

'I Feel Like Half a Woman All the Time':

**A qualitative report of HIV-positive women's experiences of
coerced and forced sterilisations in South Africa**

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Executive Summary

Sterilisation has been proposed as a contraceptive option for HIV-positive women who wish to permanently end their fertility. Given that sterilisation is generally a permanent contraceptive method, a woman's decision to sterilise should be voluntary and fully informed. However, multiple reports suggest that HIV-positive women in Southern Africa are being sterilised without their informed consent (Mallet & Kalambi, 2008; Nair, 2010).

Despite existing regulations and laws protecting women's reproductive choice in South Africa (de Bruyn, 2004), coerced sterilisations are occurring (Gatsi, Kehler & Crone, 2010). This report documents the experiences of a sample of South African HIV-positive women who reported that they were coercively or forcibly sterilised and examines the circumstances under which this alleged abuse occurred. Further, this report documents the reported impacts of coerced and forced sterilisations on affected women and identifies their immediate and long-term support needs. The data gathered in this study points to: instances where informed consent processes were deemed inadequate; instances where informed consent processes failed; where and how regulations were inadequately implemented; and the existing gaps in current legislation protecting women's reproductive autonomy.

“Coerced sterilisation occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Additionally, sterilisation may be required as a condition of health services or employment. **Forced sterilisation** occurs when a person is sterilised without her knowledge or is not given an opportunity to provide consent” (Open Society Foundations, 2011, p. 2).

According to South African law, the Sterilisation Act of 1998 (s2) requires that a patient provide his or her informed consent for sterilisations. “For the purposes of this Act, “consent” means consent given freely and voluntarily without any inducement and may only be given if the person giving it has—

- (a) been given a clear explanation and adequate description of the—
 - (i) proposed plan of the procedure; and
 - (ii) the consequences, risks and the reversible or irreversible nature of the sterilisation procedure;
- (b) been given advice that the consent may be withdrawn any time before the treatment; and
- (c) signed the prescribed consent form.”

This report is based on 22 semi-structured interviews conducted with HIV-positive women in Gauteng and KwaZulu-Natal who were identified through a screening questionnaire (appendix 1) as believing that they had undergone a coerced or forced sterilisation.

Most women in our study reported that they were coerced into having a sterilisation. These women's accounts indicate that their “consent” to sterilisation did not always meet the criteria of fully informed, voluntary and free from pressure and coercion. From their reports, it appears that the informational component of the informed consent process was not always satisfied, as the sterilisation procedure and its consequences were rarely explained. Most women described signing a consent form under very stressful circumstances, such as while they were in active labour or while being wheeled to the theatre. Others reported being coerced into accepting a sterilisation in order to receive another healthcare service like an abortion or caesarean section. Women reported that the provision of appropriate and accurate information about the sterilisation was inadequate and that they felt unable to make an independent and informed decision because they were often in distress. In most instances, healthcare providers equated the signing of consent forms with fully

informed consent. Therefore, the “consent” obtained from these women may be invalid in most cases. As is clearly outlined in the International Federation of Gynaecology and Obstetrics’ (FIGO) Guidelines on Female Contraceptive (FIGO, 2011), a signature on paper does not, on its own, signify consent. It is the process under which the consent is sought that determines if it was fully informed, coerced or forced.

A few of the women reported that they had experienced a forced sterilisation, that is, they were unaware of the sterilisations until some time after the procedure. Some recall being informed about the sterilisation by medical personnel after the surgery was complete. Others only learned that they had been sterilised months or years later when they were unable to conceive additional children.

Women described being discriminated against by healthcare providers. It is argued that the sterilisation of HIV-positive women in South Africa is rooted in pervasive stigma and discrimination that these women should be prevented from having children. This discrimination manifests in different ways. In their view, in addition to being forced or coerced to undergo sterilisation procedures, the women in this study reported being routinely abused, humiliated and bullied by healthcare workers. This is a violation of women’s rights to bodily integrity. Section 12(1) of the Constitution provides everyone has the right to freedom and security of the person, which includes the right “not to be treated or punished in a cruel, inhuman or degrading way” (Constitution of the Republic of South Africa, 1996). It also infringes on other constitutional rights such as privacy and equality (ss 14 and 9, Constitution of the Republic of South Africa, 1996).

Additionally, women who are forcibly or coercively sterilised face double the stigma because they are both HIV-positive and unable to bear children. Forced and coerced sterilisations have several negative personal and social consequences. These include, but are not limited to, emotional distress and social isolation, divorce or abandonment by partners, persistent mental and physical health problems and financial costs (often related to attempts to reverse the procedure). Many of these women (and their partners) still desired more children and our respondents reported that being sterilised has affected them profoundly, making them feel like less of a woman.

To improve the process of seeking consent for a sterilisation procedure, most women interviewed requested that in future, all women who are candidates for sterilisation be provided with detailed information on sterilisation¹, that all women be allowed to make the decision independently, free from coercion, and be provided with sufficient time to consider their options while free from duress or pain. These recommendations are consistent with existing legal requirements for informed consent in South Africa which are not being implemented in practice. The study findings point to a disjuncture between policy and practice rooted in persistent discrimination against HIV-positive women which results in a severe violation of their rights.

DISCLAIMER:

The views expressed in this report are based on an analysis of the perceptions of the women interviewed in this study. Any conclusions drawn are the views of the authors and not necessarily those of the funders of the project.

¹ This information should be provided in accordance with the procedures included in 2011 FIGO Guidelines on Female Contraceptive Sterilisation circulated with this report.

