

THEY HAVE
NO RIGHT
TO DO THAT...

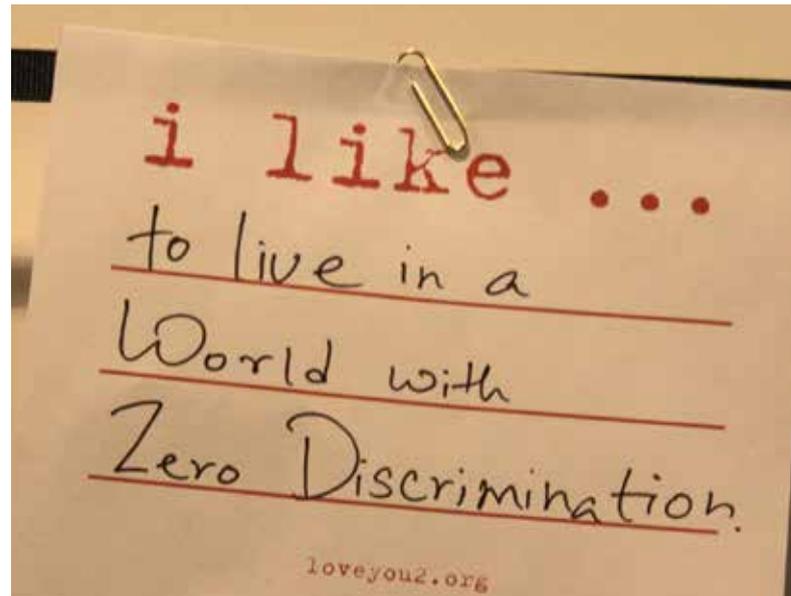
Women's experiences of accessing healthcare

JOHANNA KEHLER
AIDS LEGAL NETWORK

The enjoyment of the right to health is not just the physical possibility of accessing a medicine or medical service in case of illness. It includes a wide range of social, legal and structural factors that impact on agency, including the extent to which people are in the position to safely make informed decisions affecting their lives and leading a healthy life. Thus, the right to health is intrinsically linked with all other fundamental human rights and freedoms, ranging from the right to life and the right to equality and non-discrimination to the right to dignity, autonomy, and to be free from all forms of violence in both public and private spheres.

It is widely recognised that the constitutionally guaranteed right of access to healthcare¹ implies access to quality healthcare, which among other entails healthcare provision free of coercion, discrimination and abuse. A central aspect of quality and patient-centred care is that:

Patients are treated in a caring and respectful manner by staff who show appropriate values and attitudes and respect for patient privacy and choice.²



In addition, the Department of Health National Core Standards state that:

Patients receive the information they need before they formally consent to any treatment or participate in a study.³

THE LEGAL AND POLICY FRAMEWORK

South Africa's constitutional, legal and policy framework protects fundamental human rights and freedoms, including the right to equality and non-discrimination, to privacy, to autonomy and informed consent, and to be free from all forms of violence.⁴ Moreover, South Africa's National Strategic Plan on HIV, STIs and TB (2012 – 2016)⁵ reaffirms its commitment to a human rights-based response to HIV, and as such identifies as one of its principles that the national response 'must be rooted firmly in the protection and promotion of human and legal rights, including prioritising gender equality and

