

# Mujeres Adelante

Newsletter on women's rights and HIV • 7th SA AIDS Conference • Durban

## In Focus...

Jayne Arnott

## Human rights:

# From principle to practice...

*It needs to start with us as women understanding our rights; which goes beyond pregnancy, goes beyond marriage, goes beyond relationships, it is about understanding my rights as a woman.<sup>1</sup>*

In our busy world of work in the 'rights-based sector' we rarely have time or resources to engage our constituencies in evaluating our practice, to get in-depth feedback on their experiences of engagement in projects, and to jointly reflect on the achievements and challenges that can enrich our practice. The AIDS Legal Network (ALN) had one such opportunity when a three-year project funded by the United Nations Trust Fund to End Violence against Women (UNTF) was subject to an extensive external evaluation that was finalised in April 2015.



**T**his evaluation included a focus on promising and emerging good practice models and key lessons learned that could be shared with other practitioners on addressing HIV-related violence against women. This article looks at some of the rich feedback by women and other stakeholders engaged in the project with a particular focus on their understanding and experiences of working with ALN.

### The context

The project had the overall goal of enhancing women's access to, and benefit from, available HIV prevention, testing, treatment, care and support services without fear of violence and other rights violations. The project operated within three provinces, namely the Eastern Cape, Western Cape and KwaZulu Natal.

ALN used a multi-pronged approach that sought to lobby policy makers and service providers, whilst at the same time ensuring enhanced levels of legal literacy and capacity to advocate for the protection of women's rights in the context of HIV amongst women and their communities. In this way, the project sought to facilitate a change in the societal

### What's inside:

#### Women's Voices:

I don't know what's going to happen...

#### Women's Realities:

Successes and tribulations...

#### One the margins

Redefining who is 'key'...

#### Special Report:

The power of storytelling...

context that perpetuates HIV-related violence and other rights abuses as experienced by women living with HIV, and as such increased the extent to which women are in the position to access HIV prevention, testing, treatment, support and care services free of violence and other rights abuses, and to access redress mechanisms as and when rights violations occurred.

### Human rights approach...

The core principles of a *'human rights approach'*, as outlined by the United Nations Office of the High Commissioner for Human Rights, that this article will focus on are related to *empowerment, participation, equality, non-discrimination, and attention* to *'vulnerable'* groups:

These principles should underpin rights-based practices with the understanding that:

- *Empowerment* is about shifting the focus from need to rights, with individuals and communities knowing, claiming and defending their rights, as well as knowing their responsibilities
- It calls for active, free and meaningful *participation* by individuals and communities in this process

- *Equality and non-discrimination* are fundamental issues central to all human rights and justifies prioritisation of groups towards ensuring particular protection and promotion of the rights of these groups. These groups are *'vulnerable'* to rights violations by virtue that they are perceived by society as being *'different'* or by being excluded from power.

This understanding of equality and non-discrimination is central to work around access to rights and recourses, as it defines, directs and justifies work and resources towards addressing inequality; especially since it relates to people excluded from power and those perceived as *'different'* with the complex and multiple intersections in between.

ALN's approach is firmly rooted within this human rights approach framework and this was evident within the evaluation with women sharing their increased understanding of dominant societal norms and values that violate their rights, and increasingly transferred this towards exploring their own understanding and perceptions of what constitutes being *'different'* within a framework of dominant societal norms and attitudes. This also led to women increasingly



...understanding and realisation in the context of participants' lives, as compared to giving information in a vacuum...

engaging with issues beyond violence against women living with HIV towards exploring more broadly the inequalities and rights violations related to gender, sexual orientation, gender and gender stereotyping, disability and youth. With this came increased awareness and acceptance of *'difference'* and for some women, applying this to their daily lives within their families and communities.

### From principles to practice: What did participants have to say about ALN's approach overall?

...we like the *'provocativeness'* of ALN staff; they are always provoking, there is no change I believe without provoking a situation. *'Hunky dory'* means no change...

*...it opened my box...*

*...ALN comes with ideas that we don't know and this helps us...*

In the evaluation of the project, participants spoke about how ALN was different to other organisations, they spoke about an approach that opened their minds, made them think 'out of the box', challenged their beliefs and perceptions, and ultimately changed them.

This concept of 'provoking', of challenging and 'mind opening' was reported by participants as viewing themselves and the contexts in which they lived differently. This led to increased confidence, increased self-esteem and women themselves noting shifts from passive acceptance to active agency in addressing rights violations against them. Parallel to this process was the organic development of support structures by women within the communities concerned that supported joint movement from knowledge gain and individual change toward collective and/or supported individual actions.

#### **How does ALN do this?**

*...The other workshops they do it, like if I am a facilitator, they*

*facilitate, they don't get you to join in with the conversation, they don't do the dialogues. ALN makes the people debate what is happening in your homes, even if you don't know each other, yes they are very good at that. She makes them speak, even if you are just sitting there she asks you what do you think about that and then you talk...*

*...Even the youngsters, they even debate and they enjoy it...*

ALN has developed a highly interactive and participatory methodology within capacity building activities whereby facilitators present a range of scenarios to introduce concepts of equality and rights, without giving much input or answers, but allowing participants to process and reach their own conclusions. These sessions facilitated processes of understanding and realisation in the context of participants' lives, as compared to giving information in a vacuum.

*...In this area people always look at each other differently but now sitting in a group of different people, faces, cultures and languages then you know there are people who really care*

**...safe spaces for women to speak out and claim their own agency...**

**...lasting change happens very slowly, and needs to begin from where people find themselves...**

*and by [ALN] coming in here with discussions about things and we can say how we feel or not feel and nothing that we do or say is actually wrong because that's our choice. That's what I have come to learn, we all have choices in life no matter if it is the wrong choice my choice is mine...*

This methodology 'breaks down' perceived differences and creates safe spaces for women to speak out and claim their own agency. The caring element that was reported on is significant, as this is central to creating safe and non-judgmental spaces for participants to engage and for participation to become 'meaningful'.

*...What also makes them [ALN] different is that in most cases they will find out from the women themselves what they think will work, in order to correct what they need, whatever is not ok. Other organisations will just target women. During the research women were involved, there were meetings with women and they were part of the solutions...*

This project was grounded in the participation of women living

with HIV and/or affected by gender violence with the core aim of engaging and ‘empowering’ women to take ownership of the project processes and affect real positive change in their lives on a personal, family, community and access to services level. From the outset activities were planned to maximise participation and ‘empower’ women to take activities forward, thus the research component led to community awareness work, led to women engaging in further learning and development of personal agency that increasingly led women, individually and collectively, to assert themselves and advocate for positive changes during and after the project cycle ended.

### Non-adversarial approach...

*...Another thing is most of the time we were blaming each other, like the clinic didn't do this, the police didn't do that, but ALN taught us we must not direct our anger to a person or an institution. Like we had a march for non-violence and even the media asked us why didn't you march to the clinic or to the police station because we marched in the community and we said no the violence is all over you will find it at home so if it*

*is part of the community let us come to the community and find the solutions...*

ALN was very aware that the knowledge and evidence base this project generated contained detailed findings regarding a range of rights violations that could potentially lead to service providers becoming defensive and reactive within the project activities. In order to ensure ongoing engagement with service providers, ALN adopted the approach of ‘advocating for’ the protection of women’s rights within service provision and at a community level, as compared to ‘advocating against’ the occurrence and prevalence of rights violations experienced by women living with HIV.