Background

HIV/AIDS and its impact on women in South Africa

Sub-Saharan Africa remains the region most profoundly affected by HIV/AIDS (UNAIDS, 2009). In this context, HIV infections are disproportionately skewed toward women who account for nearly 60% of HIV infections (UNAIDS, 2009). Further, the prevalence in adolescent women is three to seven times higher than in adolescent men (Abdool Karim, Sibeko & Baxter, 2010). In South Africa, the highest prevalence rates are among women of reproductive age (Cooper, Moodley, Zweigenthal, Bekker, Shah & Myer, 2009). Women are primarily infected via heterosexual transmission with a concomitant epidemic of transmission to infants (Abdool Karim et al., 2010). Almost 90% of all HIV-positive children worldwide live in sub-Saharan Africa (Merson, O'Malley, Serwadda & Apisuk, 2008). In this region, nearly 12 million children below 18 years of age have lost one or both parents to HIV (UNICEF, UNAIDS & WHO, 2008). The feminisation of the HIV epidemic can be attributed to women's greater physiological vulnerability to HIV as well as to structural factors such as gender inequities, poverty, cultural, sexual and gender norms, a lack of education, and violence against women (cf. Quinn & Overbaugh, 2005).

Reproductive intentions of women living with HIV

"Reproduction poses dilemmas for people living with HIV (PLWHIV) and for public health and clinical care providers" (Cooper et al., 2009, p. S38). Most HIV-positive women are of reproductive age and therefore face critical decisions regarding their sexuality, desire for children and family life. HIV infection negatively impacts the ability of HIV-positive individuals to have children due to clinical implications for fertility (Segurado & Paiva, 2007). Additionally, widespread stigma and discrimination, including the perception that HIV-infected women should not engage in sexual relationships or have children, impact decisions about bearing children (Paiva, Filipe, Santos, Lima, Segurado, 2003).

Research in both developing and developed country contexts suggests many PLWHIV may continue to engage in sexual relationships and that some have expressed strong desires to have children (Cooper et al., 2009; Harries, Cooper, Myer, Bracken, Zweigenthal & Orner, 2007; Mthembu, 2009). Besides the risk of transmission to HIV-negative partners and children, and concerns about long-term childcare plans in the event that the mother becomes seriously ill or dies (Nduna & Farlane, 2009), "other health concerns for HIV-positive pregnant women are less clearly defined, and from a clinical perspective there are few reasons why HIV-positive women should not become pregnant if they choose to do so" (London, Orner & Myer, 2008, p. 14). Further, with the widespread introduction of interventions for the prevention of mother-to-child transmission (PMTCT) and increasing access to antiretroviral therapy (ART), there has been a significant increase in the number of HIV-positive women considering having children (Orner, Cooper, Myer, Zweigenthal, Bekker & Moodley, 2009). Still, the social context may pose significant challenges for women's reproductive decision-making (Nduna & Farlane, 2009) which remains constrained by a broader policy framework at both an international and local level focused on preventing pregnancy in HIV-positive women (London et al., 2008).

Research suggests that HIV-positive women in South Africa face widespread, persistent, and severe stigma and discrimination, especially when accessing sexual and reproductive healthcare in public hospitals. HIV-positive women may experience difficulty in accessing information on HIV and pregnancy as well as information on available contraceptive options (de Bruyn, 2004). In addition, if HIV-positive women decide to become pregnant, they may be subjected to intense negative attitudes and discrimination from their own communities and from healthcare providers (de Bruyn, 2004).

Much of the literature focuses on the nature and types of choices that are made by women living with HIV (Bedimo et al., 1998). Many factors have been identified which influence reproductive choices including culture, the psycho-social and economic situation, the views of partners and friends, and the attitudes of healthcare workers (Bedimo et al., 1998).

The role healthcare workers play in facilitating reproductive choices

Healthcare workers play a critical role in shaping the reproductive healthcare services available to women (Harries et al., 2007; London et al., 2008). However, healthcare workers and patients have very different perspectives on reproductive choices (Harries et al., 2007). Despite healthcare workers' awareness of sexual and reproductive rights and the principle of autonomy, they tend to locate a patient's reproductive choices within a medical perspective and focus on the impact of HIV on the health of the woman living with HIV (Harries et al., 2007). On the other hand, women themselves have expressed that societal pressure and other factors influence their decisions to have children (Harries et al., 2007). In South Africa, as in many places, there is a significant power imbalance between healthcare workers and patients. Health workers may project their personal feelings and discrimination against particular groups onto the patient and insist on the provision or denial of certain services (London, Orner & Myer, 2008). Healthcare services for HIV-positive women may also be constrained by perceptions that they should not have children to the extent that "providers may promote specific services such as sterilisation or abortion and compromise or limit women's reproductive choices" (Harries et al, 2007, p. 2). Such perceptions may result in a health decision-making context that is highly coercive and sometimes abusive (London et al., 2008).

Rochon (2008) argues that healthcare workers have shown limited understanding of the reproductive choices to which all women (including HIV-positive women) are entitled and that HIV-positive women make. Many healthcare workers believe that infected women "should not reproduce under any circumstances" (Ingram & Hutchinson, in Rochon, 2008, p. 32). Further, HIV-positive participants in a South African study reported "health worker antipathy to childbearing" and perceived healthcare workers as judgemental (London et al., 2008, p. 17). This was echoed in other studies in Southern Africa, Asia and Brazil (Moyo & Mbizyo, 2004, Bell et al., 2007 & Pavia et al., 2007, in London et al, 2008). Several studies from both developed and developing countries indicate high levels of healthcare provider stigma and discrimination toward HIV-positive people, including cases of forced HIV testing, denial of HIV treatment and care, and breaches of confidentiality (Hossain & Kippax, 2011). Jewkes et al. (1998) found that even though not all healthcare workers were abusive, patient abuse was often ritualised and influenced by organisational issues like poor conditions of service and low salaries, the sanctioning of coercive strategies and punishment, and an ideology of patient inferiority, among others. Given these structural impediments, it may be possible that healthcare workers are operating in an environment which is not conducive to autonomous informed consent and where informed consent is equated to signing a document because following the informed consent process would take too long.