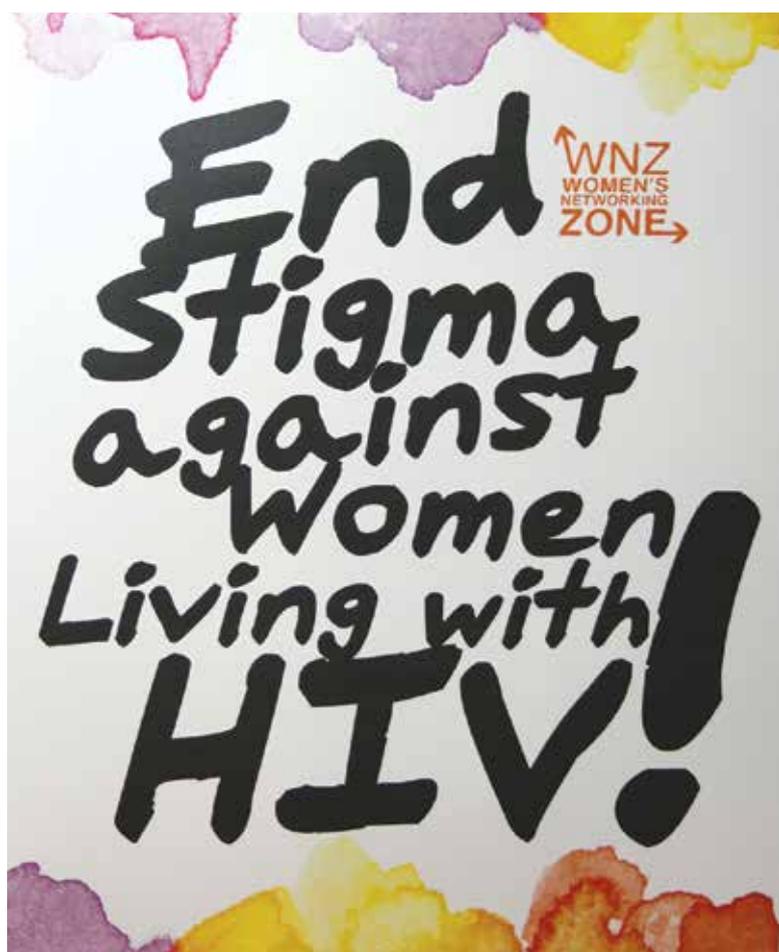
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*gender rights*⁶. The National Strategic Plan (NSP) further recognises that *'women are particularly vulnerable to HIV infection because of biological vulnerability and gender norms, roles and practices'*⁷; and aims to address *'the social, economic, political, cultural and environmental factors that lead to increased vulnerability'*.

Recognising the potential adverse effects of interventions in their implementation on the extent to which especially women are in the position to claim their agency and exercise their rights – for example in the context of access to sexual and reproductive healthcare services and HIV testing – a pivotal aspect of effective rights-based responses to HIV is to ensure that *'rights are not violated in the implementation of interventions'*, and to afford access to justice and redress mechanisms *'efficiently and effectively'*, as and when rights violations occur.⁸ However, limited levels of legal literacy and knowledge about legislative and policy provisions addressing HIV-related rights abuses, especially among women, as well as inadequate application and implementation of these provisions, create a situation in which rights continue to be compromised in the context of service provision; access to justice and redress mechanisms remain limited; and, as research revealed, the decisions by particularly women living with HIV as to whether or not and when to access services are often influenced by the fear of stigma, violence and other rights abuses within healthcare.⁹

Moreover, deeply entrenched gender and social norms, as well as prejudices and stigma, limit women's capacity to freely make informed decisions affecting their lives, including sexual and reproductive decisions, and whether or not and when to access healthcare and treatment.

Subsequently – albeit the enabling legal and policy environment, commitments and efforts to ensure rights protections within healthcare provision – women's experiences illustrate that accessing healthcare is more often than not accompanied by rights violations – ranging from coercion and lack of privacy to disrespect, humiliation and denial of services.



THE DOCUMENTATION PROJECT

This brief is based on data collected as part of a broader project aimed at documenting, monitoring and addressing HIV-related stigma, discrimination and other rights abuses – with the overall goal of creating enabling, supportive and safe environments for people to realise their rights, claim their agency, and access and benefit from available services.

This particular part of the project intended to document women's experiences of rights abuses within healthcare settings; assess the occurrence and prevalence of rights violations and implications thereof for women accessing services; and enhance the knowledge and evidence base on women's experiences of barriers to access to, and benefit from, healthcare services free from stigma, discrimination, coercion and other rights violations.

To this effect, an incident report form was designed to capture the context and conditions under which the incident occurred (i.e., what happened, when, where and who was involved); explore women's responses; and assess women's experiences of seeking redress – both '*informally*' and '*formally*'.

The documentation took place in selected areas in and surrounding East London and King William's Town (Eastern Cape) between October 2014 and May 2015. During the documentation process, the

AIDS Legal Network (ALN) worked in partnership with S.H.E. in East London and Khanyisa in King Williams Town. The assessment tool was administered in and around clinic settings at a community level.

In total, 530 incidences of rights violations against women in healthcare settings were documented. Of these, 60 incidences were excluded from the subsequent analysis, as they were either not a '*personal*' experience or not directly linked to the clinic. Thus, for the purpose of this brief, 470 incidences capturing women's personal experiences of rights violations, as well as access to redress, have been documented and analysed.¹⁰ The majority of the incidences occurred in the last year prior to the documentation (297, 63%).

WOMEN'S EXPERIENCES...

