

Make it *everybody's* business...

Lessons Learned from Addressing the Coerced Sterilisation of Women Living with HIV in Namibia

The sterilisation of positive women without their informed consent is an ongoing serious human rights violation, with documented incidences from around the world. In 2007, the ICW Namibia and the Namibia Women's Health Network became aware of cases of coerced sterilisation of positive women in Namibia and began to document cases, to build an evidence base, to make the issue public, and to advocate to end coerced sterilisation.

BACKGROUND/SITUATION – WHAT IS HAPPENING?

To date, over 40 cases of women being sterilised without their consent, or even knowledge, have been documented in Namibia; and new cases are continuously becoming known. Fifteen of these cases have been taken forward for litigation by the Legal Assistance Centre in Namibia, alleging violations of women's constitutional rights to be free from discrimination and cruel, inhumane, and degrading treatment, as well as positive women's rights to found a family and to dignity. In October 2009, six cases were lodged with the courts and in June 2010 three of these cases have been heard before the High Court. The case is ongoing and postponed to September 2010.

The coerced sterilisation of positive women in Namibia occurs primarily in the context of HIV care, specifically the prevention of vertical transmission programmes, and general obstetric care. In some cases, 'consent' to sterilisation has become a prerequisite for access to maternity care, and in other cases, 'consent' has been obtained under duress while a woman is in labour or on

her way to the operating theatre. Women were also told or given the impression that they had to consent to sterilisation in order to obtain another medical procedure, such as a termination of pregnancy or a caesarean section. In all cases, medical personnel failed to provide women with the necessary information to make an informed decision, including information on the nature of the procedure, its effects, consequences and risks, as well as possible alternatives to the procedure.

Defining concepts

'Coerced sterilisation' refers to a situation in which women are coerced/forced to agree to undergo the procedure; and 'forced sterilisation' means that women are unaware of being sterilised at the time of the procedure.

Sterilisation without consent is illegal and violates women's fundamental human rights to equality, dignity, non-discrimination and health, which includes the right to make informed decisions about healthcare. Coerced and/or forced sterilisation also severely compromises women's sexual and reproductive rights, including the right to bear children and to freely decide whether or not to reproduce, when, and how many times. In the reported cases, women were sterilised as a result of their HIV positive status – thus, violating positive women's right to equality and to be free from discrimination.

This brief is based on documentation and analysis of various advocacy approaches and responses used in the Namibian context to address the coerced sterilisation of positive women.¹

IMPACT

The coerced sterilisation of positive women has multiple implications, ranging from a woman's overall well-being and health status to her personal relationships and dealing with the socio-cultural expectations of womanhood and motherhood after being

sterilised. The impact of sterilisation without consent has serious implication for the healthcare system as a whole, as the fear of discrimination and mistreatment discourage women from seeking healthcare services, and subsequently undermine government's public health efforts on HIV and reproductive health.

...[the] family don't want to be with them again; the husband or boyfriend leave them because they cannot give birth anymore...²

...and our culture, it looks down on women who cannot have children...so how is this woman going to live in the community?...³

It is not uncommon for women who have been sterilised to be ostracised by their families and communities, and/or abandoned by their partners. Women are also often faced with socio-economic hardships and are subjected to discrimination and mistreatment when seeking healthcare.

ADVOCACY RESPONSES

...[we] decided to get involved and take up the issue, as we realised that it was another form of discrimination and abuse of positive women...[and their] rights to motherhood. We were also concerned about the negative effects on women accessing PMTCT...⁴

Cases of coerced sterilisation of positive women have been documented and brought to the attention of the government since 2008. The government has yet to announce concrete steps to explicitly prohibit the sterilisation of positive women without consent. To the contrary of taking actions to ensure an end to coerced sterilisation in Namibia, the Ministry of Health in June 2009 responded by stating that no such systemic practice of sterilisation exists.

