

Mujeres Adelante

Newsletter on women's rights and HIV • 2015 SVRI Forum • Stellenbosch

In Focus...

Emma Aldrich

HIV and sexual violence: Toward an integrated response...

Since its inception, the SVRI Forum has recognised, explored, and interrogated the links between sexual violence and HIV.

In 2009, SVRI sessions

examined the ways in which masculinity and traditionally patriarchal social norms correlate with sexual violence.

Rachel Jewkes

presented evidence

suggesting that in

South Africa, men who embody patriarchal norms and associated behaviours are more likely to have HIV, and to perpetrate intimate partner violence.

Both Jewkes and Mazedra Hossain presented research that



shows women who experience sexual abuse are vulnerable to depression, post-traumatic stress disorder, and substance abuse, and linked this vulnerability to increased risk of HIV. In this way the first SVRI Forum highlighted that HIV prevention responses and sexual violence responses must be integrated in order to be effective in meeting

the needs of those affected by sexual violence; post-rape care must go beyond legal and socio-economic support to include psychosocial and mental healthcare, and HIV responses must be cognisant of the holistic health needs and rights of

individuals, including needs related to post-rape care and primary violence prevention. In addition, the Forum explored the role of Post-Exposure Prophylaxis (PEP) for HIV, and considered it a critical component of a comprehensive rape/HIV prevention response. In particular, the issue of adherence to PEP was highlighted, and

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how the feelings many women experience after sexual trauma, including shame, blame, fear and anxiety, can be real barriers to consistent drug adherence, which is critical to the effectiveness of PEP in preventing HIV.

In subsequent years, the Forum explored the public health dimensions of sexual violence and the vulnerability of women in power inequitable relationships, where violence increases the risks of HIV acquisition. In 2011, Andrew Gibbs brought evidence that in general, gender and sexual violence are not sufficiently integrated into National Strategic Plans on HIV/AIDS in Southern and Eastern Africa. The 2013 Forum considered that while gender-based violence has been established as a driving social force that significantly impacts the HIV epidemic, hard data remains largely unavailable and the persistent gap in information creates barriers to planning and implementing evidence-based interventions.



The 2013 presentations reiterated the messages of previous Forums, that poverty, gender inequality, alcohol use, and stigma all contribute to the structural drivers that cause HIV and sexual violence to intersect and compound risks and vulnerabilities. Subsequently, the call was made for further research and a more inclusive approach to addressing structural barriers to health and rights across diverse sectors.

This year, during the 4th SVRI Forum, the dual epidemics of HIV and sexual violence continue to demand our urgent

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attention. There is growing evidence that sexual and physical violence, and the threat of violence, significantly impact the HIV prevention, treatment and care cascades. Women living with HIV who anticipate violence related to the disclosure of their HIV status are delayed in linking to the care cascade, and the experience of intimate partner violence negatively impacts on ARV adherence. With regards to HIV prevention, much like with PEP, demonstration projects for HIV Pre-Exposure Prophylaxis (PrEP) suggest young women, in particular, who have sex with men struggle with adherence, and

that their relationships with male partners strongly influence their use of PrEP.

The rationale for an integrated response to HIV and sexual violence is strong. While global guidelines do exist to guide health sector responses, there is not yet sufficient evidence to prove the efficacy of these strategies.¹ The sexual violence research sector can add significant value to HIV-related research, and vice versa. There is an urgent need to conduct action-oriented research and build evidence around the efficacy of interventions and strategies aimed at preventing and responding to HIV and sexual violence jointly. Particular interventions, including those incorporating ICT services, social media campaigns, infrastructure and transport all require further interrogation, and the success of community mobilisation and empowerment programmes for women and girls should be further explored.²

Furthermore, there are

valuable lessons that the HIV and sexual violence sectors should share with and draw from one another. Among the many questions for consideration, we should be asking, are these – How can human rights monitoring systems that have worked well in an HIV context be transferred to the context of sexual violence? How can interventions that ensure HIV testing, treatment and care are rights-based and empowering improve the quality of post-rape services? What role can peer support play in an integrated sexual violence and HIV continuum of care?