This was a highly successful approach, although not equally across all the project areas. Service providers were indeed willing and prepared to be part of the solution and to become ‘agents of change’ so as to enhance women’s access to and benefit from available services, including redress mechanisms as and when rights violations occur.

Participants and partner organisations engaged within the

project also reported adopting this approach in their own work and their daily lives.

### Conclusion

Lasting change happens very slowly, and needs to begin from where people find themselves, within the complex inter-relations in people’s lives, including geographical, cultural, as well as intellectual. This project, given its duration over three years, provided an opportunity to engage on a deeper and ongoing level utilising a methodology that is based on meeting people where they are, with the understanding that for people to internalise new information, attitudes and practices, it has to originate with them.

Practitioners and donors alike should be encouraged to support, promote and resource participatory and community-based multi-pronged projects that run over a long-term period, as these do yield significant results.

### FOOTNOTES

1. All the quotes in this article are comments from ‘beneficiaries’ of the project participating in the external evaluation process.

*Jayne is an independent consultant based in Cape Town, South Africa. For more information: [jayne.arnott@gmail.com](mailto:jayne.arnott@gmail.com).*

**...for people to internalise new information, attitudes and practices, it has to originate with them...**

Johanna Kehler

## Women's Voices...

### *I don't know what's going to happen...*

## Women's perceptions of rights abuses and access to redress

*...sometimes if you go to report, you are likely to get more of what you are complaining about...*

[Woman, 40s, New Brighton]

Evidence shows that women remain at disproportionate risk of HIV exposure, transmission and related rights abuses, despite rights protections in law and policy. At the same time, deeply entrenched gender and social norms limit women's capacity to make informed and free decisions affecting their lives, realise rights and access and benefit from services. As such, the societal context perpetuates the *status quo* of women's restricted agency and gender violence being intrinsically linked to women's risks to HIV and related rights abuses.

Recognising the causes, forms and implications of HIV related violence against women, the AIDS Legal Network (ALN) – in partnership with women and their networks – embarked in 2012 on a project to document and address violence and other rights violations against women living with HIV in Mitchell's Plain (Western Cape), New Brighton (Eastern Cape), and Illovo (KwaZulu Natal). The project was supported by the UN Trust Fund to End Violence Against Women (UNTF), and implemented from January 2012 to February 2015.

As part of the end-of-project evaluation, ALN developed a short assessment questionnaire purposed to ascertain women's levels of knowledge of HIV-related rights abuses and avenues of redress, as well as experiences with and expectations of seeking redress.

The questionnaire was administered among women

in and around clinic settings, support groups, and at a community level between January and February 2015. As with the initial data collection phase, the questionnaires were administered in partnership with women from the respective communities. A total of 1021 women from Mitchell's Plain (Western Cape), Illovo (KwaZulu Natal), and New Brighton (Eastern Cape) responded to the questionnaire.

...remain reluctant to seek redress based on the perceived risk that they may or may not receive the assistance required...

### Women's perceptions of rights violations

The questionnaire included a series of questions designed to assess women's understanding of whether certain scenarios constitute a rights violation. The scenarios included a nurse disclosing a woman's HIV status without permission; the police not taking a woman's case seriously due to her HIV positive status; the neighbour gossiping about and/or insulting a woman because she is living with HIV; partner or family members using a woman's positive HIV status whenever there is an argument and threatening to disclose her HIV status; and an employer asking a woman for her HIV status. Answer choices were 'Yes', 'No', and 'Don't know'.

Table 1: Women's perceptions of rights violations [%]

Area	Nurse			Police			Neighbour			Partner/Family			Employer		
	Y	N	?	Y	N	?	Y	N	?	Y	N	?	Y	N	?
Mitchell's Plain	85	13	2	89	8	3	91	8	1	90	8	2	59	32	9
Illovo	83	12	5	87	11	2	89	9	2	90	8	2	78	17	5
New Brighton	83	16	1	87	11	2	89	11	0	89	11	0	69	23	8
<b>TOTAL</b>	<b>84</b>	<b>13</b>	<b>3</b>	<b>88</b>	<b>10</b>	<b>2</b>	<b>90</b>	<b>9</b>	<b>1</b>	<b>89</b>	<b>9</b>	<b>2</b>	<b>69</b>	<b>24</b>	<b>7</b>

Overall, the data indicate that women have a clear understanding of what constitutes HIV-related rights abuses at a community level, within relationships and families, and within institutional settings (e.g., healthcare, police, and employment).

The data, however, also show that women are more likely to identify rights violations when perpetrated by neighbours, such as gossiping and insults (i.e., name calling), and partners/family members, such as using a woman's HIV positive status during arguments and threatening to disclose her status, (90% and 89%, respectively), as compared to rights abuses within institutional and employment settings (84, 88% and 69% respectively).

*...even if they [partner/family] know, they have no right to reveal it...it's none of their business...*

[Woman, 40s, New Brighton]

*...the neighbour is not supposed to say anything about that...you need to live in safer places...*

[Woman, 50s, New Brighton]

Responses suggest that women are less likely to perceive unlawful HIV status disclosure by a nurse (84%), or an employer asking for a woman's HIV status as rights violations (69%), whilst more women (88%) agree that the police not providing adequate services for women living with HIV would constitute a rights violation.

*...I am here and need help*

*and they're [police] supposed to help me...and no one can violate my rights...*

[Woman, 40s, New Brighton]

Further, the data suggest some degree of 'acceptance' that healthcare providers will unlawfully disclose women's HIV status, and misconception that employers have the 'right' to enquire about women's HIV status. Women qualifying their responses in the context of employment made reference to 'he has to know', 'he has the right to know', 'we have to tell the bosses', and 'it depends on the company', 'it depends on the job'.

*...I don't think it's against my rights...because he [employer] needs to know my status to secure me as an employee ...*

[Woman, 20s, New Brighton]

### Women's perceptions of access to redress

*...you can go and report all you want, but they will not help...*

[Woman, 20s, New Brighton]

The questionnaire also included a number of questions designed to ascertain whether, where, and with what kind of expectations women would seek redress. These

questions aimed to further assess levels of knowledge about redress mechanisms, as well as levels of 'trust' among women that they would receive adequate services.

*...I don't know what is going to happen...because you know you're living with HIV...and people react different to us, treat us different in some cases...*

[Woman, 30s, Mitchell's Plain]

*...I am very opinionated and I will tell people about my rights all day...but I will not go to the police and such...it takes too much time...*

[Woman, 50s, Mitchell's Plain]

The questions asked whether women felt they knew where to report the rights violations presented in scenarios, whether they felt comfortable to do so, and whether they believed that seeking redress would result in them getting the help they needed. Answer choices for each question were 'Yes', 'No', and 'Don't know'.

The data indicate that women are not only knowledgeable and aware of redress mechanisms available, but also prepared to seek redress as and when their rights have been violated. The vast majority of women (84%) who affirmed that they would feel comfortable to report rights violations indicated that they would seek 'formal' redress, referring mainly to the police, clinic, social workers, court and legal services, as well as civil society organisations as forms of redress. Responses also show that some women, despite

*...lack of trust among women to feel 'comfortable' and 'safe' whilst accessing redress...*

Table 2: Women's perceptions of seeking redress and expectations [%]

Area	Report			'comfortable'			'getting help'		
	Y	N	?	Y	N	?	Y	N	?
Mitchell's Plain	88	9	2	80	15	5	71	8	21
Illovo	91	7	2	86	11	3	77	10	14
New Brighton	95	4	1	88	8	4	75	7	18
TOTAL	92	7	2	85	11	4	74	9	17

the willingness to report rights violations, 'do not know' where to report (12%), or would seek 'informal' redress by talking to 'partners', 'family members' or 'someone they trust' (4%).