Sterilisation

American literature clearly articulates voluntary sterilisation as a valid choice for women living with HIV who wish to permanently end their fertility. Data from the USA indicate that HIV-positive women are almost three times more likely to undergo sterilisation than HIV-negative women (Bedimo et al., 1998). Female surgical sterilisation can take multiple forms, including a hysterectomy, where the uterus is removed, or bilateral tubal ligation, where the fallopian tubes are restricted in such a way to prevent fertilisation (Mallet & Kalambi, 2008). Voluntary surgical sterilisation is sometimes a preferred method of permanently ending fertility because it is considered a safe, highly effective procedure with fewer side effects than other contraceptive options (Landolt, Phanuphak, Chaithongwongwatthana & Ananworanich, 2010; Stovall & Mann, 2010).

However, sterilisation does not provide protections against HIV and other sexually transmitted infections (STIs) and is “a virtually irreversible choice” (Landolt et al., 2010, p. 696). Given the permanency of the procedure and the difficulty and expense associated with its reversal, the decision to sterilise must be voluntary – women should not be pressured by their partners, their families or their healthcare providers (Stovall & Mann, 2010). The decision to sterilise should also be an informed one. Healthcare providers should explain the details of the procedure, the risks and benefits, the permanent nature of sterilisation as well as alternatives to sterilisation including non-permanent methods of contraception (Stovall & Mann, 2010). Further, sterilisation should never be a pre-requisite for receiving another medical procedure.

The requirement for informed consent derives from the ethical principle of respect for autonomy, which entails that individuals have the right to make their own independent decisions without undue influence or coercion. This principle requires voluntary and informed consent, the freedom to withdraw consent, and respect for privacy and confidentiality (The Belmont Report, 1979).

The legal notion of informed consent to medical treatment also rests on the recognition of the rights of individuals to act as autonomous beings (Lindegger & Richter, 2000). Patients have a fundamental right to self-determination which means that the decision whether or not to undergo medical treatment is their own (*Castell v de Greef*). Consent in this context serves the purposes of: (i) ensuring that a patient’s rights to self-determination and freedom of choice are respected; and (ii) encouraging rational decision-making by patients through enabling them to weigh and balance the various options available to them (Carstens & Permaine, 2007).

Coerced and forced sterilisation of women living with HIV

There are increasing reports that HIV-positive women in various contexts are being coerced or forced into submitting to sterilisation (Gatsi, Kehler & Crone, 2010). “**Coerced sterilisation** occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Additionally, sterilisation may be required as a condition of health services or employment” (Open Society Foundations, 2011, p. 2). When women sign consent forms under coercive circumstances, their decision to consent is not considered voluntary and is therefore invalid. “**Forced sterilisation** occurs when a person is sterilised without her knowledge or is not given an opportunity to provide consent” (Open Society Foundations, 2011, p. 2). In other words, the woman is not informed that she would be undergoing a sterilisation procedure and only learns of the sterilisation after the fact (Mallet & Kalambi, 2008). Both coerced and forced sterilisations are considered involuntary.

Historically, coerced and forced sterilisations have a eugenics-based rationale which has been associated with poverty, minority cleansing, eliminating and reducing the reproduction of social scourges or those not desired by society (Mthembu, 2009; Patel, 2008). Eugenics has been associated with practices aimed at improving the genetic composition of people. HIV-positive women who are poor or otherwise marginalised are especially likely to be victims of coerced and forced sterilisation procedures. In Southern Africa, women accessing PMTCT or abortion programmes are disproportionately likely to experience involuntary sterilisations (Mthembu, 2009).

There have been increasing reports of HIV-positive women within the sub-Saharan region being coerced into sterilisation (Kardas-Nelson, *Mail and Guardian*, 2009). Non-governmental organisations (NGOs) report that HIV-positive pregnant women are compelled or deceived into having sterilisations in order to prevent future pregnancies simply because they are HIV-positive (ARASA, 2008; Patel, 2008). It has been argued that some countries with high HIV infection rates may use forced sterilisation as a mechanism to reduce mother-to-child transmission (Nair, 2010).

The extent of the prevalence of coerced and forced sterilisation of HIV-positive women in South Africa is not known (ARASA, 2008). However, reports from Namibia and South Africa have documented many cases of alleged coerced and forced sterilisations (Gatsi-Mallet, 2008; Mthembu, 2009; Patel, 2008). There are also reports of widespread coerced and forced sterilisation of HIV-positive women in Chile (Nair, 2010) and anecdotal reports of coerced sterilisation in the Democratic Republic of Congo and Zambia (Kardas-Nelson, *Mail and Guardian*, 2009).

In Namibia, the International Community of Women Living with HIV (ICW) documented the first three known cases of coerced and forced sterilisation in 2007 (Kalambi, 2008). Since then, a further 12 cases have been identified in Namibia. In many of the cases, women reported that they were subjected to sterilisation without their informed consent when they sought medical care. Multiple women reported that they were unaware that they had been sterilised until some time after the procedure (Gatsi-Mallet, 2008). In other instances, women signed consent forms for sterilisation as a pre-requisite to access healthcare services such as a caesarean section or as they are being wheeled to the operating theatre while in labour (Patel, 2008). Litigation is currently underway before the High Court in Namibia in three of these cases (Kalambi, 2008).

