Namibian Womens Health Network
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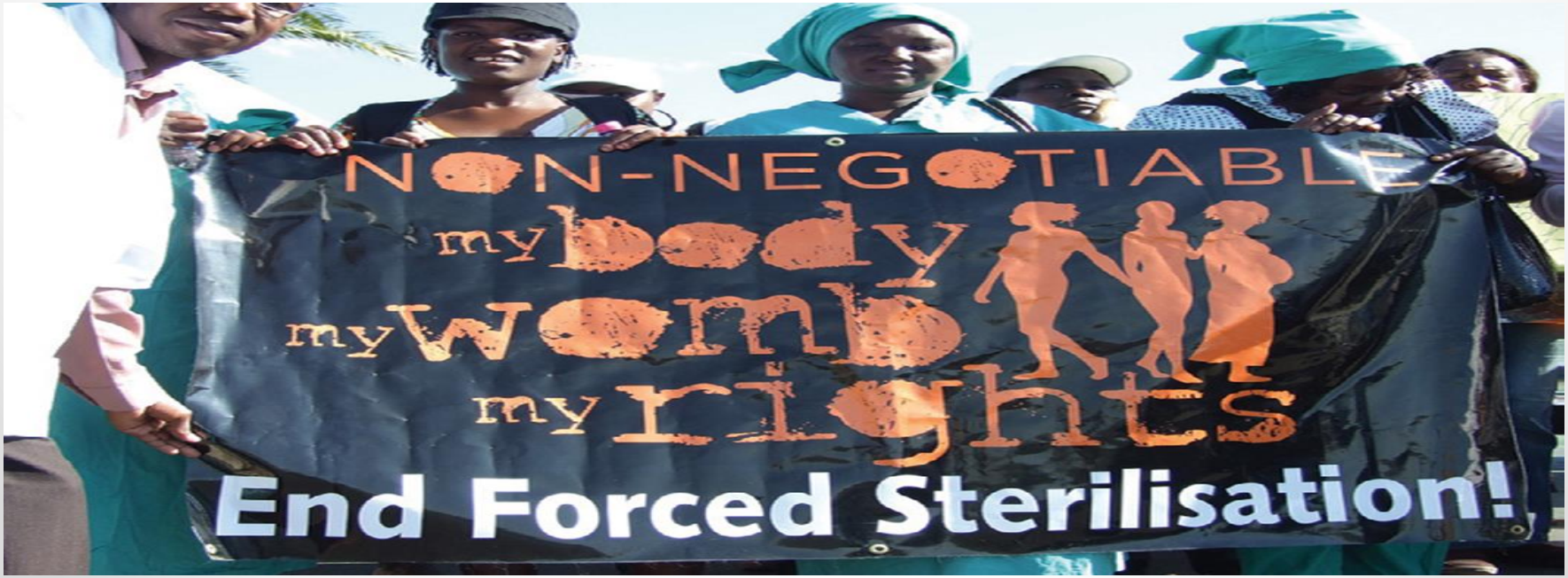
SOUTHERN AFRICA LITIGATION CENTRE
Promoting Human Rights and the Rule of Law in Southern Africa

LEGAL ASSISTANCE CENTRE

Challenging involuntary sterilisation of women living with HIV in Namibia



- **In 2007/8 the Namibia chapter of the International Community of Women Living with HIV(ICW) called the Namibian Women's Health Network (NWHN) uncovered the practice during a series of workshops they had with women living with HIV.**
- **Deputy Minister of Health & Social Services asked for evidence to launch an investigation. A coalition of organisations formed to investigate and advocate.**
- **Over 40 cases were documented out of about 240 interviews.**
- **In all the documented cases, informed consent was not adequately obtained due to one or more of the following factors:**

  - consent was obtained under duress,
  - medical personnel failed to provide full and accurate information regarding sterilisation procedure,
  - women were not informed of the contents of the documents they signed, very scientific/medical terms and initials used,
  - women were told or given the impression that they <u>had</u> to consent to sterilisation in order to obtain another medical procedure such as an abortion, caesarian section or post delivery care for them or their babies,
  - most of the women signed consent forms while they were in labor and pain,
  - many of the women could not read, write or speak English.