*...first I will report it to ALN, because they helped me in the past and I think they will help me again...*

[Woman, 50s, Mitchell's Plain]

*...I would feel more comfortable with the social worker, because they are more trustworthy and qualified for the job...*

[Woman, 20s, New Brighton]

Similarly, the data point to high levels of 'trust' among women in seeking redress and receiving adequate responses – although levels varied between the areas, with women in Mitchell's Plain demonstrating the least belief that seeking redress would yield an adequate response.

Women who indicated that they would not feel 'comfortable' seeking redress for HIV-related rights abuses (11%), stated 'do not trust', 'people will judge me', 'they'll laugh at me', 'don't want people to know my HIV status' and 'they won't take me serious' as reasons for their response.

*...they're going to shout and ask all kinds of silly questions...*

[Woman, 20s, New Brighton]

*...the police don't always take HIV stuff serious and won't do anything about it...*

[Woman, 40s, Mitchell's Plain]

*...because even those people that I will be reporting to will know my HIV status...and will also treat me bad...*

[Woman, 30s, Illovo]

At the same time, a fairly high percentage of women willing to report (17%) said they 'don't know' if they would receive the help needed; many of whom qualifying their responses 'that it depends on who is taking the case'. This suggests that while women may trust individual service providers to assist, this does not translate into 'trust' at an institutional level. Hence, women may overall remain reluctant to seek redress based on the perceived risk that they may or may not receive the assistance required, as well as the time and resources it takes to both report and follow-up on the progress of a case.

*...maybe...it depends on who is in charge, handling the case and which mood the person is in...*

[Woman, 30s, Mitchell's Plain]

*...depends on who helps you... some will listen and some make it a joke...*

[Woman, 50s, Illovo]

*...these days you must know someone from somewhere to get real help... it will depend of what kind of person helps me...*

[Woman, 20s, New Brighton]



Women convinced that they would not receive an adequate response when seeking redress further explained that 'they won't take it seriously', 'they will take their time', 'they will blame us', and 'they will ignore you'.

*...no, I don't believe I will get help, because everybody will think or believe that you deserve it, because you are HIV positive...*

[Woman, 20s, Illovo]

*...the police...I am not sure...sometimes the police take their time and they don't take it seriously...and sometimes they have attitude with us...I think the best thing to do is to report to the ALN helpline, because they understand this issue...we as women keep quiet sometimes when we get threatened...*

[Woman, 30s, New Brighton]

*...well, I know in the community if people go to the police and try to report one of these incidences like gossiping or whatever, the police tell them 'go resolve it alone'...I've never seen someone come back and say yes, we opened a case, they will follow through and everything...*

[Woman, 40s, Mitchell's Plain]

Responses further highlight that far more women indicate that they would feel *'comfortable'* seeking redress (85%), than women believing that they would receive the necessary help when reporting HIV-related rights abuses (74%). This suggests that women clearly differentiate between *'seeking'* redress and *'receiving'* redress, and that women's levels of preparedness to *'seek'* redress, outweighs the fact that they do not necessarily *'trust'* that they would receive adequate recourse.

*...it's not right...because if you go to make a case and you are HIV positive, they make you wish you weren't...*

[Woman, 30s, New Brighton]

### Women's experiences of seeking redress

*...I've gone to the police, because someone was talking about my status...when I get back to the clinic, my supervisor told me there was no need to go to the police, because it was an internal matter...I felt very bad...*

[Woman, 40s, New Brighton]

The final part of the questionnaire explored women's lived experiences of seeking redress. As such, women were asked whether or not they personally ever reported a rights violation, and if so, what their experiences have been (on a 5-point rating scale ranging from 'very good' to 'very bad').

Notwithstanding high levels of knowledge of HIV-related violence and redress mechanisms, as well as

the willingness to access redress, only 18% of women participating affirmed that they have reported an incident of HIV-related rights abuse. This, arguably suggests a fair degree of disconnect between the *'theory'* of capacity and skills to identify and respond to rights abuses and the *'practice'* of reporting rights violations and seeking redress.

Women's accounts of seeking redress reflect to an extent women's perceptions of risks associated with accessing redress, most notably in the context of *'individual'* versus *'institutional'* trust that seeking redress will result in justice for women living with HIV.

*...whenever someone I tell something in confidence goes and tells the people, I go to the police and they help me resolve this a lot...some of them are very good to us, but there are a few who are bad...*

[Woman, 30s, New Brighton]

It is within this context that women's experiences of seeking redress equally varies from 'very good' (31%) to 'very bad' (25%). Women who indicated that they had positive experiences with

**...deter women whose rights have been violated from accessing redress and justice...**



seeking redress mentioned that they *'did get the help needed', 'perpetrator was arrested', 'got a protection order', 'the court helped me', and 'police took me serious'.*

*...the perpetrator got what he deserved and the service at the police station was good...*

[Woman, 30s, Mitchell's Plain]

*...I went to the police to report the people who were calling me by names and gossiped, shouted at me because of my HIV status...and the police treated me with respect...*

[Woman, 20s, Illovo]

*...I go to the police and I tell them that I'm HIV positive and that there are always people discriminating and they opened a case...now I am ok with my neighbours...*

[Woman, 40s, New Brighton]

Further elaborating on their negative experiences, women made reference to *'they blamed me', 'needed to disclose to people I didn't know', 'they didn't help me', and 'they didn't take me serious'.*

*...I reported to SAPS the abuse of my rights as a woman living with HIV and was asked 'are you not HIV positive'?... which I think was not an appropriate question...it made me feel angry and humiliated...I felt, as a woman, like they don't take me serious...*

[Woman, 40s, New Brighton]



*...I just felt that I am the guilty one...I felt very bad when I reported...*

[Woman, 50s, Mitchell's Plain]

*...I did not get any help...I went to the clinics and they just refused to assist me...*

[Woman, 40s, Illovo]

### Conclusion and way forward

The data show that women have high levels of knowledge, capacity and skills to not only identify HIV-related violence and other rights abuses, but also respond to these violations as and when they occur. However, women's perceptions and expectations of seeking and receiving adequate redress in a safe environment also point to a lack of trust among women that available redress is truly accessible and beneficial to women's realities and needs.

The data further underscore that enhanced levels of knowledge

of HIV-related rights violations and available avenues for redress and justice do not necessarily translate into greater access to and utilisation of such avenues. As such, the lack of trust among women to feel 'comfortable' and 'safe' whilst accessing redress, and/or to receive the assistance required, would seem to continue to deter women whose rights have been violated from accessing redress and justice.

Although this assessment has arguably proven enhanced levels of knowledge and understanding of the various forms of HIV-related violence and other rights abuses against women – as set out in the beginning of the project – the findings also highlight persistent challenges. These range from the need to enhance service providers' capacity and skills to respond to women's realities and needs; to ensuring that available redress mechanisms are accessible to women in a safe and supportive environment; to changing the

societal context perpetuating rights abuses against women in the context of and the response to HIV.