The situation in South Africa

There are regulations and laws to protect women's reproductive choice in South Africa (de Bruyn, 2004). South Africa has a comprehensive ethical-legal framework which includes a well-established set of norms regarding informed consent to medical treatment. These norms are established both in terms of the law and ethical guidelines. Legally, the right to informed consent is found within the right to "freedom and security of the person" in the Constitution (s12, Constitution of the Republic of South Africa, 1996); the National Health Act which describes the rights of users (patients) to be treated only with their informed consent except in certain defined circumstances (s6–9, Act No. 61 of 2003); and the common law (McQuoid-Mason, 2001). Legally, consent operates as a defence to what would otherwise be an unlawful act (McQuoid-Mason, 2001). However if the principle is to operate as a defence the following must exist, the patient should:

- (i) have knowledge of the nature and extent of the harm or risk involved (McQuoid-Mason, 2001);
- (ii) appreciate and understand the nature of the harm or risk (*C v Minister of Correctional Services*); and
- (iii) voluntarily consent to the harm or assume the risk (*Esterhuizen v Administrator, Transvaal*).

Ethically, the need for healthcare providers to respect the rights of patients to autonomy is set out in the Ethical Rules of Conduct for Practitioners Registered under the Health Professions Act of 1974.

South Africa has dedicated legislation setting out when and how sterilisations may take place and the patient protections which must be adhered to (Sterilisation Act, No. 44 of 1998). Section 4 of the Sterilisation Act provides unambiguous protection regarding the obtaining of consent. "For the purposes of this Act, 'consent' means consent given freely and voluntarily without any inducement and may only be given if the person giving it has—

- (a) been given a clear explanation and adequate description of the—
 - (i) proposed plan of the procedure; and
 - (ii) consequences, risks and the reversible or irreversible nature of the sterilisation procedure;
- (b) been given advice that the consent may be withdrawn any time before the treatment; and
- (c) signed the prescribed consent form."

In essence, the Sterilisation Act requires knowledge, voluntariness and agreement (through the signing of the informed consent form). The Sterilisation Act also explicitly states that a person capable of consenting should not be sterilised without consent and that women should be informed that they may refuse to undergo a sterilisation procedure (s4, Sterilisation Act, 1998).

Section 4(c) of the Sterilisation Act requires consent to the sterilisation to be in writing. This is a special requirement which has been imposed by the Act, as ordinarily consent for a medical procedure does not need to be in writing. Nevertheless, the courts have held that where patients are given a consent form to sign they must be made aware of any unexpected terms in the consent form (*Fourie NO v Hansen*, 2001).

As part of the consent process, South African law requires patients to be provided with information on the proposed procedure, its risks and possible consequences. The Sterilisation Act re-iterates this by stating that patients are to be given “a clear explanation and adequate description” of the sterilisation. This should include information on the procedure, its risks, and implications (s4, Sterilisation Act, 1998). Case law has established that a patient’s right to information on the procedure places a corresponding duty on the medical practitioner to inform them of any material risk that may accompany the treatment. A risk will be a material one, if a reasonable person in the patient’s position, would attach significance to it (*Castell v de Greef*). Consent to treatment will only be “informed” if it is based on substantial knowledge concerning the nature and the effect of the act consented to. Thus a medical practitioner is obliged to warn a patient of the material risks and consequences which may ensue during and consequent to the proposed treatment (*Castell v de Greef*).

The National Health Act requires that healthcare providers must, where possible, provide this information to patients in a language that they understand and in a manner that takes into account their level of literacy (s6, National Health Act, 2003).

Consent should be obtained freely and voluntarily (*Esterhuizen v Administrator, Transvaal*). It should not be induced by fear, force, threats, duress, coercion, compulsion, deceit, fraud, undue influence, perverse incentive or financial gain (Van Oosten, 2000).

Despite this protective legislation, the Women’s Legal Centre (WLC) has documented 12 cases of women living with HIV, who allege they were compelled to undergo medical sterilisation (Kardas-Nelson, *Mail and Guardian*, 2009). In these cases, HIV-positive women were told that in order to obtain medical treatment they had to undergo a sterilisation. No litigation against the Ministry of Health has been instituted to date (Kardas-Nelson, *Mail and Guardian*, 2009).

The impact of coerced sterilisations on women living with HIV

Coerced sterilisations appear to be rooted in high levels of stigma and discrimination in the healthcare sector (de Bruyn, 2006; Satande & Strode, 2010). The capacity to stigmatise appears to be ingrained deep within human nature, as exemplified by the long history of stigmatisation against people with a wide variety of illnesses and diseases (Rochon, 2008).

It has been argued that involuntary sterilisation is a form of medicalised violence against women living with HIV which infringes their rights to bodily integrity and equality (Mthembu, 2009; Satande & Strode, 2010). In many instances, it also forces HIV-positive women to use their reproductive rights as bargaining chips, giving up their right to bodily integrity (and the autonomy to choose a method of birth control) in return for the right to access healthcare services, for example, a termination of pregnancy (Mthembu, 1998; 2009).

Coerced and forced sterilisations have several negative consequences. The inability to reproduce may threaten a woman's feminine identity – particularly in contexts in which motherhood is perceived to be the norm (Sandelowski, 1986 in Rochon, 2008). South Africa remains a pro-natal society and motherhood forms a central feature of women's social identities (Dyer et al., 2002, in Cooper et al., 2007). Being unable to conceive children could inadvertently serve to further marginalise women (Mthembu, 2009) and may diminish their social status (Dyer et al., 2002, in Cooper et al., 2007). The impact of this practice is the further social exclusion and marginalisation of women living with HIV (Mthembu, 2009). In addition to the negative impact on a woman's self-worth, affected women may not be valued by their families or may be looked down upon by women who are able to have children. Sterilised women risk losing access to marriage and to other socio-economic spaces and opportunities (Mthembu, 2009; Mamad, 2009), as in many cultures and contexts (including many parts of South Africa) there is pervasive stigma facing childless women (Mamad, 2009). Women in Namibia who report being coercively or forcibly sterilised indeed report that sterilisation comes at great social costs for them, including limited marriage prospects, stigmatisation and isolation (Nair, 2010). Furthermore, the inability to have children after a coerced or forced sterilisation places women at risk for a range of negative outcomes, including partner violence and abandonment (Mamad, 2009).