An important step toward a more integrated joint response to sexual violence and HIV is to ensure this integration within the 2015 SVRI Forum itself. The Forum agenda has relegated ‘*HIV and violence*’ to a singular session; this is disappointing, and arguably wastes a critical opportunity to act upon the recurrent calls of previous Forums to move toward a truly

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integrated response to HIV and sexual violence. It therefore falls to all Forum participants to interrogate the research presented across sessions and themes and ask: what do these findings mean in the context of HIV risks? What questions does this evidence bring up around HIV vulnerabilities?

The SVRI Forum must capitalise on this opportunity to ensure HIV remains visible on the global sexual violence research agenda, so that research can contribute to an HIV and sexual violence response that aims to meet the holistic health needs and rights of those affected by HIV and by sexual violence worldwide.

FOOTNOTES

1. Sinead Delany-Moretlwe, MBChPhD DTM & HRHI, University of the Witwatersrand, SA AIDS, Durban, June 2015.
2. See Sinead Delany-Moretlwe presentation.

Emma is with the International HIV/AIDS Alliance. For more information: ealdrich@aid alliance.org.

Gemma Oberth¹, Felicity Daly²,
Ath'enkosi Sopotshi³,
Phoebe Kisubi Mbasalaki⁴ & Erin Stern⁵

Women's Voices...

Marginalising the evidence...

Presenting research on women who have sex with women

The authors of this article are all women who are involved in research projects, which focus on women who have sex with women and HIV. In this piece, we aim to contribute to the discussion Logie has begun, sharing our experiences presenting 'WSW research' at two recent HIV conferences in South Africa, among other fora. The experiences are varied – some negative, some positive, some in between – demonstrating both progress as well as persistent prejudice around this research topic.

The bulk of HIV research on the experiences of sexually and gender diverse people centres around interactions at health facilities with service providers. A smaller body examines social and structural barriers to accessing care, including engagement with friends and family, law enforcement (in many places where homosexuality is illegal), and other groups. Further, the vast majority of all of this research is focused on gay men and other men who have sex with men, and to a lesser extent transgender people. Women who have sex with women (WSW) have been historically excluded from HIV discourse⁶.

More recently, there has been increasing recognition that women who have sex with women do face HIV vulnerability⁷, and are not a 'no risk' group as was previously argued.⁸ Despite this evidence, research on HIV among women who have sex with women is

still met with disproportionate and often unfounded scepticism and rejection.⁹

Carmen Logie, Assistant Professor in the Factor-Inwentash Faculty of Social Work at the University of Toronto, has documented her experiences presenting research on women who have sex with women and HIV at major international HIV conferences. Her article, '(Where) do queer women belong? Theorizing intersectional and compulsory heterosexist in HIV research' published in *Critical Public Health*, explores how her conference audiences called her and her research into question in ways which reproduced and reinforced the invisibility and exclusion of women who have sex with women. Logie describes two specific interactions in which older white men dismissed her position as either invalid or irresponsible:

CASE 1:

'LESBIANS ARE NOT AT RISK FOR HIV'

Logie's presentation at an international HIV conference focused on applying a structural violence framework to theorise the lack of representation of queer women in HIV research. Following her presentation, an older white male academic from the audience stood up to respond and turned his back to her to face the audience. He argued that Logie's presentation was not relevant as 'lesbians are not at risk for HIV', and if lesbians were to experience homophobic rape in South Africa they could simply go to the police.

CASE 2: 'YOU'RE TRYING TO TAKE HIV MONEY AWAY FROM GAY MEN'

Logie's presentation at an international HIV conference discussed qualitative data that highlighted how queer women experienced sexual violence and other HIV infection risks. Directly following her presentation, an older white male academic expressed concern that she was trying to 'take HIV money away from gay men'. She clarified that she was not asking for equal funding, just inclusion of queer women in HIV prevention research. The audience member reinforced that funding was scarce and any money directed towards lesbians would detract from fulfilling gay men's health needs.

At the 9th South African AIDS Conference (SA AIDS) in Durban (9-12 June 2015), Oberth presented a critical literature review on WSW risk and vulnerability in South Africa. Stern and Sopotshi are co-authors on this review. The critical review focuses on the

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rejection...**

layers of vulnerability that women who have sex with women in South Africa face, including sexual violence, transactional sex and drug use. The main message of the presentation was that women who have sex with women are not at risk of HIV because of their sexuality per se, but because of the structural and environmental context which surrounds that sexuality, particularly in South Africa. She opened her presentation by sharing Logie's observations about the manner in which 'WSW research' is often received at conferences, and challenged the audience to interrogate their prejudices during the presentation as they may arise. Overall, her experience was a positive one, with both the *Times* and the *Beeld* newspapers running stories on the research findings the next day.