Moving forward, it is crucial to facilitate more 'safe' spaces for meaningful engagement between women, their communities, policy makers and implementers so as to collectively ensure women's access to and rights protections within service provision. Moreover, it remains essential to ensure that processes and actions calling for non-violence and women's rights protections are not only based on and informed by women's experiences, but also led and defined by women in the community. Finally, the much needed shift in deeply entrenched social norms, attitudes and prejudices that among other manifest and maintain women's risks to HIV and related violence seems to be as pertinent as it is urgent – so as to ensure that women are in the position to claim agency, realise rights, and access and benefit from available services, including redress mechanisms.

*Johanna is with the AIDS Legal Network (ALN), South Africa. For more information: [jkaln@mweb.co.za](mailto:jkaln@mweb.co.za).*

**...crucial to facilitate more 'safe' spaces for meaningful engagement between women, their communities, policy makers and implementers...**

Alyssa Beck

## Women's realities... Successes and tribulations... Community access to healthcare<sup>1</sup>

According to Section 27 of the South African Constitution

*...everyone has the right to have access to health care services, including reproductive health care...<sup>2</sup>*



### Getting to the clinic...

The ability to locate a judgment-free clinic can be a huge undertaking for the general public, especially for someone who is HIV positive. Due to the community social stigma against people living with HIV, a person may walk or otherwise travel hours in order to avoid sitting side-by-side with other community members at their local healthcare facility. The chances of being seen by a family member, a relative, or other family friend pushes patients away from the convenience of a familiar clinic. One might beg the question, if the patient is in a public waiting area, then how are they in danger of being labelled HIV positive, when there is no visible separation? However, it is relatively common that clinics or day hospitals offer HIV counselling and medical examination in a separate wing, hallway, or consultation room. Because of this practice, confidentiality is completely broken for the patient living with HIV.

**G**overnmentally, we recognise this right and its implementation among all provinces of the nation. when it comes to receiving healthcare and claiming the right of access to healthcare.

However, the right to access healthcare comes with its own successes and challenges, both those institutionally and domestically put in place. Observations and eyewitness testimony, as well as interviews among professional healthcare providers, can reveal some of the largest barriers facing the public

...to locate a  
judgment-free clinic can  
be a huge undertaking...

One can easily tell the 'status' of a person by the area of the healthcare facility that they wait in or by the name of the doctor or counsellor they see. Therefore, between the possibility of risking their HIV status or the choice of travelling to a further destination for healthcare, the latter usually wins.

Since the decision is often made to reach beyond community boundaries for assistance, a new series of challenges may arise. One may need to miss a day or two worth of work, resulting in a loss of income, thus a loss of potential expenditure on food, family necessities, school fees, or other daily costs of life. Added to this, the money spent on transportation can be excessive, such as the taxi fare spent for a round trip to get to and from the clinic.

### **While at the clinic...**

According to the physicians interviewed and their opinions on access to healthcare whilst working in a mixed township clinic, *waiting times* are the single largest barrier facing individuals

**...exhaustion and a lesser quality of care are endorsed...**

seeking treatment. Since appointments are scheduled based upon which day the patient should return and not the time nor the hour, it creates a first-come first-serve basis of admittance. From the hour that the clinic opens, the waiting room overfills with people. Mothers, grandparents, young children, working fathers, the homeless, and all the like can be seen crowding the waiting area from as early as eight o'clock in the morning. They are told that the earlier they come, the better. However, it is the triage unit that makes this decision.

**...posing threats to accessing a good standard of care...**

If one is not in need of urgent medical treatment, the wait can last for up to five or six hours before a doctor is seen.

One patient interviewed described their arrival at the clinic at 9:30 in the morning and failure to see their physician until 2:30 in the afternoon. For those in need of transference to another hospital, hours can pass before ambulances or other emergency assistance arrives. Because of this, workers daily offer bagged sandwiches to those waiting in the lobby for the lunchtime hours. The

wait extends itself even longer when the patient is told to seek pharmacy to receive their prescriptions after the consultation.

The afternoon then houses all of the pharmacy-seekers and the clinic witnesses the same issues of overcrowding as the morning saw. The waves of people follow the same pattern, from triage to doctor to pharmacy, thus there is never a balance or organisational flow. The masses all move as one and so do the excruciating waiting times, frustration, and pressure mounting on the doctors to see as many patients as they can (this number reaching from thirty to forty in one day). There are little or no breaks given for rest and none provided in the space between patient appointments for doctors. Added to chronic understaffing, exhaustion and a lesser quality of care are endorsed. Patients, in turn, must frequently leave only to return the following day for their medications, since the waiting times were too much to bear, lowering the overall productivity of the workday. Even then, one may not be given all of the medication that was prescribed.

*Confidentiality* is most likely the second largest issue among clinics with regards

to a legal standard of healthcare. Folders can be labelled with personal information outwardly visible and are effortlessly tossed between patients and staff without discretion. It is also likely that the doctor may leave a computer screen up on their desktop with patient history and lab results for their next consults. The loss of confidentiality can also be seen in the inner workings of the clinic through consistent interruptions during consultations by other patients and staff. Discussions of health history in front of other patients and sisters, including topics such as CD4 counts and HIV diagnoses, can be heard. If it is the case that a sister or nurse cannot perform a procedure on their own or are having difficulty with a patient, consults can be walked in on and halted as the doctor is called away to attend to the matter, leaving the patient alone and delaying their care.

We also see issues with *technology and modern day techniques* posing threats to accessing a good standard of care. Day hospitals are huge organisations, and those that have access to technology

**...morality and religious beliefs interfere with the objectiveness of healthcare...**

are able to enter patient information on an online database that reaches across provincial borders. Doctors can access their patients history and lab results from other clinics should they be from the Eastern Cape or beyond. However, if the computer systems are down or the electricity fails, which does happen, the physician is unable to access this crucial information for their patient's consult. These systems usually run slowly otherwise. Other medical equipment, such as X-ray backlights,

**...the emotional toll of being denied care or the judgment imposed can discourage patient return...**

can also lose functionality in this respect, and the ability for a physician to diagnose is inhibited. X-rays themselves can be blurry or of poor quality, due to the lack of financial resources for proper machinery.

This lack of access to technology as compared to western medicine can be seen as a huge hindrance to the timeliness of appointments. The doctor must rely on the previous medical provider's notes, which are difficult to read and messily written among papers,

to gather patient history. A large portion of the consult is spent pasting patient ID's to registers and updating written information. While doctors face many of these challenges, nurses also play a large role in how patients receive their healthcare. Since many nurses are practicing during their education and immediately after graduation, many can be inexperienced with proper care and medical procedures. Often, it is unlikely to have IVs inserted correctly on the first or second try, causing unnecessary patient discomfort. There have been instances of ECGs being executed incorrectly, which forces the patient to undergo the same procedure twice, due to the nurse's error. The print outs and paper copies from these machines are easy to lose or tear, since such information is not stored electronically.