- **In a ministerial statement in Parliament on 1 July 2009 Minister stated that the findings of an investigation at various state hospitals did not indicate any specific trend with regard to bilateral tubal ligation performed on HIV positive women. He said the investigation clearly established that all women who had had a caesarean section as well as a sterilisation had signed the relevant consent forms before the operation was done.**
- **Investigation never publicized.**
- **Unsatisfied with Ministry of Health process, litigation was the next logical step. Over a dozen cases were identified and filed.**
- **Three cases involving different public hospitals were pursued. Patients claimed that they had been reproductively sterilized by means of bilateral tubal ligations without their having given informed consent.**
- **Patients claimed that the sterilisation procedure was done on them without their consent because they were HIV-positive.**

High Court Process

Issues before the Court:

1)Informed Consent

a) Whether the Namibian government state hospital medical practitioners performed sterilisation procedures without obtaining informed consent from the plaintiffs.

b) Whether the failure to obtain informed consent from the plaintiffs by the medical practitioners infringed the following constitutional rights:

- The right to life in terms of Article 6 of the Constitution;
- The right to liberty in terms of Article 7 of the Constitution;
- The right to human dignity in terms of Article 8 of the Constitution;
- The right to equality and freedom from discrimination in terms of Article 10 of the Constitution; and
- The right to found a family guaranteed in terms of Article 14 of the Constitution.

High Court Process

Issues before the Court cont.

2) ***Discrimination on the basis of HIV-positive status***

a) Whether the forced sterilisation was in fact due to the HIV positive status of the women and therefore constituted discriminatory practice

b) Whether the following constitutional rights were infringed:

i) The rights mentioned in issue (1)(b) above

ii) The right to equality and freedom from discrimination

Court analyzed the doctrine of informed consent (*Castel v De Greef* 1994 (4) SA 408 (C))

- Consent to medical procedure is an act of self-determination.
- Health provider doctor has duty to provide adequate and sufficient information to enable the patient make an informed decision. Information should enable the patient to appreciate the nature and extent of the harm or risk involved.
- Consent must be clear and unequivocal. It therefore must be given freely and voluntarily and should not be induced by fear, fraud or force.

- Onus is on the defendant to prove that the informed consent.

- Whether the defendant's agents obtained informed consent was a question of fact rather than law.

- Court found that in each instance, the women signed consent forms while in extreme pain at the height of labour and that this could not constitute informed consent.
- Although sympathetic to the tremendous pressures faced by the Namibian public healthcare system, the Court held that the onus is on the hospital to keep clear and accurate records to prove that informed consent has been obtained.
- The women are entitled to damages to be determined at a later date.
- The plaintiffs thus succeeded on the first claim that they were sterilized without informed consent. Since the Court decided that the plaintiffs had succeeded in their main claim, it decided not to make a determination on the alternative claim on constitutional rights.
- The Court dismissed the discrimination claim on account of there being 'no credible or convincing evidence' to substantiate that the sterilizations were performed because of the women's HIV-positive status.

Supreme Court Process

Issue before the Court:

Whether the agents for whose conduct the appellant was responsible had performed sterilisation procedures without obtaining informed consent from the respondents.

- Supreme Court related informed consent to the rights recognized in the Namibian Constitution, especially the rights to dignity, to physical integrity and to found a family.
- Court recognized that it was the woman's choice to decide to bear children or not, and that the decision must be made freely and voluntarily.
- Court assessed intellectual and emotional capacity of the patients to give informed consent. It held that labour is not conducive to obtaining informed consent.
- the Court relied on absence of any clinical record that indicated that the health providers had discussed the nature and risks of the sterilisation procedure with the respondents, to find that on the balance of probabilities, the health providers had not properly obtained informed consent.
- Agreed with the High Court on discrimination

necessary to make the following general remarks. The Namibian Constitution affords every individual in Namibia the right to dignity,[1] to physical integrity,[2] and to found a family.[3] The right to found a family includes the right of women of full age to bear children and of men and women to choose and plan the size of their families. In the case of an unmarried woman, it is primarily her choice, in the exercise of her right to self-determination, whether or not to bear children. Against this background, the decision of whether or not to be sterilised is of great personal importance to women. It is a decision that must be made with informed consent, as opposed to merely written consent. Informed consent implies an understanding and appreciation of one's rights and the risks, consequences and available alternatives to the patient. An individual must also be able to make a decision regarding sterilisation freely and voluntarily.

'(I)t must be clearly shown that the risk was known, that it was realised, and that it was voluntarily undertaken. Knowledge, appreciation, consent - these are the essential elements; but knowledge does not invariably imply appreciation, and both together are not necessarily equivalent to consent.'

'In this context, valid consent can only be given by someone with the intellectual and emotional capacity for the required knowledge, appreciation and consent. Because consent is a manifestation of will, "capacity to consent depends on the ability to form an intelligent will on the basis of an appreciation of the nature and consequences of the act consented to." Van Heerden and others *Boberg's Law of Persons and the Family* 2nd ed at 849.'