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On the same panel, Kisubi Mbasalaki presented original research from more than 200 South African women who have sex with women around sexual identity, behaviour and potential HIV risk. After both presentations, five questions were asked about the two presentations, all by men. The questions asked of Kisubi Mbasalaki were both by black men. Two questions asked of Oberth and Kisubi Mbasalaki on the same subject stood out:

CASE 3: 'BUT REAL LESBIANS AREN'T AT RISK FOR HIV'

The content of both questions sought to distinguish between women who have sex with women who may also have sex with men (either by choice or through forced sex) and those who do not. The audience members felt compelled to reassert rigid understandings of sexuality, which the presentation explicitly sought to disrupt. The focus was shifted back towards the biological risk factors of woman-on-woman sex, rather than considering the message of the presentations, which emphasised the importance of socio-structural and environmental factors. One of the questions on this topic asked if Kisubi Mbasalaki had documented any evidence of seroconversion from women who have sex with women who strictly had sex with only other women. Both questions undermined the content of the presentations. As the presenters attempted to shed light on contextual risk factors, the questions from the audience disregarded this message and redirected the conversation back towards biomedicalising risk.

Also presenting at the SA AIDS conference, Daly shared her doctoral research on South African policy analysis, with a focus on women who have sex with women. Her presentation was entitled 'Claiming the right to health for women who have sex with women: Analysing South Africa's National Strategic Plans on HIV and STIs'. She felt her panel

was not an ideal platform for this paper, dubiously headlined 'Vectors, Victims, Vulnerability and Values?', and featuring just one other presenter focusing on sexual minority issues, which was on men who have sex with men (MSM). Stern noted similar challenges with the composition of panels and panel subjects where 'WSW research' was presented at international conferences. When 'WSW research' is presented as part of predominantly MSM-focused panels, or on panels which focus on gender rather than sexuality, 'WSW research' comes across as confused and out of place from the outset.

Despite the strange panel, Daly felt that her research was generally well received at SA AIDS. She felt affirmed as a white male South African audience member in his 40s remarked that the organisation he works with would soon be piloting 'WSW-competent' centres of excellence, based on successes of an 'MSM model'. Although this comment was welcomed as positive feedback on Daly's presentation, there remains cause for querying the ability of MSM organisations to provide 'competent WSW services'.

However, Daly has faced significant push-back presenting her research

... 'WSW-competent' centres of excellence, based on successes of an 'MSM model'...

in other fora, particularly related to the quality and quantity of evidence supporting the notion that women who have sex with women are at risk for HIV.

Sopitshi's experience presenting the same WSW critical review (as was presented by Oberth at the SA AIDS conference) at the end of the 3rd Conference of the Association for the Social Sciences and Humanities in HIV (ASSHH) in Stellenbosch (06-09 July 2015) was slightly different; highlighting the importance of space and composition in shaping the experience of the researcher. Sopitshi noted that those who attended her presentation were almost all older white women. There was only one man in the audience. She also noted the overwhelmingly white racial composition of the conference in general, which she felt was problematic considering that many of the papers presented were focusing on content related

CASE 4: 'THE EVIDENCE IS NOT (GOOD) ENOUGH'

At a 'work in progress' seminar at the Health Economics and HIV AIDS Research Division (HEARD) at University of KwaZulu-Natal, where Daly was a Research Associate, a senior male academic questioned her conduct of health policy analysis on WSW in South African HIV policy. He argued that recent findings of a quantitative study conducted by the Human Sciences Research Council (HSRC)¹⁰ and others did not convincingly demonstrate HIV risks faced by women who have sex with women. He marshalled no evidence to back this up other than expressing vague doubts about research methods.

Similarly, Daly also faced this kind of evidence-questioning at the London School of Hygiene and Tropical Medicine (LSHTM) while scoping and conducting the study for her Doctor of Public Health degree there. Early on, a senior female academic specialising in sexual health advised that Daly would not be able to conduct any thesis research on women who have sex with women and HIV, due to a lack of evidence. Encouragingly, after feeding this exchange back to the university Director, Daly was relieved that he thought the concept that there was no evidence-base on HIV among women who have sex with women was nonsense.