This lack of medical technology and other supplies for the nurses and staff means that the reuse of materials is compulsory. Thermometers and ECG equipment are merely wiped down or rinsed with water before being used on the next patient, which raises the concern of the spread of bacterial infection. Gloves, if they are used, often are not sterile. Also, medical apparatus such as CT scans or certain blood tests as well as materials, such as fiberglass for casts, are not available to patients at most clinics and require referrals to

larger units which may be a far distance from the patient's home or accessibility. Sometimes, the equipment that a clinic does have can be stolen, lost, or otherwise misappropriated.

may not employ permanent doctors and can be entirely run by sisters, which often do not carry medical degrees, but nursing ones. One or two of the sisters may have their nurse practitioner

corruption here when morality and religious beliefs interfere with the objectiveness of healthcare. In the doctor's words, *'the patient is always right even when they are wrong.'*

The question in totality must be raised, of what is the standard of healthcare with which we are using to measure these failures? Is it that of North America, Europe, or another international location? Or is it that of the constitution and the basic rights by each human seeking treatment? Issues of confidentiality, sterility of equipment and facilities, and other procedural dealings heavily depend upon this definition.

### **Returning to the clinic...**

Clinics that are in denser rural settings

### **...behaviour that inhibits the right of access to healthcare...**

certifications, but usually only one is issued per site. These sisters will run triage for the clinic and determine if the patient can be seen by the clinic or needs to be referred or denied care. Visiting doctors rotate in and out, but the sisters complete the majority of facility upkeep. Issues can arise with

The own attitude of a sister or doctor can push or chase a patient away, which has been seen in peripheral clinics that lack management and staff guidance. Whether or not termination of pregnancy, for instance, is acceptable to the sister can determine if the patient can receive the procedure or will be forced to find care elsewhere. The emotional toll of being denied care or the judgment imposed can discourage patient return. Nurses may also exhibit behaviour that inhibits the right of access to healthcare for the patient, such as sleeping, using cellular devices during work hours, or taking longer or more frequent tea times or breaks than allotted.

The fear of rejection from these untrained or unprofessional nurses and staff can drive away patients even further. Legally, women from the age of twelve to sixteen are entitled to receive family planning without adult or parental consent. However, when morals mix with healthcare, many cases have been reported of sisters refusing to supply birth control to these women,

using the excuses that they are 'too young' or they 'know their mother would be displeased'. Patients bear the load of this criticism.

Organisationally, issues arise when patients decide to not return and default their appointments. This generates issues for doctors when the person may show up later in time or not according to their scheduled appointment date. It could be too early or too late in the week or month, which means that their treatment is of a reduced quality or use to the person himself or herself. Bookings themselves take six weeks to be made and walk-ins are not usually allowed. During these decisions, it is important to recognise that it is an amenity to be seen by the same doctor for more than one visit, since the staff rotates and the patient does not have the entitlement to be seen by the same provider unless upon request. Thus, the continuity of care is disturbed and efficacy weakens, while patient-to-provider trust declines. The general likelihood of a patient returning diminishes.

**...patients bear the load of this criticism...**

### **Successes of the public healthcare system...**

As compared with the healthcare systems of other worldwide countries, such as the United States, the ability of South African provincial clinics to offer completely free access and care to the



public is quite unique. There are few instances in the U.S. in which one is able to access healthcare without insurance or added out-of-pocket costs.

The internationally recognised institution by the name of Planned Parenthood can offer this due to healthcare cost-reimbursement programmes created by state governors for those without employer coverage and unqualified for Medicaid. In these rare circumstances, which depend upon the nature of the organisation

providing the care, it is possible to be treated without charge if one is not supported by the government already. However, in the context of South Africa, the ability to find free healthcare institutions is abundant. This means that concern is highly recognised for families

and individuals with low income and resources.

In addition to the ability to access free healthcare, or that funded by the government, patients are also able to access other departments, such as psychological and mental health assistance, social work, and HIV/sexual health counselling in the same facility. Before a visitor sees their primary care physician, they are able to have sessions with HIV counsellors on staff. Topics of discussion can range from family

...the continuity of care is disturbed...imposed can



planning to termination of pregnancy to HIV testing and emotional support services. Free condoms, although mostly male condoms, are available upon request, and are often times in plain sight for whomever so chooses to take.

Employed by the clinic are sets of special workers titled '*Community Health Workers*,' who play an important role in the return rate of patients. If a person misses their appointment, or '*defaults*' too many times, and their health is in turn put in jeopardy, the community health workers are allowed to seek these patients out at their homes. The goal is not to scare the person and scold or reproach their actions, but rather to encourage them to continue treatment for themselves. This is especially important in the case of patients living with HIV, who may run out of ARV medication from month to month. This type of patient advocating and support is difficult to find in the United States on behalf of limited time and the use of technology in place of person-to-person communication.

#### Concluding remarks...

Thus, these successes should not be overshadowed by the tribulations seen in the public healthcare system today. Nevertheless, much work and progress needs to be made in the arena of public clinical healthcare throughout the country.

Confidentiality, sterility, clinic organisation, staff treatment and oversight, and other topics of discussion all play a holistic role in the way in which a person views their personal access to healthcare. One must consider the government's funding, the educational system of healthcare

providers, clinic administration practices, and even personal choices to promote and seek future change in the way our country treats its people.

A clean, fair, and timely access to healthcare without discrimination based on race, age, sex, or personal preference is a human right we have yet to fully acknowledge, but still yet should fully strive toward.

#### FOOTNOTES

1. This article is based on observations, eyewitness testimony and interviews in a day hospital in Khayelitsha, Western Cape in July 2014.
2. Constitution of South Africa, Act 108 of 1996.

...successes should not be overshadowed by the tribulations...

*Alyssa is a graduate from the University of Wisconsin. For information: beck.alyssa@gmail.com.*

On the *margins...*

Gemma Oberth, Phoebe Mbasalaki

## Redefining who is 'Key'... Women who have sex with women and HIV

Definitions of key populations in the HIV response are often vague, broad and inconsistent. Each country seems to have its own unique list, as does each funding partner, and indeed each conversation. When I say 'key populations' you may think I mean men who have sex with men, injecting drug users and sex workers when in fact I mean truck drivers, fisher folk and herd boys.<sup>1</sup> Not to mention the absurdity of conceptualising these as distinct categories to begin with. Intersectionality is critically important, yet almost always ignored..

**D**espite this confusion, there does appear to be some clarity on who *are not* 'key populations' – women who have sex with women (WSW).

Though sometimes included under the 'LGBTI' umbrella, on their own, women who have sex with women are rarely considered 'key'. But what does the evidence really say? Three oral papers on women who have sex with women

are on the programme for the 7<sup>th</sup> South African AIDS Conference in June 2015, each bearing a familiar message: Women who have sex with women in South Africa are vulnerable to HIV, and nobody is paying attention.

The first paper is a critical review of recent WSW research in South Africa ('*South Africa's Invisibles: HIV Risk and Vulnerability among Women Who Have Sex with Women*'). Based on a meta-analysis, HIV prevalence among women who have sex with women were found to be 10.6%, just marginally less than the general population (12.2%).<sup>2</sup> However, among adolescents in Soweto, one study found that women who have sex with women are five times more likely to be HIV positive (10.3%), than their heterosexual peers (2.3%).<sup>3</sup>

Forced sex was also an important risk factor, with one study finding that 45% of HIV positive women who have sex with women had been raped<sup>4</sup>, and another concluding that forced sex was the single most important factor for sero-conversion among women who have sex with women.<sup>5</sup>

The second paper, which will be presented in the same session ('*Sexing in the Cities: Sexual risks, prevention knowledge and practices of women who have sex with women in South African townships*'), shares doctoral

research on sexual practices and risk behaviours among women who have sex with women in South Africa. Based on a survey of 205 women, 38.6% stated they had had sex during menstruation. Further, although 62.3% of women had HIV prevention knowledge, only 10.4% used that knowledge to protect themselves during sex. This finding may be related to risk perception. In addition, the critical review further highlights one study which found that 39% of women who have sex with women reported not testing for HIV, because they do not believe they are at risk.<sup>6</sup>

...the absurdity of conceptualising these as distinct categories...