Methodology

Rationale and aims

While cases of coerced and forced sterilisation have been documented in Southern Africa and elsewhere (ARASA, 2008; Gatsi, Kehler & Crone, 2010; Mallet & Kalambi, 2008; Nair, 2010), there is limited data from South Africa on the circumstances in which these involuntary sterilisations occur and on the implications and the impact of such sterilisations on women's lives. There is also a paucity of literature on how and why legal frameworks are ineffective in protecting the rights of HIV-positive women against these violations of their sexual and reproductive rights.

Her Rights Initiative (HRI) together with the Health Economics AIDS Research Division (HEARD), University of KwaZulu-Natal, Justice and Women (JAW), Positive Women's Network and the AIDS Legal Network (ALN) conducted a qualitative study to document HIV-positive women's experiences of coerced or forced sterilisation in Gauteng and KwaZulu-Natal. The study was conducted between June 2010 and June 2011.

This study aimed to:

1. Document the experiences of a sample of HIV-positive women in South Africa who indicated that they had undergone a coerced or forced medical sterilisation procedure in a public or private healthcare facility;
2. Identify the social, psychological and financial impacts of coerced or forced sterilisations on these women; and
3. Identify their immediate and long-term support needs.

Ethical approval for this study was obtained from the University of KwaZulu-Natal, Human and Social Sciences Ethics Committee.

Sample, procedure and instruments

HIV-positive sterilised women, 18 years and older, were recruited at support groups for HIV-positive women and also via a snowball sampling method where interviewees were asked to identify potential participants (cf. Silverman, 2005).

HIV-positive sterilised women interested in participating in the study provided their informed consent to complete a screening questionnaire to distinguish between those HIV-positive women who were voluntarily sterilised and those who were involuntarily sterilised (see appendix B). A total of 32 women completed the screening questionnaire of which 27 (84%) were identified as having undergone an involuntary sterilisation procedure. All 27 women were invited to participate in semi-structured interviews (see appendix A) to further discuss their experiences of sterilisation. The interviews were done at venues selected by the participants. However, five of these interviews were excluded from the data analysis because the women reported that they were sterilised because they had cervical cancer and not because they were HIV-positive. Individual informed consent was sought from participants for interviews to be conducted and for audio-recording of interviews. Interviews were conducted by trained research assistants from Her Rights Initiative and partner organisations.

Most of the women in the sample were unemployed and unmarried and most reported that sterilisation occurred at public healthcare facilities with one participant being sterilised at a private facility.

A legal counsellor met with each of the 22 women after the interview was complete to provide legal advice and answer any questions they may have had regarding whether their rights had been infringed and possible remedies available to them.

Data processing and analysis

Interviews were audio-recorded and transcribed and, where necessary, translated. Each interview was coded thoroughly, using NVIVO (a qualitative computer data management package). Data were analysed using hybrid inductive-deductive thematic analysis (cf. Fereday & Muir-Cochrane, 2006) to identify issues as they related to the key research questions as well as any emerging issues across interviews. Data analysis involved both an inductive and deductive thematic analysis, where the research questions and previous literature were used to develop an *a priori* coding template. The coding template also consisted of data-driven codes related to key issues emerging from the data. All key issues were prioritised, discussed and debated amongst the research team with the aim of consolidating themes relevant for local, provincial and international advocacy.

Linked to the legal counselling provided to each woman individually, the Women's Legal Centre, a collaborating partner, conducted a legal analysis of all transcripts to establish whether any of the women could institute claims against the state or medical practitioners involved in the procedure. The Women's Legal Centre established that five of the participants could potentially bring damages claims against the healthcare facilities that had sterilised them. The claims of all other participants had prescribed as more than three years had passed since the date of the sterilisation.

Ethical considerations

Prior to the implementation of the research, a consultation was held with key stakeholders to inform them about the study, describe the study to them and get their inputs and feedback concerning the study. All participants provided written informed consent for participating in the screening questionnaire and individual interviews. Confidentiality and anonymity were ensured by removing all identifiers from public reports. Given the sensitive nature of this research, trained counsellors from partner organisations were available to counsel women when required. Arrangements for referrals were also made for services that partner organisations did not have the expertise to provide.

All audio-recordings have been securely stored on the computers of members of the research team.

Results and discussion

Meeting ethical-legal requirements for informed consent

Requirement 1: Information must be provided on the procedure, its risks and consequences

South African law and ethical guidelines require patients to be informed of the material risks of any treatment or surgical procedure. Where women are being sterilised it would mean that they would need to be aware of: (a) the range of birth control options available to them; (b) reasons why sterilisation may be appropriate in the circumstances; (c) the type of sterilisation procedure that could be performed; (d) the risks associated with the procedure; (e) the implications of the sterilisation on the woman's reproductive system, now and in the future; and (f) the permanence or reversibility of the procedure.

Based on the interviews with the study participants, it appears that none of them was adequately informed of the nature of the sterilisation process, nor of the risks and implications, as required by law. Their reports indicate that the information they received was unrelated to the procedure, its risks and implications:

R: So you think it was illegal? How was it wrong?

Participant 11: "Yes. No information was given. [You] were just told and others also said he was right since the information came from a doctor. Even if I was 40 years old, I could still have been able to have children. They did not even inform me about my rights. "

"I was not told anything, I just don't know" (Participant 14).

"No information was given. In fact, to date I do not know anything, even what form of sterilisation was performed and whether there is a chance for me in future to ever get a baby. Even what would happen to my life was not discussed" (Participant 17).