Kisubi Mbasalaki also experienced a questioning of the quality of her evidence at SA AIDS, where a male audience member asked her whether the empirical research findings were 'really true' that forced sex among women who have sex with women to be at 8.1% with a female partner and 1% with a male partner.

to black communities. She also noted that as a woman of colour, who does not necessarily identify as heterosexual, the space was not one where she felt she could openly talk about her identity. These contexts, though more subtle and insidious than the scenarios presented in Cases 1 through 4, also contribute to a silencing of women who have sex with women – particularly women who have sex with women of colour – presenting on this research subject. These topics surrounding the identity of the researcher were echoed by Daly in

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Conclusion

The findings of the authors of this article both confirm Logie's¹¹ experiences as well as present promising change in the landscape. Many of the authors did not share Logie's experience of compulsory heterosexism in HIV research, though many were exposed to new and potentially more subtle forms of exclusion and marginalisation. There

remain intrinsically moral and political factors which continue to undermine the reception to evidence of HIV and STIs among women who have sex with women. Issues, such as the

...highlighting the importance of space and composition in shaping the experience of the researcher...

CASE 5:

'YOU WOULDN'T KNOW. YOU'RE NOT A LESBIAN'

While completing her field work, another female academic from LSHTM, who Daly had approached to be on her advisory committee, asked her why she was researching lesbians and HIV. The woman outed herself to Daly, professing that she was 'from that community' and that lesbians are not vulnerable to HIV. This woman's assumptions about Daly's identity were both incorrect and revealing about how 'WSW research' is wrapped up in notions of ownership and 'in groups'/'out groups'.

the final case: Sopitshi's experience presenting the same WSW critical review (as was presented by Oberth at the SA AIDS conference) at the end of the 3rd Conference of the Association for the Social Sciences and Humanities in HIV (ASSHH) in Stellenbosch (06-09

...experience of compulsory heterosexism in HIV research...

social marginalisation of women, especially gender non-conforming women, and non-heteronormative female sexuality are embedded in WSW sexual health studies; as the evidence is marginalised, so too are the women producing it. Unless we can foster more productive intellectual spaces to engage on these issues – and some experiences from the authors of this paper suggest we might



be improving – queer women will never belong.

FOOTNOTES

1. Visiting Academic at the Center for Social Science Research, University of Cape Town, South Africa.
2. Executive Director at Kaleidoscope Trust, United Kingdom.
3. Project Coordinator at the Inclusive Healthcare Innovation Initiative, Bertha Centre for Social Innovation, Graduate School of Business, University of Cape Town, South Africa.
4. PhD Candidate in the Graduate Gender Programme of Utrecht University, The Netherlands .
5. Post-doctoral Research Fellow with the London School of Hygiene and Tropical Medicine (currently based on Rwanda).
6. Dworkin, S. L. 2005. 'Who is epidemiologically fathomable in the HIV/AIDS epidemic? Gender, sexuality, and intersectionality in public health'. In: *Culture, Health & Sexuality*, 7(6), pp615-623; Logie, C. H. et al. 2012. "We don't exist": A qualitative study of marginalization experienced

by HIV-positive lesbian, bisexual, queer and transgender women in Toronto, Canada'. In: *Journal of the International AIDS Society*, 15(2.)

7. Sandfort, T. G. et al. 2013. 'Forced sexual experiences as risk factor for self-reported HIV infection among southern African lesbian and bisexual women'. In: *PloS One*, 8(1), e53552; Matebeni, Z. et al. 2013. "I thought we are safe": Southern African lesbians' experiences of living with HIV. In: *Culture, Health & Sexuality*, 15(sup1), pp34-47; Poteat, T. et al.

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(2014). 'Sexual practices, identities and health among women who have sex with women in Lesotho: A mixed-methods study'. In: *Culture, Health & Sexuality*, 16(2), pp120-135.