The third paper (*'Claiming the right to health for women who have sex with women: Analysing South Africa's National Strategic Plans on HIV and STIs'*) discusses the importance of recognising HIV vulnerability of women who have sex with women in national strategic planning. Erasure from policy and programming means women who have sex with women are facing a serious HIV risk, without access to adequate information or services.

...disproportionate skepticism or even downright rejection at international HIV conferences...

So while acknowledging the inherent problems with defining 'key populations', these definitions are very important.

They determine funding priorities, guide policy and inform programming. Despite some very robust data, it has been documented that women who have sex with women and HIV research is often received with disproportionate skepticism or even downright rejection at international HIV conferences.<sup>7</sup> When will evidence speak louder than prejudice? It is time we redefine who is 'key'.

#### FOOTNOTES:

1. Fisher folk are defined as key populations in Uganda, referring to those who work in the Great Lakes Region. Herd boys are defined as key populations in Lesotho, referring to those who work on the mountains herding cattle.
2. Shisana, O. et al. 2014. *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*. Cape Town, HSRC Press.
3. Miller, C. L. et al. 2013. 'Implications for HIV prevention: Lesbian, gay and bisexual adolescents in urban South Africa are at increased risk of living with HIV'. In: *The Pediatric Infectious Disease Journal*, 32(6), ppe263-e264.
4. Cloete, A., Sanger, N., & Simbayi, L. C. 2011. 'Are HIV positive women who have sex with women (WSW) an unrecognized and neglected HIV risk group in South Africa?' In: *Journal of AIDS and HIV Research*, 3(1), pp1-5.
5. 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), pe53552.
6. Cloete, A., Sanger, N., & Simbayi, L. C. 2011. 'Are HIV positive women who have sex with women (WSW) an unrecognized and neglected HIV risk group in South Africa?' In: *Journal of AIDS and HIV Research*, 3(1), pp1-5.
7. Logie, C. H. 2014. (Where) do queer women belong? Theorizing intersectional and compulsory heterosexism in HIV research. *Critical Public Health*, (ahead-of-print), pp1-12.

*Gemma is a Post-doctoral Visiting Research Scholar at the Centre for Social Science Research at the University of Cape Town in South Africa, and Phoebe is a PhD candidate at Utrecht University in the Netherlands. For more information: [gemma.oberth@gmail.com](mailto:gemma.oberth@gmail.com); [P.K.Mbasalaki@uu.nl](mailto:P.K.Mbasalaki@uu.nl).*

## Key Events on women who have sex with women and HIV at the 7th SA AIDS Conference

Wednesday, 10 June 2015 • 11h30 – 13h00, Hall 4

**DR GEMMA OBERTH • South Africa's Invisibles:** HIV Risk and Vulnerability among Women Who Have Sex with Women

**MS PHOEBE MBASALAKI • Sexing in the Cities':** Sexual risks, prevention knowledge and practices of women who have sex with women in South African townships

Thursday, 11 June 2015 11h30 – 13h00, Hall 3

**DR FELICITY DALY • Claiming the right to health for women who have sex with women:** Analysing South Africa's National Strategic Plans on HIV and STIs



Simone Thomas

# Special report:

## The power of storytelling in addressing HIV-related stigma

***In 1994, apartheid was legally abolished and South Africa had officially survived almost 50 years of apartheid rule. People like Nelson Mandela and Robert Sobukwe are considered heroes for dedicating their lives to such a noble cause; with statues and monuments erected in their honour. They (and many others) spent decades behind bars so that their fellow black South Africans could enjoy the benefits of a democratic, egalitarian society where everyone would be treated equally and with respect, irrespective of the colour of their skin. Because of their work, we now live in a country where 'Blacks' and 'Whites' can enter the same establishments, walk hand in hand, and be a part of the same communities.***

**D**espite the radical change we have seen since the apartheid era, we are still living with an unbelievable level of stigma, discrimination, and segregation. Today, South Africa has the largest HIV epidemic in the world with approximately 17.9% of adults living with HIV (2012)<sup>1</sup>. And although the number of people living with HIV is so high, people who have received a positive HIV diagnosis continue to be isolated, ridiculed, and abused for their positive HIV status. This reality raises a number of questions, including how is it possible that a country where the marginalisation of an entire race of people was a very tangible reality only a mere twenty years ago, can continue to do the exact same thing to a group of people based on something as superficial as a medical diagnosis? How is the stigmatisation of HIV and people living with HIV any different than the Western ideologies and institutionalised racism that was present during apartheid rule?



While it is apparent that there are numerous entities, such as NGOs, government departments, and international and domestic donors, who are socially and financially invested in finding effective treatment and a cure for AIDS<sup>2</sup>, the majority of efforts have been from a Western perspective. As Nuttall (2004) writes,

*...Histories will always be laced with structures of racism and violence because it's a part of the culture. The only way to write and narrate to the future will be through an in depth examination of these constructs.<sup>3</sup>*

...storytelling has been long known as an African form of socialisation that bridges the perspectives of young and old...

Rather than focusing on 'key populations', which as much 'teaches' people to marginalise and stigmatise these groups, as it 'justifies' it, this paper attempts to connect themes used in pre-colonial South African oral traditions with issues in the current HIV epidemic as a way to mitigate the stigma associated with a positive HIV diagnosis.

### **HIV prevention: The disconnects with women's realities**

Ever since research scientists in South Africa have begun studying how culture affects the exposure and transmission of HIV, they have largely ignored the orality of the culture. Instead, the existing

documentation largely represents a view that Tyler (1991) describes as

*...discredits or discourages narrative, subjectivity, confessional, personal anecdote, or accounts of the ethnographer's or anyone else's experience.*<sup>4</sup>

A well-documented example of this disregard for especially women's lived experiences is the highly publicised ABC (Abstain, Be Faithful, Condomise) campaign<sup>5</sup> meant to reduce the 'spread of HIV'. This prevention message fails to take into account the perspective of South African women; the very people the campaign is meant to protect. How, when there is such a high rate of gender violence, is a woman supposed to 'abstain' from sex when a lot of times the decision whether or not and how to engage in sex is not hers in the first place?<sup>6</sup>

In addition, many HIV prevention intervention programmes in the past have followed the Knowledge-Attitude-Practice approach<sup>7</sup>, whereby it is the understanding that if a 'target group' is provided with sufficient information, they will subsequently approach each situation with an attitude that reflects the information they have received, and as such, put

these attitudes into practice. Unfortunately, this will not always be the case, especially in an environment where there are a multitude of factors that contribute to the way a person behaves. A study by Campbell (1997) regarding the psycho-social aspects of HIV exposure and transmission in the South African gold mines shows that even people with high levels of knowledge about HIV still continue to engage in 'high risk sexual behaviours'<sup>8</sup>; thus questioning the theory that access to information will lead to behaviour change. This paradigm is further established during a peer group discussion in rural KwaZulu Natal with a group of young women between the ages of 16-19. This peer group discussion was facilitated by Harrison (2001) and depicts the perceived risks that young women face and the disconnect between these perceptions and actions they are willing to take to mitigate those risks.<sup>9</sup>

**I: As you're growing up, do you see yourselves at risk of pregnancy, STDs and HIV/AIDS?**

N: Yes.