When participants were provided with information on the sterilisation, this information was imparted in a biased manner that favoured sterilisation. It focused on the reasons why sterilisation was in their best interests rather than outlining the nature of the procedure, its implications and concomitant risks. Furthermore, the information was not provided to facilitate informed decision-making as they felt that it was always assumed that they would agree to the procedure.

Information on the range of birth control options

While some of the women reported knowledge of contraceptive options at the time of the sterilisation, none of the participants mentioned being informed about other family planning alternatives to sterilisation by healthcare providers:

R: ... did he ever suggest other alternatives, family planning alternatives to you?

Participant 15: "No."

"I was young. I did not get given options" (Participant 21).

Reasons provided for sterilisation

Most women reported that healthcare workers provided them with reasons why they should be sterilised. One of the primary reasons for sterilisation reported by women was their HIV-positive status:

"HIV is always the reason that a woman has to be sterilised" (Participant 15).

"They just said that a person with this disease is not allowed to have more children" (Participant 1).

"They only told me that they will sterilise me because I was HIV positive and I was never supposed to get another child. I remember this because I was scared" (Participant 19).

"They kept talking about it among themselves but I was never told anything. In the ward, they would talk about the fact that I was HIV positive and that therefore I needed the procedure done" (Participant 19).

Some women also reported being told that being HIV-positive and pregnant poses an adverse health risk for women, and could potentially result in death:

"I was told that if I got another child I would die" (Participant 19).

"I was told that if I was pregnant and HIV positive and that I would die since we are always told that HIV pregnant women are most in danger during this period. Because of this, you are then simply sterilised and instructed to accept this decision" (Participant 18).

"There was no information about sterilisation. They were only scaring me that if I ever got pregnant again, I would die. So even if I was in my right senses I would not have had a choice" (Participant 19).

Some participants also reported being informed by healthcare workers that they would transmit HIV to their children and that being sterilised would prevent more babies being born with HIV. Likewise some participants recalled being informed that sterilisation would mean that when they die they would not leave orphaned children who would become a burden to others:

"They then told me that I had to be sterilised because I was HIV positive. They only had a file but they said if I were to have a child again, who would raise it because I was going to die soon" (Participant 11).

"She just said to me you know your status... Now why do you still want to make another baby?... I think they're trying, that's how I thought, it means they're trying to limit babies what/ what because of people who are sick and homeless children who don't have parents, orphans and what" (Participant 9).

Healthcare workers reportedly told women who were older and unmarried that they should be sterilised because if they were not sterilised they would conceive again. A 28-year-old participant described that healthcare workers informed her that she was too old to conceive again:

"They asked whether I was married to which I replied that I was not. The doctor argued that I was too old and that I would no longer get married... They insisted that because I was not only old but also HIV positive, the chances of me getting other children were very slim" (Participant 11).

Previous studies have also found that medical professionals, in particular, discourage HIV-positive women from becoming pregnant (London et al., 2008). One of the key reasons put forward for sterilising women was to prevent orphans (cf. Nduna & Farlane, 2009), fully ignoring the ability of HIV-positive women to be fit mothers who live long and productive lives when they have access to HIV treatment, care and support. Negative attitudes toward HIV-positive women conceiving serves to strengthen the belief that "[HIV-positive] women are irresponsible for having babies who may face early death and whose future care may be a burden to society" (Levine & Dubler, 1990, p. 323).

Information on the type of sterilisation procedure

Only a few participants in this study were informed about the type of sterilisation they would undergo: a bilateral tubal ligation. One woman reported that she was shown a picture of a uterus, and the nurse explained that the doctors were going to tie the tubes on the sides of the uterus.

Another woman was shown physically on her body how the tubes would be tied. However, even the women who were told about the bilateral tubal ligation felt that they were provided with insufficient information on the procedure to make an informed choice:

"They just said TL" (Participant 21).

Some women were given so little information that they did not even know that sterilisation was a surgical procedure until they got to the theatre:

R: *...were you aware of the type of sterilisation you had done?*

Participant 15: *"No. I wasn't (.). I didn't know what is it that they'd done."*

"They didn't tell me anything" (Participant 10).

"I did not know which procedure was followed, that is, whether my tubes had been tightened or whether my womb was removed. They did not explain anything to me" (Participant 17).

A typical example of the way in which sterilisation was introduced and the information provided was:

"She called me whilst holding my file. 'X' [name of participant] I got up and came to her. She then said, 'Why don't you sterilise?' I answered, 'sister, I said no.' She said, 'Why no? You have two children already. This is the third one. Why don't you sterilise? You know that I don't have time for this, I'm tired, you see that there's no one. I won't agree to keep giving a lecture. I'm tired'" (Participant 9).

"The doctor arrived. I guess it was our wards turn to go. The doctor comes and checks the slate. He first goes on the opposite side of the room and checks things and then he comes over to my side oh and he reads my card and sees that I'm HIV positive. He asks how many kids I have. I say it's the second one uhm do I have any knowledge about how risky it would be for me to get another child being HIV positive? And so I turned into a laughing stock. I said to him yes I do have in-depth knowledge about being HIV positive. Then he said the way he sees it I must be sterilised because it's a risk" (Participant 16).

Information on the risks

Study participants also reported that they were not provided with the opportunity to ask questions about the sterilisation procedure and any accompanying risks. The power differentials between patients and healthcare providers can create a situation in which a patient's choices and autonomy to make decisions are both constrained and determined by the perceptions, values and preferences of the healthcare workers (London et al., 2008). The accounts of women in this study suggest that the power imbalance in South African hospitals creates an environment of coercion in which many HIV-positive women are unable to resist pressure from medical providers to accept sterilisation. Most of the women in our study were afraid to question any information they received about the sterilisation:

"I wouldn't have asked anything because the doctor said nothing must be requested of her... even if you're talking, one can see in any case that, no, she (the nurse) has apples so she was an important somebody and she'd say she doesn't want to be questioned" (Participant 14).