8. Robertson, P. & Schachter, J. 1980. 'Failure to identify venereal disease in a lesbian population'. In: *Sexually transmitted diseases*, 8(2), pp75-76; Dworkin, S. L. 2005. 'Who is epidemiologically fathomable in the HIV/AIDS epidemic? Gender, sexuality, and intersectionality in public health'. In: *Culture, Health & Sexuality*, 7(6), pp615-623; Raiteri, R. 1998. 'Lesbian sex and risk of HIV transmission'. In: *AIDS*, 12, pp450-451.
9. Logie, C. H. 2014. '(Where) do queer women belong? Theorizing intersectional and compulsory heterosexism in HIV research'. In: *Critical Public Health*, (ahead-of-print), 1-12.
10. Sandfort, T. G. et al. 2013. 'Forced sexual experiences as risk factor for self-reported HIV infection among southern African lesbian and bisexual women'. In: *PloS One*, 8(1), e53552.
11. Logie, C. H. 2014. '(Where) do queer women belong? Theorizing intersectional and compulsory heterosexism in HIV research'. In: *Critical Public Health*, (ahead-of-print), 1-12.

For more information, please contact Gemma Oberth on gemma.oberth@gmail.com.

UPCOMING EVENTS

Tuesday, 15 September

09:00-11:00 *Plenary: Opening*

Auditorium

Trafficking, transactional sex and sexual exploitation

Historic Old Wine Cellar

11:30-13:00 *Conflict, post-conflict and emergencies: Community responses*

Auditorium

14:30-16:00 *Special session: Violence Against Women and Girls*

Simonsberg Room

Sex work: Epidemiology and responses

Helderberg Room

16:30-18:00 *Care and support*

Helderberg Room

14:30-16:00 *Conflict, post-conflict and emergencies: Tools and methods*

Stellenberg Room

Addressing violence in people with disabilities

Historic Old Wine Cellar

Trafficking, transactional sex and sexual exploitation

Historic Old Wine Cellar

Extended definitions of gender-based violence

Amphitheatre Board Room 2

16:30-18:00 *Special session: Integrating culture into interventions to prevent gender-based violence*

Simonsberg Room

Thursday, 17 September

Sexual and gender-based violence in South Africa

Helderberg Room

09:00-11:00 *Special Session: The What Works to Prevent Violence against Women and Girls Initiative*

Auditorium

Special Session: The challenges and hopes of interventions around gender equality and intimate partner violence prevention

Simonsberg Room

Wednesday, 16 September

09:00-11:00 *Plenary: Interventions*

Auditorium

Special Session: What is 'gender-based violence'? And why does it matter

Historic Old Wine Cellar

11:30-13:00 *Using research to influence policy*

Auditorium

11:30-13:00 *Economic empowerment interventions for the prevention of violence against women and children*

Auditorium

HIV and violence

Simonsberg Room

Prevention interventions

Historic Old Wine Cellar

13:00 *Plenary: Closing Session*

Auditorium

Johanna Kehler

Women's realities...

They have no right to do that...

Women's experiences of accessing healthcare¹

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 lives and leading a healthy life.



...an obvious gap between the policy of 'rights protections' and the practice of 'rights violations'...

Furthermore, the Department of Health National Core Standards further state that:

Patients receive the information they need before they formally agree to any treatment or participate in a study.⁴

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 healthcare² 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.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 consent, and to be free from all forms of

violence.⁶ Moreover, South Africa's National Strategic Plan on HIV, STIs and TB (2012 – 2016)⁶ reaffirms its commitment to a human rights-based response to HIV, and thus 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 gender rights*'.⁷ 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*'⁸; and aims to address '*the social, economic, political, cultural and environmental factors that lead to increased vulnerability*'.

Recognising the potentially 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

...access to services seem
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...leaving women at a
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make informed decisions...

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.⁹ 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.¹⁰

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 provisions – 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.

WOMEN'S EXPERIENCES...

Coercion

...it is supposed to my decision to get tested, not for them to decide that...¹¹

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 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'*¹².

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.

A recent documentation and assessment of rights abuses within healthcare settings conducted by the AIDS Legal Network (ALN) and partners between October 2014 and May 2015 in selected areas in and around East London and King Williams Town (Eastern Cape) 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.¹³

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

Especially in the context of sexual and reproductive healthcare,

...adversely impact on treatment access and adherence...

...healthcare is often characterised by a lack of agency and power to make decisions...