**I: Which are the ones that you see yourselves most at risk of?**

N: Death. (laughter)

**I: From the ones that I mentioned, which ones?**

N: HIV/AIDS.

P: Pregnancy.

Pr: All of them.

**I: What are you doing then to avoid these risks you have mentioned?**

P: I'm doing nothing.<sup>10</sup>

It should be noted that this study took place in the Hlabisa District of KwaZulu Natal where the average annual income is R9000 and the majority of people (and especially women) are living well below the poverty line and may not know where their next meal is coming from.<sup>11</sup> It is in conditions like these where

*...many women engage in transactional sex in order to survive and in order to support both themselves and their family.*<sup>12</sup>

All of this seems to indicate that when we are providing people with information there has to be a higher degree of sensitivity to their realities and personal histories, so as to ensure that interventions are indeed responsive to peoples' realities and needs. If we wish to reduce both the HIV transmission rate and the stigma associated with it, we must make the assumption that 'social identities play a key role in shaping people's sexual behaviour'<sup>13</sup> and then put real efforts into understanding these social realities and identities from the perspective of the individual.

### **Storytelling: Concepts and potentials**

Oral history, at the heart of it all, is a dialogue between two or more people about some aspect of the past.<sup>14</sup> It gives a human face to history and creates an importance surrounding the individual experience that is normally seen as quite ordinary.<sup>15</sup> Oral history can also be seen as storytelling or folklore where historical accounts with traditional themes, lessons, and rituals are passed down

from generation to generation. According to the Sinomlando Centre for Oral History and Memory Work at the University of KwaZulu-Natal, storytelling has been long known as an African form of socialisation that bridges the perspectives of young and old.<sup>16</sup>

This aspect of oral tradition is especially important in opening up the lines of intergenerational communication. Through the *Understanding Safe Sex* study, Harrison (2001)<sup>17</sup> revealed that many of the older generations are maintaining strong ties to their traditions, while the young adults are being exposed to an extremely well-developed transport system that easily links them to major cities, mass media, and the influence of 'urban youth culture'<sup>18</sup>. The passing down of traditions through spoken word from one generation to the next could prove to be a very effective model in bridging the communication gap between young and old. Regardless of what community dialogue programmes are put in place, the stigma surrounding sex and HIV will continue to persist if a person walks into their own home and feel as though they cannot speak about the issues that are concerning them with their own family.

For narratives to become an

effective method of bridging communication gaps and addressing the stigma associated with HIV, there is some preliminary work that needs to be done. There are some key themes that are normally associated with oral tradition – the discussion of sex, marriage, and HIV not being any of them. We cannot expect that a society free of HIV-related stigmas will be the end all and be all of revisiting the tradition of storytelling, but merely a by-product of increased intergenerational and cross-gender communication.

Historically, storytelling has been quite an intimate tradition that is shared between family and community members. There is a certain level of respect and sensitivity that needs to be adhered to when we explore the idea of using an old family tradition to solve a relatively modern issue. As a form of socialisation:

*One of the most enduring stereotypes in South African oral literary studies is that of woman as storyteller. Almost invariably a grandmother, preferably seated in the vicinity of a fire, this figure has dominated virtually all local research into oral narrative.*<sup>19</sup>

This age old image places a woman at the centre, as the matriarch if you will, if even just for a moment. This is an influential role to play, but unfortunately is one that gets lost in South Africa's patriarchal nature and as such, deprives the younger generation a chance to see everyday women holding a position of power. A large obstacle in the way of mitigating HIV related stigma is the gender norms that are so heavily integrated in society. These norms dictate that women should speak only when spoken to, be 'docile creatures', and that women are inherently 'inferior' to men. 'Ukuhlonipha' is a common theme in oral history a core aspect of Zulu

**...oral tradition is especially important in opening up the lines of intergenerational communication...**

...merely a  
by-product of increased  
intergenerational  
and cross-gender  
communication...

culture, which says that respect is of utmost importance, especially towards men and elders.<sup>20</sup> At the same time, most South African socio-cultural contexts have adopted the *'ukuhlonipha code of respect'*, or a similar code of conduct placing a high value on *'respect'* towards some members of society; with women being mostly excluded. Thus, for women, inclusion into the *'ukuhlonipha code of respect'* arguably equates to inclusion into the heteronormative and patriarchal society.

If we can use traditional storytelling to shine a new light on the role women play as *'respected members'* of the community, we can begin to shift the consciousness in terms of the way women are viewed and treated, regardless of their sex and/or HIV status. In a societal context in which women are the least respected members of society and

HIV remains highly stigmatised, women living with HIV are thus most at risk of gender and HIV related violence and other rights abuses – a reality, which *'story telling'* has the potential to address and transform.

**'Rites of passage' in the context of women and HIV**

Another common theme in oral tradition is that of the ritual; the common denominator being the *'communitas'* mentality. Many traditional folktales revolve around coming of age stories or rites of passage. As Van Gennep (1960) states, there are three stages to a traditional *'rite of passage'*: separation, *liminality/communitas*, and reintegration.<sup>21</sup> Separation from the community happens after a specific event that triggers a need for the particular ritual. The *liminality* and *communitas* stages are terms coined by Turner (1961), whereby participants no longer hold the status they held prior to the ritual beginning, but do not yet hold the status that they will once the ritual is over.<sup>22</sup> *Communitas* refers to a community where all people are equal and share a common experience, more often than not, through these rites of passage<sup>23</sup>. Once the period of isolation had passed, the participant would re-enter the community as a mature figure, a source of wisdom and

knowledge, and as a beacon of hope.

Although these coming of age rituals were usually associated with men and may be out-dated, learning about them through storytelling can still provide valuable lessons, assist in re-defining the concept and creating an all inclusive version of the term *'rite of passage'*. The stage that should hold the most importance in this learning lesson should be that of reintegration into the community with a

...greater knowledge of the world, deeper consciousness, insight and wisdom.<sup>24</sup>

Currently, in the context of women and HIV, a positive diagnosis is seen as a direct translation to shame. There seems to be no *'beacon of hope'* in finding out that you are HIV positive. The dialogue in communities makes women who are living with HIV feel as if they are relegated to a life in the margins. Women being exiled from their homes, subjected to forced sterilisation, and refused employment are just some of the examples of how women living with HIV experience the same emotional and physical isolation that young men did during their *'rites of passage'*. The only difference is that the young men had the luxury of reintegrating into society that was willing to accept them.

Recounting personal experiences of rites of passage provides a basis for open communication and a source of commonalities between other members of the community. Those who have experienced what it is like to be positively diagnosed with HIV might argue that they too experience a type of ritualistic *'rite of passage'*, however they may experience stagnancy in the *communitas* stage where they feel a sense of equality only

...gender norms  
that are so heavily  
integrated in  
society...

between others who have also been diagnosed. There is never a sense of equality when they are reintegrated into society, but yet a constant sense of marginalisation, stigmatisation, and discrimination.