[100] I respectfully agree with the above observations. In the case before us, it is crucial to determine whether the respondents had the intellectual and emotional capacity to give their informed consent in the light of the peculiar circumstances in which they found themselves when signing the consent forms. The records of all three respondents do not indicate what information was conveyed to the

[101] As previously noted, Dr Kimberg testified that because of the particularly invasive nature of a sterilisation procedure and its potentially permanent effects, it is not advisable to obtain the consent of a pregnant woman while she is in labour. As already mentioned, he also testified that labour pains could be of such a severe nature that a woman may lose sense of reality and 'grasp at straws' to be relieved of the pain. In the case of an operation such as BTL, which has the consequen of rendering a woman incapable of bearing any future children if not done wi reversal in mind, informed consent must not be obtained without ensuring that tl woman is capable of giving it.

[102] I did not understand the doctors who testified for the appellant to challenge Dr Kimberg's opinion in this respect. It can be accepted that the state of mind of the respondents at the time they signed the forms was not only affected by the labour pains but by other complications as well. The first respondent was diagnosed with CPD, the second respondent's foetus was in a breech position, and the third respondent was in a prolonged first stage of labour. Both sides agree that as a consequence of these complications, the respondents had to undergo emergency operations and it is not seriously disputed that they were in varying degrees of pain at the time they signed the consent forms.

[108] The consent obtained was invalidated by the respondents' lack of capacity to give informed consent in light of the history of how the decision to sterilise them was arrived at and the circumstances under which the respondents' consent was obtained. It was merely written rather than informed consent, which in my opinion is not sufficient for the performance of a procedure as invasive and potentially irreversible as sterilisation. The important factor which must be kept in mind at all times is whether the woman has the capacity to give her consent for sterilisation at the time she is requested to sign consent forms. Therefore, it is not decisive what information was given to her during antenatal care classes or at the moment she signed the consent form if she is not capable of fully comprehending the information or making a decision without any undue influence caused by the pain she is experiencing.

[109] For all these reasons, it is my considered opinion that none of the respondents gave informed consent because they were in varying degrees of labour and may not have fully and rationally comprehended the consequences of giving consent for the sterilisation procedure. This is especially the case given that

'When it comes to a straight choice between patient autonomy and medical paternalism, there can be little doubt that the former is decidedly more in conformity with contemporary notions of and emphasis on human rights and individual freedoms and a modern professionalised and consumer-orientated society than the latter, which stems largely from a bygone era predominantly marked by presently outmoded patriarchal attitudes. The fundamental principle of self-determination puts the decision to undergo or refuse a medical intervention squarely where it belongs, namely with the patient. It is, after all, the patient's life or health that is at stake and important though his life and health as such may be, only the patient is in a position to determine where they rank in his order of priorities, in which the medical factor is but one of a number of considerations that influence his decision whether or not to submit to the proposed intervention. But even where medical considerations are the only ones that come into play, the cardinal principle of self-determination still demands that the ultimate and informed decision to undergo or refuse the proposed intervention should be that of the patient and not that of the doctor.'

[106] There can be no place in this day and age for medical paternalism when it comes to the important moment of deciding whether or not to undergo a sterilisation procedure. The principles of individual autonomy and self-determination are the overriding principles towards which our jurisprudence should

move in this area of the law.[4] These principles require that in deciding whether or not to undergo an elective procedure, the patient must have the final word. Unlike some life-saving procedures that require intervention on a moment's notice, sterilisation allows time for informed and considered decisions. It is true, as


FORCED
STERILISATION
IS TORTURE


to forced
sterilisation!

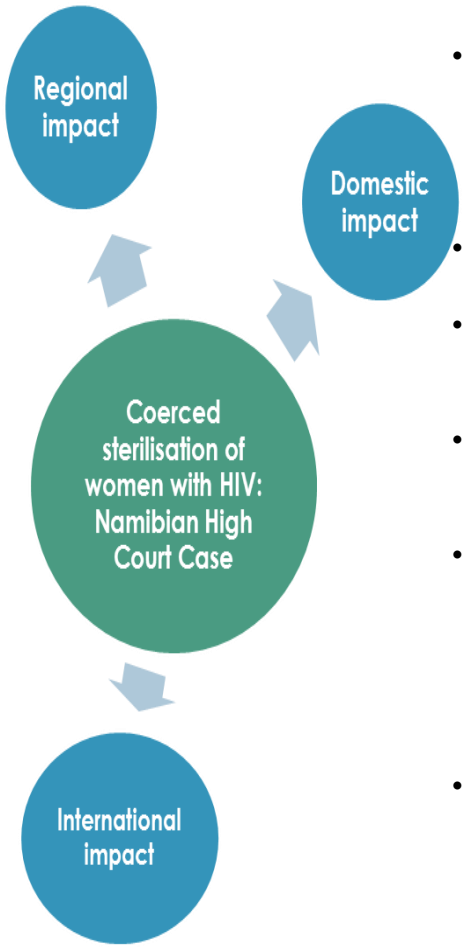

YOU STERILISE ME?