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 seek when going to the healthcare facility.

As a result, women often feel that *'you have to get tested before you get helped'*; a sentiment often confirmed by healthcare providers at the clinic, leaving women at 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...

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

...I went for prevention, but the nurse said I need to test for HIV before I can get prevention in front of everyone...if you don't agree you will not get the prevention you came for...

...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...

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 needed, which in most cases is not associated with HIV testing; beyond the *'need to know your status'* argument.

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

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

...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...

everyone that I was there for an HIV test, even though that is private and confidential...

result of the heightened risk of right violations) adversely impact on treatment access and adherence.

Women's experiences 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...

...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...

...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...

Lack of privacy

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

The right to have one's dignity respected and protected, and the right to privacy are constitutionally guaranteed¹⁴; thus central to South Africa's legislative and policy framework. The National Health Act further clearly prohibits the disclosure of any information relating to a person's health status and/or reason for accessing healthcare without consent.¹⁵

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 seem to potentially not only compromise the right to privacy, but also (as a

...lack of trust in both the rights protections embedded in access to healthcare and redress mechanisms...

Healthcare providers' attitudes are one of the recognised barriers to access to healthcare services.¹⁶ 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

...I had to say in front of

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 risk of HIV and unintended pregnancy.

...they got attitudes...I considered skipping treatment because of this...they are rude...they must treat us like patients, not streetwalkers...

...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...

...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...

...the nurses don't respect us... they scream for everyone to hear what medication we take or why we're there...

Moving on and seeking redress

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



Notwithstanding the need for enhancing levels of legal literacy, many women are arguably (contrary to common assumptions) aware of their rights to agency, consent and privacy. Irrespective of whether or not women express these rights explicitly, 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') as by a sentiment that there is 'no use to complain', and/or 'no use in reporting'.

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

...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...

At the same time, women feel cautious and scared to lay a complaint, as they fear the consequences of such actions for their next visit to the healthcare facility.

...I got scared of reporting thinking if I do I do it will be a serious matter and I will end up not getting any help next time...

...you will be treated even worse if you complain...

Women's experiences also highlight a certain level of lack of trust in both the rights protections embedded in access to healthcare and redress

...legal and policy frameworks by themselves do not translate into social environments...

mechanisms available as and when their 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...

...we don't have any other options...

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

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. This article is an excerpt from the broader documentation project focussing on women's experiences of accessing healthcare in the Eastern Cape and Limpopo.
2. Constitution of the Republic of South Africa, Act 108 of 19, Section 27.
3. National Department of Health. 2011. Fast Track to Quality: The six most critical areas for patient-centred care. p6.
4. *Ibid.*
5. Section 9, 12 and 14 of the Constitution.
6. National Strategic Plan on HIV, STIs and TB, 2012 – 2016 [www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf]
7. *Ibid*, p25.
8. *Ibid*, p35.
9. National Strategic Plan on HIV, STIs and TB, 2012 – 2016, p54.
10. 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.
11. Quotes, unless otherwise specified, are from women participating in the documentation study.
12. National Health Act, No 61 of 2003, Section 7(1).
13. During this period, a total of 530 incidences were documented.
14. Section 10 and 14 of the Constitution.
15. Section 14(1) and (2) of the National Health Act.
16. 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.

Johanna is with the AIDS Legal Network (ALN). For more information: jkebler@icon.co.za.

Claire Mathonsi

Innovations and intersections...

The International HIV/AIDS Alliance (the Alliance) considers the 2015 SVRI Forum a critical global advocacy space which offers an important opportunity for advocacy and engagement around the links between HIV and sexual and gender violence. In order to significantly impact the dual epidemics of HIV and sexual violence, the relationship between HIV, violence and coercion must be brought back into focus of both research and human rights discourse.

Through partnering with the SVRI Forum, the Alliance hopes to raise awareness and interest around the links between HIV, gender-based violence and intimate partner violence within the Forum agenda and programme, and amongst important stakeholders at a global level and within the Southern African region. The Alliance's relationship with the SVRI Forum allows for cross-sectoral engagement with the growing evidence around rights-based, effective and transformative responses to HIV and violence against marginalised, criminalised and excluded groups of people. It is within this context that the Alliance hopes to participate in exploratory debates with donors, partners, and community members and to share its vision for accelerating the elimination

of violence based on and in the context of HIV, especially violence against women, and criminalised and marginalised populations.

