, Questionnaire 84.
149. Tafelsig, 31 May 2012, Questionnaire 166.
150. New Brighton, 12 May 2012, Questionnaire 222.
151. Illovo, 17 April 2012, Questionnaire 364.
152. New Brighton, 21 August 2012, Questionnaire 67.
153. Tafelsig, 24 May 2012, Questionnaire 85.
154. Illovo, 28 April 2012, Questionnaire 617.
155. New Brighton, 27 August 2012, Service Provider Focus Group Discussion 1.
156. Beacon Valley, 10 July 2012, Service Provider Focus Group Discussion.
157. Beacon Valley, 10 July 2012, Service Provider Focus Group Discussion.
158. New Brighton, 27 August 2012, Service Provider Focus Group Discussion 1.
159. New Brighton, 27 August 2012, Service Provider Focus Group Discussion 1.
160. Illovo, 27 August 2012, Interview 5.
161. New Brighton, 28 August 2012, Focus Group Discussion 2.
162. Illovo, 29 August 2012, Focus Group Discussion 2.
163. Illovo, 25 July 2012, Focus Group Discussion 1.
164. Illovo, 29 August 2012, Focus Group Discussion 2.
165. Tafelsig, 17 August 2012, Focus Group Discussion.
166. Beacon Valley, 16 August 2012, Focus Group Discussion.
167. New Brighton, 27 August 2012, Focus Group Discussion.
168. Illovo, 29 August 2012, Focus Group Discussion 2.
169. Illovo, 29 August 2012, Focus Group Discussion 2.
170. Tafelsig, 17 August 2012, Interview 3.
171. Illovo, 25 July 2012, Focus Group Discussion 1.
172. Beacon Valley, 31 August 2012, Interview 3.
173. Illovo, 29 August 2012, Interview 7.
174. Illovo, 27 August 2012, Interview 5.
175. New Brighton, 28 August 2012, Focus Group Discussion 2.
176. New Brighton, 24 August, Interview 7.
177. New Brighton, 23 August 2012, Focus Group Discussion 1.

CONCLUSIONS & RECOMMENDATIONS

*...I must not be seen as a woman who is HIV positive,
but as a woman who is a human being...¹*

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.

The data, although indicating a certain degree of awareness and understanding among communities of violence perpetrated against women living with HIV, also demonstrates high levels of prejudice, stigma and discrimination against women living with HIV prevalent in the study areas.

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.

CONCLUSIONS

In summary, the data clearly highlights the need to design and implement programmes and initiatives that are based on and informed by women's experiences of the multiple causes,

forms, and effects of HIV-related violence in their lives, so as to ensure effective responses to the realities, risks, and needs of women living with HIV. Moreover, the study reveals the urgency to redesign service provision, as women participating in the study experience access to healthcare as an element in the continuum of violence perpetrated against them.

Similarly, the data points to the dire need to ensure that redress mechanisms available are indeed accessible to women living with HIV who have been abused and violated, as women's experiences of taking legal actions against the perpetrator(s) are laden with humiliation and further abuse, inadequate investigations and even denial of services by the police, as well as insufficient sentences by the court.

Recognising the various risks associated with women's HIV disclosure, the data seems to raise the question as to the potential role that societal expectations of, and pressures on, women to disclose their HIV status play in the continuum of abuse and violence women experience in all aspects of their lives, irrespective of whether or not women themselves decided the time of, and the way in which, their HIV status became known.

Communities' responses reveal a certain degree of awareness and understanding of risks associated with women's HIV status disclosure within families and households, at a community level, within healthcare provision and within the workplace. However, the data underscores communities' misconceptions, in that families and healthcare centres are perceived as main sources of support, as compared to communities and workplaces which are seen as rejecting and discriminating environments. Although aware of the risks, communities feel strongly that women need

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to disclose their HIV positive status, which arguably indicates a great disconnect between beliefs that women's HIV disclosure is essential and the awareness and knowledge of the risks for women who do disclose their HIV status.

Especially in the context of women's rights to make sexual and reproductive choices, the data clearly demonstrates high levels of prejudices, stigma and discrimination against women living with HIV, and seems to underscore common prejudicial beliefs that women give up their right to decide whether or not and when to engage in sex, have children and to get married upon an HIV positive diagnosis. Data indicating that almost a third of community members participating believe that women living with HIV should be encouraged to be sterilised, is of great concern, especially in light of the vastness of sexual and reproductive rights limitations and violations experienced by women living with HIV.