Coercion

*...it is supposed to my decision to get tested,
not for them to decide that...*

[Woman, 30s, East London]

Agency, choice, consent and informed decision making are human rights principles centrally embedded in South Africa's constitutional, legal and policy frameworks. Section 12(2) of the Constitution guarantees everyone the right to bodily and psychological integrity; with specific reference

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to sexual and reproductive choices, and informed consent in the context of health. At the same time, the National Health Act clearly stipulates that *'no health service may be provided without a person's informed consent'*¹¹.

Women's experiences of accessing healthcare however illustrate an obvious gap between the policy of *'rights protections'* and the practice of *'rights violations'* within healthcare settings.



The documentation and assessment of rights abuses within healthcare settings revealed that women's experiences of accessing healthcare is often characterised by a lack of agency and

power to make decisions affecting their health and life.

...they make us feel like we don't have powers...

[Woman, 40s, King William's Town]

Especially in the context of sexual and reproductive healthcare, women seem to have least agency to make informed decisions affecting their lives, as women often find themselves in a situation in which access to services seem *'impossible'* without an HIV test. And despite law and policy provisions placing informed consent at the centre of HIV testing procedures, women's experiences seem to indicate a *'practice of conditional HIV testing'*; in that without an HIV test women may not receive the treatment or care they sought when going to the healthcare facility.

As a result, women often feel that *'you have to get tested before you get helped'* [Woman, 20s, King William's Town]; a sentiment often confirmed by healthcare providers at the clinic, leaving women in a position of least agency to make informed decisions.

...we're waiting to get helped and the nurse came and told us to go to the room to get tested before we get helped, because we need to know our status...shouting at us that we are not using condoms, but we don't come to test...I feel angry, because she has no right to force us...

[Woman, 30s, King William's Town]

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...she [the nurse] saying it is necessary for every patient to test for HIV...and if I don't, I won't be helped... [Woman, 30s, East London]

...I went for prevention, but the nurse said in front of everyone that I need to test for HIV before I can get prevention ...if you don't agree you will not get the prevention you came for...
[Woman, 20s, King William's Town]

...I went to the clinic, because I was not feeling well...I was told I had to test for HIV first in order to get help... and if I don't, I won't get help... I didn't feel good about it, because it was not my decision... [Woman, 20s, King William's Town]

Women in need of care thus often feel inclined, pressured and coerced to 'consenting' to an HIV test in order to get the treatment they need, which in most cases is not associated with HIV testing; and beyond the 'need to know your status' argument.

...I was shocked, but agreed to test, because I needed to be helped...

[Woman, 20s, King William's Town]

...I did test for HIV, because they insisted...

[Woman, 30s, East London]

...I tested, because I knew if I wouldn't, I wouldn't

be helped...I did not feel good about it, because I wasn't ready...

[Woman, 20s, King William's Town]

LACK OF PRIVACY

...she wasn't supposed to do that, she was supposed to help me...

[Woman, 20s, King William's Town]



The right to have one's dignity respected and protected, and the right to privacy are constitutionally guaranteed¹²; thus central to South Africa's legislative and policy framework. The National Health Act further clearly prohibits the

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disclosure of any information relating to a person's health status and/or reason for accessing healthcare without consent¹³.

...I had to say in front of everyone that I was there for an HIV test, even though that is private and confidential... [Woman, 30s, King William's Town]

In reality, however, it is as much the infrastructural set-up of healthcare settings as healthcare providers' attitudes towards and treatment of service users that often lead to the disclosure of peoples' HIV status – without their consent. As such, accessing healthcare seems to potentially not only compromise the right to privacy, but also (as a result of the heightened risk of rights violations) adversely impact on treatment access and adherence.

Women's experiences clearly illustrate the extent to which women feel a lack of agency while accessing healthcare as to whether or not, when and to whom to disclose their HIV status.

...I worry a lot because people are going to find out my status... [Woman, 30s, King William's Town]

...I am HIV positive and I go to the clinic for my treatment...I feel so uncomfortable, because they isolate us from other people and I am not ready to come out to other people...

[Woman, 30s, East London]

...I take treatment for HIV...when I go to the clinic I have to tell everything to the security guard before they let me in...even when I go inside, I have to explain to everyone that I am here for the HIV treatment...and when I finally do get seen, I have to go to the special HIV room... [Woman, 30s, King William's Town]

Healthcare providers' attitudes are one of the recognised barriers to access to healthcare services.¹⁴ Sharing their experiences of accessing healthcare, many women made specific reference to healthcare providers 'shouting' and being 'rude' (115, 25%). Reference was also made to 'nurses not doing their job', since they are 'sitting in the sun' and 'talking on their phones', while patients are waiting (146, 31%).

...she was supposed to help me, not yell at me...