At the SVRI Forum the Alliance champions a truly integrated research agenda and health system response to HIV and sexual and gender violence. As Alliance Linking Organisations bring ongoing research and best practice lessons on violence to this global research space, the Alliance raises its voice to join others advocating for the protection of women and men in all their diversity from sexual and gender violence. Through enhancing the awareness of all those present at the SVRI Forum of the complex realities, and multiple and intersecting risks and needs of diverse people in the context of preventing HIV and sexual and gender violence, the International HIV/AIDS Alliance delivers on its commitment to ongoing, long term engagement on HIV and sexual and gender violence and galvanises Forum attendees and partners to push innovative HIV, sexual and gender violence work forward, to deliver maximum impact.

...the relationship between HIV, violence and coercion must be brought back into focus...

For further information contact Claire Mathonsi on cmathonsi@idsalliance.org.

Emma Aldrich

Special report:

Looking beyond what we think we know... 'Key populations', women and gender violence

Despite the concerted efforts of the multi-faceted global HIV response, proverbial key populations continue to be disproportionately affected by HIV. It is commonly accepted by global stakeholders that targeted approaches toward the most marginalised and hardest to reach populations, who are routinely, systematically stigmatised and discriminated against, are critical if we are to reach the end goal of a world without AIDS.

This targeted, hyper-focused approach to programming is largely supported by evidence; in Swaziland, 2 in 3 female sex workers are living with HIV¹;

in Kenya, HIV incidence among men who have sex with men is as high as 35%²; and it is estimated that up to half of the 25,000 people who inject drugs in Tanzania are living with HIV³.

However, the justification to programme for key populations extends beyond the epidemiology of the epidemic, and the social and legal contexts in which key populations experience human rights violations. The categorisation of key populations provides a useful demarcation and lens for analysis; the concept provides opportunities for multi-country human rights-based programming based on the shared identities and realities of people across national borders, as well as a wealth of lessons learned across diverse regional contexts.



Unintended consequences...

What are the unintended consequences of programming for key populations? Who defines the *key* in key populations, and who are we leaving behind? These questions become especially pertinent when it comes to understanding risks and vulnerabilities of *women* in all their diversity to gender violence.

...Evidence shows that violence in its various forms greatly impact on the extent to which women are in the position to claim and exercise their rights, and to access and benefit from available HIV prevention, testing, treatment, care and support services. Violence, including the fear of violence, also has an effect on women's decisions as to whether or not and when to access services, as well as whether or not and to whom to disclose an HIV positive diagnosis.⁴

When programmes hone in on key populations of women (including female sex workers, women who inject drugs, lesbian women and other women who have sex with women, transgender women, and women living with HIV), it is necessary to be mindful that the intended programme beneficiaries are *women*, who may or may not occupy *several* key population identities.

As HIV programmes and interventions seek to reach the most underserved, vulnerable

and marginalised groups, who are routinely subject to stigma, discrimination and violence, it is imperative that we remember that individuals can identify and be identified with multiple identities, and can therefore experience *multiple* risks and vulnerabilities to violence. In the patriarchal societies in which HIV interventions operate, women largely have less access to critical resources and less autonomy over the decisions that shape their lives. Layer on top of this context the threat, and lived reality, of violence that women experience on a daily

**...routinely,
systematically
stigmatised and
discriminated
against...**

basis, due to their gender expression or identity, and on top of that, the threat of stigma, violence and discrimination that women, who do not conform to societal norms face (inclusive of women within key populations), we are making a big ask of the women in all their diversity whom we aim to reach and connect to prevention, treatment and care. The *ask* is to self-identify with a highly stigmatised (key population) group, and to make themselves known to providers of an intervention (who may or may not be a source of further stigmatisation and discrimination).