While the data suggests overall trends of communities' perceptions of violence against women living with HIV for the total sample, it is important to note the distinct differences between areas and between women and men in these areas, especially with regard to levels of knowledge about rights protections for women living with HIV.

Although encouraging that almost half of the total sample knew about women's right to take legal actions against the perpetrator(s) of violence, the data, however, also seems to suggest a general lack of knowledge among community members not only about women's realities in seeking redress, but also about their own role in perpetuating and perpetrating violence against women living with HIV.

RECOMMENDATIONS

Women's experiences clearly illustrate the multiple risks, and prevalence, of violence against women based on their HIV positive status – thus implying a general lack of adequate programmes and interventions adequately responding to the realities, risks and needs of women living with HIV.

Communities' perceptions highlight both a certain degree of awareness of women's risks upon HIV disclosure, as well as prevailing levels of HIV-related prejudices, stigma and discrimination against women living with HIV – thus indicating a general lack of rights awareness and knowledge.

Service providers' responses clearly point to the understanding of women's ill-treatment, abuse and other rights violations within healthcare provision – thus underscoring the dire need for interventions to enhance women's access to healthcare services.

What do women recommend?

- **Equal treatment and respect**

...we are all human beings; we just need to be treated the same...²

...we are part of the community, you should accept us...³

- **Education and information on HIV and women's rights**

...I know, if people are informed, they treat women differently... so something needs to be done to educate people...⁴

- **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...⁵

- **Access to healthcare and quality of services**

...the nurses at the clinic really need an ongoing training; especially focusing on their attitude...nurses need to change their attitude...⁶

...I would like to see government employing people who are passionate about patients, people who really care about people living with HIV...⁷

CHAPTER FOUR: CONCLUSIONS & RECOMMENDATIONS

- **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...*⁸

- **Access to justice and redress**

*...they have to get more privacy for people who want to come and lay a charge...*⁹

*...the police must be more informed about the charges to be laid and how to deal with people like us when they come to the police station...*¹⁰

*...they must make an example and throw people who call you names in jail for a very long time...*¹¹

What do communities recommend?

- **Education and awareness raising**

*...we need more educational programmes addressing stigma and abuse...*¹²

*...we need educational programmes which will enlighten peoples' minds and change their attitude towards women in general...*¹³

- **Women to speak up and claim their rights**

*...women who are being abused must speak up and stand up for their rights...*¹⁴

*...women living with HIV must report these incidences to the police, so that people will learn and stop...*¹⁵

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 and create sustained change in the following areas:

Societal and community level

- 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
- Increase levels of knowledge and understanding about the rights of women living with HIV, especially women's sexual and reproductive rights
- Improve knowledge about relevant legislative and policy provisions so as to enhance women's access to justice and redress as and when rights violations occur
- 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
- Guarantee women's central participation in the design and implementation of policies, programmes and interventions meant to address violence against women living with HIV
- 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

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a broad and inclusive understanding of violence against women

- Review and/or develop laws and policies so as to explicitly provide for HIV-related violence and abuse as an offence

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
- Audit and improve healthcare settings so as to guarantee that women living with HIV are not subjected to violence and abuse while accessing healthcare

FOOTNOTES:

1. Illovo, 27 August 2012, Interview 5.
2. Tafelsig, 17 August 2012, Interview 3.
3. New Brighton, 23 August 2012, Focus Group Discussion 1.
4. Illovo, 27 August 2012, Interview 5.
5. Illovo, 29 August 2012, Interview 7.
6. New Brighton, 28 August 2012, Focus Group Discussion 2.
7. New Brighton, 27 August 2012, Focus Group Discussion 1.
8. New Brighton, 25 August 2012, Interview 7.
9. Tafelsig, 31 August 2012, Interview 6.
10. Tafelsig, 31 August 2012, Interview 6.
11. Tafelsig, 18 August 2012, Interview 4.
12. Illovo, 13 April 2012, Questionnaire 205.
13. Illovo, 17 April 2012, Questionnaire 364.
14. Tafelsig, 24 May 2012, Questionnaire 85.
15. New Brighton, 21 August 2012, Questionnaire 67.

NOTES



MITCHELL'S PLAIN NETWORK
OPPOSING ABUSE



South African
Positive Women Ambassadors



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Suite 6F, Waverley Business Park, Mowbray, 7700 • PO Box 13834, Mowbray 7705, Cape Town, South Africa

Tel: +27 21 447 8435 • Fax: +27 21 447 9946 • E-mail: alnapt@aln.org.za • Website: www.aln.org.za

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