This paper is arguing that it is a sense of community and open communication that South Africa needs in order to overcome a history of silence and discrimination surrounding HIV. Farmer (2004) shows

*...how conditions of chronic poverty, gender inequality, and everyday violence limit the life choices of the HIV-positive poor women [sic] she encounters at her HIV/AIDS clinic.*<sup>25</sup>

If we can limit some of these external factors through respect and communication, women will begin to experience the power of choice – the power to choose if they want to disclose their status, when and with whom in the absence of stigma and discrimination. When there is an overwhelming sense of respect and *Ubuntu* in the community, we will notice a shift in the treatment of women – not only living with HIV, but a shift in the treatment of women in general.

### Concluding remarks...

In the same way anthropologists immerse themselves into a culture of gaining a first person perspective and better understanding of people, we, as a society striving for change, need respectful, open dialogue in communities so that partners, families, neighbours, co-workers, and classmates, can begin to better understand each other. From that deeper understanding arguably comes a sense of respect and dignity for all community members, as a community saturated with respect leaves no room for discrimination and stigmatisation.

Using storytelling and oral tradition is only one way that we can come about this result. At the end of the day, it does not matter how we reach the conclusion of communication and respect. What does matter is that we make it our mission to reach a point of understanding, acceptance, and an overall '*I am because we are*' mentality. A mentality, which among other manifests itself as '*safe spaces*' wherever women go, where they feel like they can openly express themselves on any platform, regardless of whether they are speaking to their mother or the sister at the clinic, regardless of their HIV diagnosis.

### FOOTNOTES:

1. HIV & AIDS in South Africa. AVERT. [www.avert.org/hiv-aids-south-africa.htm]
2. *Ibid.*
3. Nuttall, S. 2004. 'City forms and writing the "now" in South Africa'. In: *J South Afr Stud.* 30(4), pp731-748. [doi:10.1080/0305707042000313988]
4. Tyler, S.A. 1987. *The Unspeakable: Discourse, dialogue, and rhetoric in the postmodern world.* Madison: University of Wisconsin Press.
5. Elfenbein, R. 2005. "'ABC": A gendered look at HIV prevention'. In: *ALQ*, November Edition, pp10-13.
6. *Ibid.*
7. Overland, L. 2005. 'The role of HIV and AIDS communication'. In: *ALQ*, November Edition, pp37-39.
8. Campbell, C. 1997. 'Migrancy, masculine identities and AIDS: The psychosocial context of HIV transmission on the South African gold mines'. In: *Soc Sci Med*, ???
9. Harrison, A., Xaba, N., & Kunene, P. 2001. 'Understanding safe sex: Gender narratives of HIV and pregnancy prevention by rural South African school-going youth'. In: *Reprod Health Matters*, 9(17), pp63-71. [doi:10.1016/S0968-8080(01)90009-6]
10. *Ibid.*
11. *Ibid.*
12. Elfenbein, R. 2005. "'ABC": A gendered look at HIV prevention'. In: *ALQ*, November Edition, pp10-13.
13. Campbell, C. 1997. 'Migrancy, masculine identities and AIDS: The psychosocial context of HIV transmission on the South African gold mines'. In: *Soc Sci Med*, ???
14. Shopes, L. 2015. What is Oral History? *Mak Sense Oral Hist.* [http://historymatters.gmu.edu/mse/oral/oral.pdf]
15. Strydom, B., Groenewald, R., & Changuion, L. 2007. 'Out of the Mouths of the Alumni: The University of Pretoria as a Case Study'. In: *Natl Arch Rec Serv South Africa*. 6. [www.national.archives.gov.za/rms/ARCHIVES\_NEWS.pdf]
16. Denis, P. 2007. 'Oral History: An African Art?'. In: *Natl Arch Rec Serv South Africa*. 1, pp39-42.
17. Harrison, A., Xaba, N., & Kunene, P. 2001. 'Understanding safe sex: Gender narratives of HIV and pregnancy prevention by rural South African school-going youth'. In: *Reprod Health Matters*, 9(17), pp63-71. [doi:10.1016/S0968-8080(01)90009-6]
18. *Ibid.*
19. Denis, P. 2007. 'Oral History: An African Art?'. In: *Natl Arch Rec Serv South Africa*. 1, pp39-42.
20. *Ibid.*
21. Van Gennep, A. 1960. *The Rites of Passage.* London: Routledge and Kegan Paul.
22. Turner, V. 1961. *Ndembu Divination: Its symbolism and techniques.* Manchester: Manchester University Press.
23. Robins, S. 2006. 'From "Rights" to "Ritual": AIDS Activism in South Africa'. In: *Am Anthropology*, 108(2), pp312-323. [doi:10.1525/aa.2006.108.2.312]
24. Denis, P. 2007. 'Oral History: An African Art?'. In: *Natl Arch Rec Serv South Africa*. 1, pp39-42.
25. Farmer, P. 2004. 'An Anthropology of Structural Violence'. In: *Current Anthropology* 45(3), p305.

*Simone is an intern at the AIDS Legal Network (ALN).*

*For more information: sthoma12@binghamton.edu.*

## Women marching for change...

Women and their allies came together calling for non-violence and women's rights protections; marching for change. These marches took place in Mitchell's Plain (Western Cape), New Brighton (Eastern Cape), and Illovo (KwaZulu Natal) in October and November 2014.

It was a time for women to mobilise among themselves, to take their priorities into their own hands, to raise their voices in unity, and to come out with urgency and agency to say: **enough is enough**.<sup>1</sup>

### Women say 'no more'...

We, as women are coming together to make our voices heard; to say 'no more'!

1. See also AIDS Legal Network. 2015. *Coming together to make our voices heard: Community advocacy: Building solidarity, bridging communities.* [www.aln.org.za]

## THE 10 DEMANDS OF WHAT WOMEN WANT:

1. We demand respect and equal treatment – everywhere and all the time!
2. We demand to be free from violence and abuse
3. We demand to be free from judgement and discrimination – in our homes, communities and within service provision
4. We demand to be safe in our homes and our communities
5. We demand access to 'safe' and responsive health services – women say: **no more** denial of treatment if we miss the appointment, **no more** shouting, **no more** refusal of condoms and contraceptives, because we are too young
6. We demand our right to privacy to be protected – women say: **no more** disclosing of our HIV positive status
7. We demand integrated services – women say: **no more** separate queues and coloured folders, **no more** exposing of women living with HIV to judgement and rights violations
8. We demand agency and the right to make decisions – women say: **no more** 'coerced' HIV testing, because we are pregnant or because we want access to contraception, **no more** 'telling us' what is best for us
9. We demand access to justice and responsive police services – women say: **no more** delays in police responses to domestic violence cases, **no more** delays in sexual abuse and rape cases
10. We demand police protection – women say: **no more** judgment and attitudes, **no more** arbitrary 'stops and searches'



**We, as women, demand change! We demand respect! We demand justice!  
And we demand it NOW!**

**Editor:** Johanna Kehler [jkebler@icon.co.za](mailto:jkebler@icon.co.za)  
**Photography:** Johanna Kehler [jkebler@icon.co.za](mailto:jkebler@icon.co.za)  
**Design:** Melissa Smith [melissas1@telkomsa.net](mailto:melissas1@telkomsa.net)  
**Printing:** FA Print

Supported by Oxfam