Within the South Africa context, for instance, if an intervention refers a female sex worker, for example, to sexual and reproductive health services, she may have to make herself and her profession known to HIV testing providers. In a context where sex work is illegal, this is highly problematic and can expose women to a number of safety and security risks. And then, there is the protection of women's human rights to consider. For example, there is increasing evidence that healthcare providers in South Africa frequently *coerce* women seeking sexual and reproductive health services into HIV testing. Also, when HIV testing is conducted on certain days of the week, as

**...social and legal
contexts in which key
populations experience
human rights
violations...**

is common practice amongst government-funded health centres, confidentiality around HIV testing is harder to ensure. If this woman receives a positive HIV diagnosis, and leaves the health centre or testing site visibly upset, how confidential really are the results of her test? And how safe is she from violence (related to her multiple identities and vulnerabilities), as neighbours and community members notice her leaving the health centre and make assumptions about why she was there in the first place and why she seems upset?

...is it possible we inadvertently place individuals at greater risk of violence...

Questions to consider...

This scenario, and others like it, raises pertinent questions for all of us who are active in the global response to *key populations* and HIV. In the context of *disabling* social and legal environments, by programming for specific stigmatised populations, is it possible we inadvertently place individuals at greater risk of violence? Are we programming holistically for the whole person, or creating key population siloes? Do our programmes challenge gender inequalities or reinforce structures of oppression; leaving systemic violence unchallenged? Are our programmes potential risks of further violence; the very same we are trying to respond to? Are we looking for holistic solutions to collective, community problems, or zeroing in on siloed groups of people?

Programming (especially HIV testing and treatment) for key populations, from a rights point of view, must take into consideration issues of gender

inequality, gendered coercion and gender violence in order to both prioritise and ensure consent, confidentiality, safety and agency. How then should we programme for women in all their diversity, whose identities are multiple and intersecting, and whose risks and vulnerabilities are many?

From a gender violence perspective; perhaps it is time to start thinking outside the *key population* box.

In the words of AIDS Legal Network Executive Director Johanna Kehler:

...my identities are not the problem. My identities are your problem...so start programming to transform communities.⁵

FOOTNOTES:

1. See www.avert.org/hiv-aids-swaziland.htm.
2. See www.avert.org/hiv-aids-kenya.htm.
3. See www.avert.org/hiv-aids-tanzania.htm.
4. AIDS Legal Network. 2012. *'If I knew what would happen I would have kept it to myself': Gender Violence and HIV. Report Summary*. Cape Town, South Africa.
5. Presentation, International HIV/AIDS Alliance, June 2015.

Emma is with the International HIV/AIDS Alliance. For more information: ealdrich@aidsalliance.org.

...prioritise and ensure consent, confidentiality, safety and agency...

Leigh Ann van der Merwe

In my opinion...

A shifting narrative...

Transgender women and HIV

Transgender communities are often most marginalised in the response to HIV. Needless to say, this has exacerbated HIV and the risk of gender-based violence. There are a number of unique factors that shape HIV vulnerability for transgender women, such as the likelihood of performing sex work, family rejection, lack of access to gender-affirming care, and criminalisation of gender-diverse identities.

I have born witness to the death of so many transgender women, and I continue this fight not only for HIV programming for transgender women, but also for the equitable resources to create an enabling environment for myself and other transgender women.

The biggest lesson for me as a transgender woman and activist over the past 15 years is that inappropriate, or exclusion from, HIV and gender-affirming care further fuels the epidemic among transgender women. One particular example to mention is that the inclusion of transgender women in programmes for men who have sex with men was not useful (or even appropriate) for transgender women. If anything, it really misplaced the health needs of transgender women. One big lesson to take from this is that transgender women, like any other key population, should be at the centre of the response. Further to that, the criminalisation of diverse gender identities and sex work continues to hamper HIV programming for transgender people. I have learnt that there needs to be radical policy change and

political commitment towards social justice and change for transgender women.

My biggest hope for the future is scientific advances in HIV prevention. I am also hopeful about the shifting narrative for myself and my community around acceptance, love and sisterhood with women in all their diversity. I sincerely hope that the next development framework will stray from heterosexual and gender-normative language and practice and will encapsulate the issues of all women.

...transgender women, like any other key population, should be at the centre of the response...

...there needs to be radical policy change and political commitment...

Leigh Ann is with S.H.E. Feminist Collective of Transgender and Intersex Women in Africa. For more information: transfeminists@gmail.com.

Editor: Johanna Kehler jkeehler@icon.co.za
Photography: Johanna Kehler jkeehler@icon.co.za
Design: Melissa Smith melissas1@telkomsa.net
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