Some respondents reported that they were not well versed in their rights and felt unable to ask questions. This said, even when a woman is knowledgeable about her rights, the power imbalance and fear of healthcare providers, limits a woman's abilities to exercise her rights:

"[S]he's (the nurse) already painted me, on what I should do. It means she has already made a decision on what I should do. You understand? So, I felt that she knows more than me, you know? That she knows better" (Participant 9).

"I mean like that doctor that said personally I/ I don't want anyone that will tell me that, you will get your womb closed. The one that wants to oppose must come and see me..." (Participant 14).

Information on the implications of the sterilisation for their reproductive health systems

Participants generally reported that the implications of the procedure were down-played:

"I was told to be sterilised. They said it was a simple procedure. Only when I went to the theatre did I begin to realise the seriousness of my situation. They had not told me that I would be taken to a theatre. But then they started enquiring about who would sign if there was a mistake. I signed. Even after the operation I was told that I had problems recovering from the anaesthetic. This is when it really dawned on me that I was coerced into a very serious procedure" (Participant 21).

Information on the permanence or reversibility of the procedure

Many participants were told that the procedure could be easily reversed:

"That's what she said. When you want a baby, you'll decide then... to go and get it opened and get another baby" (Participant 9).

"They said they would sterilise me and I would be able to reverse it one day" (Participant 11).

"They also said if I wanted to get children again I would be able to reverse the procedure" (Participant 21).

"That's what she said, when you want a baby you'll decide then to go and get it opened and get another baby" (Participant 9).

Only one woman reported being informed that sterilisation is a permanent method of contraception:

"... he did say that if I get sterilised I will not be able to conceive again" (Participant 15).

Incorrect information about the ease with which the procedure could be reversed weighed heavily in favour of many women agreeing to sterilisation. However, it is well known that sterilisation is very difficult to reverse. It requires major surgery which is not always successful, is seldom covered by medical aid schemes, and is not available through the public healthcare system (Stoval & Mann, 2010).

In terms of satisfying the requirement that information must be provided on the procedure, its risks and consequences, our findings suggest (as reflected in the section below on voluntariness) that healthcare workers often do not see patients as rational and authoritative decision-makers who require information, but rather as passive persons in need of medical services at the doctors' or nurses' discretion. This is consistent with the work of Harries et al. (2007) who suggested that healthcare workers and patients have very different perspectives on reproductive choices. Healthcare workers often focus exclusively on the impact of HIV on the physical health of the HIV-positive woman while ignoring psychological and social implications of potential treatment courses or procedures such as surgical sterilisation (Harries et al, 2007). South African research by London et al. (2008) argued that many HIV-positive women were aware of healthcare workers' negative attitudes, and they perceive healthcare workers as being opposed to pregnancy in HIV-positive

women. This further alienates HIV-positive women from healthcare services and exacerbates feelings of fear and rejection.

Requirement 2: Consent must be voluntary and may be withdrawn at any time

From the data, it appears that involuntary sterilisation plays out in two ways. First, some women were simply informed by a healthcare worker that they were to be sterilised and were not given the choice to decline the procedure. Some of these women report that they did not sign consent forms for the sterilisation. For example, one woman who was having a baby in a private hospital says she was instructed by her doctor (whilst she was on the operating table) that she was to be sterilised after the birth. Likewise, a woman who was sterilised at a rural public hospital reported that she and a number of others using antenatal services were notified by the doctor that they would be sterilised when they returned to deliver their babies. Second, most of the study participants signed consent forms indicating that they agreed to the sterilisation but did not actually want the sterilisation procedure. They felt that their consent was coerced by a range of factors including severe labour pain, fraudulent information about the procedure, fear of the healthcare provider, and inability to access necessary medical services unless they signed the form. Respondents reported signing the consent forms for reasons unrelated to a desire or ability to make an informed choice on a permanent form of birth control method. Most felt compelled to sign the form in order to access help with the birth of their child.

Many participants made the decision to sterilise under duress. One respondent recalled that she had to decide whether or not to be sterilised whilst her doctor was shouting at her in front of others:

“He was shouting at me while all were listening. I did not have time to say anything as we were arguing. He said all black people are careless. I was embarrassed and I just signed without getting time to read the form” (Participant 11).

Another participant recalled being detained in the hospital after giving birth until she agreed to be sterilised:

“I stayed 3 months in hospital and they were keeping me so that I could not go home and conceive again” (Participant 21).

Some participants were asked to consent to sterilisation when they were already in active labour and enduring great pain:

“They made me sign this paper after I had collapsed in the toilet” (Participant 1).

Others were asked to sign the consent forms for sterilisation en route to the theatre for a caesarean section. One participant spoke about how she was already in theatre for another procedure and experiencing post-operative pain when the healthcare workers told her that she was to be sterilised. Another commented:

“I was under an emergency of getting a child. They should not have operated on me during the time of distress when I was in labour” (Participant 17).

A number of participants made their decision in other coercive circumstances. Some felt that they had little choice but to agree to sterilisation in order to access another service like an abortion or caesarean section. Often, participants perceived that a sterilisation was packaged as a pre-requisite to access these services:

“It felt like, you know, if you are in a trading situation where you part with your R5 (five rand), to get/ a R5 which you need but you also need a loaf of bread (R: ja). It felt like you know, I'm really glad that I have this right to choose but it felt like I'm having to bargain some of my rights in order to access this particular one” (Participant 15).

"He (the doctor) was willing to help me... but he can only help me if I sign to sterilisation because he didn't wish to see me in the hospital a year later with another request for abortion. I sort of was sort of desperate... and I signed... for sterilisation" (Participant 15).

"Even if I had been in my full senses prior to childbirth, I wouldn't have been able to ask them anything because they were scaring me. I was just going to sign" (Participant 19).