Regional impact:

- Protests on case at Namibian embassies in Zambia, SA, increased awareness on coerced sterilisation, women's rights
- African Commission on Human and People's Rights adopted a Resolution on Involuntary Sterilisation and Protection of Human Rights in Access to HIV Services on November 4 2013 and influenced General Comment 1 on article 14 1(d)&(e).
- Many new reports on forced sterilisation from women in Namibia, Swaziland, Lesotho and similar cases has since been launched in South Africa and Kenya

International impact:

- Advocacy and litigation in Namibia fed into OSF's international advocacy on forced sterilisation as torture which engaged various International HR Bodies, developed guidelines
- Post decision CEDAW, HRC, concluding observations



Domestic impact:

- Partnership between SALC, NWHN, LAC in litigation and advocacy supported by OSF
- Stronger HIV+ women's movement
- Publicity on case resulted in increased awareness about women's SRHR in Namibia and women more aware about risk of sterilisation
- Reports of improved service for women linked to NWHN
- Some reports that women who want sterilisation now need police affidavit
- Improvement in local jurisprudence on informed consent
- Statements made by government representatives in questions from African Commission and Global Commission on HIV and Law will be useful to hold government accountable in future
- UN Special Rapporteur on Extreme Poverty and Human Rights on her mission to Namibia in 2012, met the Applicants. The Rapporteur urged the government to stop forced sterilisation of women with HIV and questioned the government's appeal of the case. Also various other official communications to Namibia on case

Almost 10 percent of HIV-positive women report forced sterilisation – study

by **Laura Lopez Gonzalez** on June 10, 2015 in **HIV/AIDS**, **Women's Health**

South Africa's first national HIV stigma index has found that seven percent of HIV-positive women surveyed reported being sterilised against their will and about 40 percent reported contraception was a pre-requisite of accessing antiretrovirals (ARVs).

Launched yesterday at the SA AIDS Conference in Durban, South Africa's HIV stigma index surveyed about 10,500 people living with HIV across the country in what is the world's largest survey of its kind.

Commissioned by the South African National AIDS Council (SANAC), the report also showed that 14 percent of surveyed women living with the virus reported not receiving ARVs during pregnancy despite national policies.

The index also found that five percent of respondents also reported that they did not seek health services at their local clinic due to stigma.

Following from this, the study found that while HIV-related stigma is much lower in South Africa than in other African countries, women and young people continue to bear the brunt.

"We heard from people living with HIV who had refused marriage due to stigma, had avoided work promotion, or had been coerced into undergoing sterilisation," said the research's project manager Sindisiwe Blose. "Behind the figures, lies a depth of suffering that struggles to be addressed."

The report comes almost 20 years after Durban HIV activist Gugu Dlamini was beaten to death for disclosing

REPRODUCTIVE HEALTH matters

FEATURE

"She made up a choice for me": 22 HIV-positive women's experiences of involuntary sterilization in two South African provinces

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Abstract: *Since 1998 South African law has provided that adults should have access to sterilization but only with their informed consent. However, the right to sterilization and other sexual and reproductive rights have not been fully realized as women struggle to access limited services, and there are allegations of discrimination and sterilization abuses. This qualitative study explores the experiences of 22 HIV-positive women in two provinces who reported being sterilized between 1996 and 2010 without their informed consent (n=18) or without their knowledge (n=4). Key issues reported by participants included failure to respect their autonomy, lack of information given about what sterilization entailed, and subtle or overt pressure to sign the consent form. Although the legal framework was intended to ensure informed decision-making regarding sterilization, these protections appear to have failed the HIV-positive women in this study. The findings suggest that some health professionals may consider a signature on a consent form as sufficient regardless of how it was obtained. Furthermore the women's perceptions that they were singled out as needing to be sterilized simply because they were HIV-positive warrants further investigation. More research is required on the nature of the problem and on other stakeholders' perceptions.* © 2012 Reproductive Health Matters

ROBBED OF CHOICE

Forced and Coerced Sterilization Experiences of Women Living with HIV in Kenya

The Forced and Coerced Sterilization of HIV Positive Women in Namibia

The International Community of Women Living with HIV/AIDS (ICW)

MARCH 2009

Outstanding Issues

- Discrimination
- Redress for Victims
- Prescription/Limitation of Liability Legislation.