[Woman, 30s, King William's Town]

Being scolded and ridiculed while accessing HIV and pregnancy prevention methods arguably do not only constitute a violation of one's fundamental human right to dignity and respect, but also potentially lead to a situation of not accessing these services again, due to fear of further abuse; thus, among others, leading to a situation in which women may knowingly place themselves at greater risks of HIV and unintended pregnancy.

...they got attitudes...I considered skipping

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treatment because of this...they are rude...they must treat us like patients, not streetwalkers...

[Woman, 50s, King William's Town]

...I went to the clinic to get contraceptives for the first time...I'm 17 years old and the nurses shouted at me in front of everyone saying I am too young to have sex...but they should be happy that at least I am preventing pregnancy...

[Woman, 20s, East London]

...it makes me feel like I don't want to go back to that clinic...I'm pregnant now, but I'm scared to go back...many people are scared to go to that clinic... [Woman, 30s, King William's Town]

...the nurses don't respect us...they scream for everyone to hear what medication we take or why we're there... [Woman, 40s, East London]

While many women felt 'angry', 'upset' and 'disappointed' about the way they were treated (195, 41%), some shared that they felt 'humiliated' and 'ashamed' (39, 8%). Albeit emotional reactions, women also clearly articulated that 'the nurses were wrong to do this' [Woman, 30s, King William's Town], as 'they didn't have to act like this' [Woman, 20s, King William's Town].

...I was so disappointed. I didn't expect that from them... [Woman, 20s, King William's Town]

Women's narratives also highlighted the impact of the inherent power imbalance between service providers and service users. As a result, women often feel that they have limited power to participate in healthcare decisions.

...I could not say no, because she was the nurse...

[Woman, 20s, King William's Town]

Moving on and seeking redress

...they have no right to do that...

[Woman, 50s, King William's Town]

Access to justice and redress as and when a person's rights have been violated are central aspects of



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an enabling legal environment. In South Africa, the right of access to justice is constitutionally guaranteed¹⁵, as well as a key element of laws and policies affording access to justice and redress both within and outside the realm of healthcare.

The National Health Act outlines that any person has the right to not only 'lay a complaint about the manner in which he or she was treated at a health establishment', but also to 'have the complaint investigated'.¹⁶ Further underscoring the importance of access to redress and when a person's rights have been violated within healthcare settings, one of the indicators for 'improving values and attitudes' in the Department of Health National Core Standards makes reference to:

*Patients who wish to complain about poor services are helped to do so and their concerns are properly responded to by management, who use complaints to improve service delivery at that facility.*¹⁷

Recognising the ill-treatment received at the clinic, women participating in the documentation study sought advice and redress both formally and informally. However, women's experiences of lodging a complaint about the 'poor services', differ greatly from these policy provisions.

...every time I write a complaint, I throw it in the box, but we hear nothing about it...a waste of my time, because they don't pay attention to my complaints... [Woman, 20s, King William's Town]

Follow-up questions as to with whom and when women shared their experience of accessing healthcare revealed that the majority of women shared what happened at the clinic with a family member (192, 59%), partner (22, 7%), or friend (61, 19%) on the same day of the incidences.

...she told me to go back to the clinic and demand to be helped, because it is my right...
[Woman, 30s, East London]

TABLE 1: WOMEN SEEKING REDRESS [%]

AREA	INFORMAL REDRESS		FORMAL REDRESS	
	Yes	No	Yes	No
King Williams Town	80	20	24	76
East London	60	40	21	79
TOTAL	70	30	23	77

Levels of support and advice afforded to women seeking informal redress greatly varies, ranging from expressing ‘*surprise*’ about the ill-treatment and ‘*affirmation*’ of rights abuses occurring (100, 30%) to underscoring the ‘*need to report*’ (59, 18%).

...it is wrong and needs to change...

[Woman, 40s, King William's Town]

The responses women received also highlighted a certain level of ‘*acceptance*’ that the violations of rights experienced at the clinic are ‘*normal*’ and ‘*just the way it is*’ when accessing healthcare. Thus, there is ‘*nothing you can do*’, except to ‘*go back*’ (82, 25%).

...she told me to just accept the situation, because we don't have any other options...

[Woman, 30s, East London]

Contrary to this, women were also advised to ‘*look for services elsewhere*’ and ‘*change clinic*’ (40, 12%), which arguably indicates as much a recognition of systemic rights abuses within healthcare settings at a community level, as a lack of confidence that the situation will improve.

...I thought they will improve their attitude and poor services, since many people told them to their faces that their services are poor and unacceptable...but nothing has changed...