Parallel to documenting cases and building an evidence base, an important focus of the advocacy has been to build and enhance the capacity of positive women on human rights, particularly sexual and reproductive health and rights, in the context of HIV and AIDS, as well as in human rights documentation and redress mechanisms. This approach, seeking to catalyse a positive women-led response, also facilitated a process in which women could better understand and identify violations, as well as seek accountability and redress.

The Namibia Women's Health Network and partners have also been engaged in various advocacy activities over the years

aimed at awareness raising on, and highlighting the occurrence of, human rights abuses that positive women are subjected to in the context of sexual and reproductive healthcare.

Increasing advocacy demands leading up to the first appearance of the case in court also led to the launch of a national 'End Forced Sterilisation' campaign. The continuing documentation and building of an evidence base coupled with capacity building, litigation, forging alliances, launching a campaign, and gathering broader support have all been essential components in raising the visibility of both the occurrence of, and the need to provide redress for, coerced sterilisation of positive women in Namibia. Subsequently, the voice collaboratively calling to end the sterilisation of positive women in Namibia has become louder and will not as easily be 'silenced' again.

LESSONS LEARNED – LOOKING FORWARD

Key issues that have emerged in the efforts to address the coerced sterilisation of positive women in Namibia include:

Importance of dialogue and of 'breaking the silence'

The issue of coerced sterilisation was first recognised in a dialogue with young women living with HIV, and the community led response to it has resulted from the ongoing work of the Namibia Women's Health Network to bring positive women into conversation about their experiences, and the ongoing rights violations they are subjected to. At the core of these conversations has been, and continues to be, positive women's right to bodily autonomy, including the right to make free and informed sexual and reproductive decisions.

Importance of information

It is crucial to share information among women, particularly women who are facing or have undergone coerced sterilisation, about their bodies and their rights; and to also raise awareness among the broader community of allies and stakeholders about HIV, reproductive health, and human rights.

The other aspect of this information flow is to ensure that developments that occur at a national level feedback to women at a community level, just as experiences at a community level need to inform efforts at the national level.

Need for dedicated resources

Funding and human resource challenges have limited the scope,

reach, and momentum of the work to date. The national campaign to end forced sterilisation has achieved tremendous success in raising the visibility of, and awareness around, the sterilisation of positive women without informed consent. However, the lack of a dedicated, salaried coordinator and adequate funding could potentially affect both the future impact and sustainability of the campaign.

Importance of ongoing engagement and support for affected women

In supporting women who have been sterilised and engaging with communities where coerced sterilisation has been identified as a pattern, all of the partners involved in the campaign and in the litigation process need to continuously and consistently interact with one another and led by, and with, affected women.

Partners in the campaign further identified the need for attention to the lived experience of coerced sterilisation and to the community impact, as campaign initiatives to date have largely focused on the court cases and have not had the ability to adequately meet the individual needs of affected women.

Addressing stigma and discrimination

The sterilisation of positive women without their informed consent not only forms part of a larger social fabric, but also manifests the prevailing stigma and discrimination against people living with HIV. Women who have been sterilised often face an additional layer of stigma and discrimination, partly based on socio-cultural expectations of motherhood and the importance placed on women's ability to bear children.

Limited or lack of support structures assisting women with these and other consequences of making their experiences public is an ongoing challenge. In some cases, women speaking out and expecting to be supported by their communities and/or support groups have found, for example, that many of their peers believe that women living with HIV should not have the right to have children. It is, therefore, crucial to ensure sufficient and ongoing support to the women concerned.

Addressing the stigma and discrimination that both underline, and perpetuate the occurrence of coerced sterilisation of positive women is paramount to ensure not only the halt of this practice, but also a more adequate access to redress as and when positive women's rights to free and informed sexual and reproductive choice have been violated.

Involving healthcare professionals

The work around coerced sterilisation has highlighted a

general lack of knowledge about patients' rights, particularly positive women's rights, as well as the urgent need to work with healthcare professionals at all levels, to educate them about both their professional responsibilities and the rights of the patient, including consequences of mistreating patients. Capacity building of healthcare providers about HIV, sexual and reproductive health, and rights, is an important step towards ensuring that patients are in the position to make free and informed decisions about their bodies and their health.