[Woman, 20s, King William's Town]



Women who reported the incident (106, 23%) have primarily done so within the healthcare system by either lodging a complaint with the sister in charge or the clinic committee (48, 45%) or by using the ‘*suggestion box*’ as a means of seeking redress (25, 24%). However, many women felt that ‘*nothing came from it*’, as ‘*no actions were taken*’ to respond to their complaints and change the way in which services are provided.

...if we report to the clinic, we see no change and we do not see any follow-ups...so, I see no need to report it... [Woman, 30s, East London]

Notwithstanding the need for enhancing levels of legal literacy, many women are (contrary to common assumptions) arguably aware of their rights to agency, consent and privacy. Irrespective of whether or not women express these rights explicitly,

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women's narratives of accessing healthcare facilities show that they feel ill-treated, coerced and abused. As such, women's decisions as to whether or not to seek redress are as much determined by a lack of knowledge as to where and how to report incidences of rights abuses within healthcare settings ('*I did not know where to complain*', 110, 30%) as by a sentiment that there is '*no use to complain*' and '*no use in reporting*' (154, 42%).

...if the nurse can speak to us like that in front of her colleagues...there is no use in reporting...

[Woman, 40s, King William's Town]

At the same time, women also feel cautious and

scared to lay a formal complaint, as they fear the consequences of such actions for their next visit to the healthcare facility (30, 8%).

...I got scared of reporting thinking if I do it will be a serious matter and I will end up not getting any help next time... [Woman, 30s, East London]

...you will be treated even worse if you complain... [Woman, 30s, King William's Town]

Women's experiences also highlight a certain level of lack of trust in both the rights protections embedded in access to healthcare and redress mechanisms available as and when rights are violated.

...we can't change the situation, because we live with it...and it will be a waste of my time to complain about it...

[Woman, 20s, King William's Town]

...there is nothing I can do, I need my treatment...

[Woman, 40s, King William's Town]

CONCLUSION

Women's experiences clearly indicate that enabling legal and policy frameworks by themselves do not translate into social environments facilitating the realisation of rights; as many women, irrespective of rights protections in law and policy,



experience access to healthcare as yet another aspect of their lives in which their agency is undermined and their rights are threatened. As such, the persistent gap between policy and practice seems to be not only a central part of women's realities while accessing healthcare (in that women continue to have limited agency), but also perpetuate to an extent women's greater risks to rights violations (in that the gendered context of society to an extent justifies the very same).

Without intensified efforts to create enabling social environments (through transforming the societal context in which rights are realised and services are accessed), women will continue to be least in the position to claim agency and realise rights – irrespective of both the rights protections afforded to 'everyone' in law and policy and women's levels of legal literacy.

As long as women feel '*there is nothing I can do, I need my treatment*', the enabling legal environment will continue to have little to no impact on women's realities; thus nullifying the progress made. Thus, it seems to be time to both prioritise and '*fast track*' women's needs in accessing healthcare, as well

as ensure that women's experiences of accessing healthcare are not only '*heard*' and '*responded to*', but instead become the '*evidence*' informing efforts to enhance access to quality healthcare.

FOOTNOTES:

1. Constitution of the Republic of South Africa, Act 108 of 19, Section 27.
2. National Department of Health. 2011. Fast Track to Quality: The six most critical areas for patient-centred care. p6.
3. *Ibid.*
4. Section 9, 12 and 14 of the Constitution.
5. National Strategic Plan on HIV, STIs and TB, 2012 – 2016 [www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf]
6. *Ibid.*, p25.
7. *Ibid.*, p35.
8. National Strategic Plan on HIV, STIs and TB, 2012 – 2016, p54.
9. Kehler, J. et al. 2012. *Gender Violence and HIV: Perceptions and experiences of violence and other rights abuses against women living with HIV in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa*. AIDS Legal Network.
10. Of the 470 incidences included in the analysis, 237 were from King Williams Town areas and 233 from East London.
11. National Health Act, No 61 of 2003, Section 7(1).
12. Section 10 and 14 of the Constitution.
13. Section 14(1) and (2) of the National Health Act.
14. National Department of Health. 2011. Fast Track to Quality: The six most critical areas for patient-centred care; UNAIDS. 2013. *Getting to Zero: HIV in eastern and southern Africa*, pp70-71.
15. Section 34 of the Constitution.
16. Section 18(1) of the National Health Act.
17. National Department of Health. 2011. Fast Track to Quality: The six most critical areas for patient-centred care. p6.