In looking forward, there is a need for community advocates and healthcare providers to be in dialogue, to share concerns, to collectively seek to overcome stigma and fear, and to identify solutions, which are mutually beneficial, rights-based, and facilitate positive women's access to quality sexual and reproductive healthcare.

Importance of a broader sexual and reproductive health and rights framework

A key success of the advocacy and work to date has been the alliance-building between women living with HIV and the broader gender, human rights, and sexual and reproductive health and rights communities. Coerced sterilisation has been one 'wedge' bringing different stakeholders together in addressing a wide range of issues at the intersection of sexual and reproductive health and rights and HIV, including positive women's right to make free and informed sexual and reproductive choices.

This advocacy approach affords the opportunity to raise awareness about women's sexual and reproductive rights in the context of HIV, and to advance women's rights to autonomy and bodily integrity, to be free from all forms of violence, and to equality and non-discrimination. The recognition, advancement and protection of a woman's right to make sexual choices; to decide whether or not to have children, with whom and how many; to have access to safe and legal abortion; and to have control over decisions regarding her life and health is paramount to end forced sterilisation of positive women and to guarantee the right of safe and healthy motherhood for positive women.

Footnotes:

1. A copy of the full report can be obtained from the authors, Jennifer Gatsi (j.gatsi@criaasadc.org), Johanna Kehler (jkaln@mweb.co.za), and Tyler Crone (tyler.crone@gmail.com).
2. Katutura Dialogue, 23 March 2010.
3. Jennifer Gatsi, 24 March 2010.
4. Interview with Namibia Women's Health Network, March 2010.

'Best practice'

- 1) Positive women led processes and meaningful community involvement at every level:** The leadership of women living with HIV has been fundamental to the success of the advocacy to date in Namibia, as well as the process of seeking accountability, which in itself has been empowering and transformative.
- 2) Investment in positive women's organisations and initiatives:** The leadership of positive women is not possible without funding for the institutional platforms and the organisational capacity to support and enable leadership.
- 3) Training of positive women in sexual and reproductive health and rights:** Ongoing training has advanced women's empowerment and agency through expanding their knowledge of their bodies and of their rights.
- 4) Expanding capacity and expertise in human rights documentation:** Investing in community led documentation and related advocacy has built a new cadre of human rights advocates and has enabled positive women to engage directly as fact-finders and evidence gatherers.
- 5) Engagement of human rights partners with litigation expertise and the capacity to litigate:** Bringing on partners with litigation expertise has provided new avenues for redress and technical support to community partners.
- 6) Use of traditional and new social media:** The use of media allowed for outreach to large audiences in Namibia and outside Namibia, and for more women to learn of the violations and related advocacy, as well as to step forward and share their experiences.
- 7) Dedicated resources to:**
 - a. Undertake detailed and far-reaching documentation;
 - b. Support litigation; and,
 - c. Facilitate awareness raising, mobilisation, and campaigning, including to support a dedicated co-ordinator of these efforts are all essential to building a solid evidence base, sustaining advocacy, and ensuring that the occurrence of violations is halted.
- 8) Building a national movement and engaging in grassroots activism:** Building alliances between women living with HIV and other gender, sexual and reproductive health and rights, and human rights advocates fostered new platforms for affected women to have a voice.
- 9) Engaging international, regional, and national human rights mechanisms:** Partners used the mechanisms of the Special Rapporteurs, the African Commission on Human and Peoples' Rights, and the Ombudsman's Office to raise the profile and visibility of coerced sterilisation.
- 10) Tapping into the women's global sexual and reproductive health and rights movement:** Building alliances with global movements brought broader support, awareness, and momentum, as well as expertise, strengthening the visibility of the advocacy and campaign efforts.