"He told me that the nurse would give me a paper that I must sign. I didn't ask what the paper was for because the way I saw it, it seemed like the paper explained that I agreed to what he was saying. The nurse gave it to me because the nurses are always with doctors. And because the nurse was also headed that way he gave her that paper, I took the paper, signed it and the nurse filed it and that was that. I was put on the slate because if I had not signed that I'd be sterilised I don't think I would have gone to the hospital because the way I saw it they saw it as a good opportunity that seeing as I was going to the theatre they'd be able to proceed and put me in, the way I saw it" (Participant 16).

Some respondents felt so disempowered by the way they were treated by healthcare workers that they felt compelled to agree to the sterilisation. For example, a participant reported that her opinions on the sterilisation were of little value as they had not "asked her politely" to undergo the procedure. Others felt alienated from the decision-making process. One woman reported that the decision regarding her sterilisation was made by healthcare workers who spoke about it in front of her but not with her. Other respondents felt that they should defer to healthcare workers who "knew better than they did". This sense of disempowerment appears to have been heightened amongst women who felt a sense of social disadvantage because they were HIV-positive, single and pregnant. They could sense the disapproval of the healthcare workers. Another participant stated:

"Today, I would have said no, I would have taken my own decision. But in those days we did not know much about our rights. One was simply told and to say to a doctor 'I do not want', was unheard of. You were just told to do this or else you had to leave the clinic or hospital" (Participant 17).

"I was young. I was only 18 years. I consented to being sterilised because of the way they influenced me" (Participant 21).

Some respondents allege their consent was sought fraudulently because they were led to believe that they were consenting to another procedure – such as a caesarean section – and not a sterilisation (see section on forced sterilisation below).

Some respondents reported signing consent forms due to fear. Additionally, many of the respondents were sterilised in hospitals with limited access to treatment and where death due to HIV-related complications was an imminent reality. Fear of dying appears to be a significant motivator, and many women agreed to the sterilisation as they were afraid of dying and/or feared leaving orphaned children.

Healthcare workers over-emphasised the impact multiple child births have on the health of HIV-positive women. Some participants felt so disempowered and intimidated that they felt unable to question the decision of the doctor that they should be sterilised.

"I mean like that doctor that said 'personally I, I don't want anyone that will tell me that [they will not be sterilised], you will get your womb closed. The one that wants to oppose must come and see me'" (Participant 14).

Participants felt pressure not to disappoint healthcare workers who were assisting them under difficult circumstances, e.g., by providing an abortion when other doctors wouldn't or by delivering a baby when the healthcare providers were on strike:

"[T]o some degree I also felt that if I don't sign I'd be disappointing this doctor (.) who has agreed to help me because others have refused" (Participant 15).

"[I signed the paper]... because they were in a hurry, they're on strike, they're tired because I still feel that they were a doing a favour for me" (Participant 9).

Women's descriptions of the circumstances in which they signed the consent form were characterised by fear, duress, coercion, compulsion, fraud, intimidation and undue influence and clearly violate the provisions of the Sterilisation Act and National Health Act.

For some women, the decision to sign the consent form was informed by previous negative experiences within the healthcare system:

"I don't think I could have said 'no' because it means I would've continued waiting there in the hospital. And I have first-hand experience with my first child that there was a problem, you see, with the way [the baby] arrived. The way they were so inattentive, my child nearly died" (Participant 16).

Respondents reported that attempts to avoid or delay the sterilisation were usually thwarted and resulted in heightened aggression by healthcare workers. One respondent shared the story of the patient in the bed next to her in hospital:

"[S]he was a neighbour by our beds. The doctor first started with her before he came to me. She was quite an older woman and you could see that it's those mothers from rural areas because she was from X (name of area). He asked her as well how many children she had, she said she had four and he went on to tell her that she must have her womb closed. It will be too much and he's thinking about himself that she's sick. This lady then said she thinks that with what he was suggesting she requests that she waits on her husband, talk to her husband. The doctor said you're not going to the theatre if you're still waiting to talk to your husband and ultimately she ended up agreeing that she would sign" (Participant 16).

This study's findings corroborate those from Namibia in which many women signed consent forms under duress and while in labour (Mallet & Kalambi, 2008; Nair, 2010). Based on the women's accounts, the signatures on those forms did not constitute valid consent because the women claimed they were not informed about the contents of the documents they were requested to sign and/or because healthcare providers failed to give complete and accurate information on the sterilisation procedure (Mallet & Kalambi, 2008). Many women in our study felt disempowered in the patient-provider relationship. Healthcare workers are indeed in a privileged and powerful position compared to their patients, and some may use abuse this power to get the cooperation of their patients (d'Oliveira et al., 2002). Also similar to the reports from South African women in this study, women in the Namibian cases described that while they signed informed consent forms, they did not receive information on the risks and benefits of the procedure and its implications nor were they informed of alternative methods of birth control and family planning (Mallet & Kalambi, 2008).

Requirement 3: Consent for the sterilisation must be in writing

Most of the women in this study acknowledged that they had signed consent forms. While a few women could not actually recall signing consent forms, they conceded that they may have signed them. However, where women did sign informed consent forms, acknowledging that they were agreeing to the sterilisation, they report that they did so under coercion and duress, and with the apparent belief that they had no ability to control the outcome or refuse the procedure:

"He (the doctor) told me that the nurse would give me a paper that I must sign. I didn't ask what the paper was for because the way I saw it, it seemed like the paper explained that I agreed to what he was saying. The nurse gave it to me... I took the paper, signed it and the nurse filed it and that was that" (Participant 16).

"She (the nurse) gave me some papers. She said 'take some papers and go there.' I kept quiet and sat down. There were other girls that were seated. Now that you talk, I never read the paper. I was feeling the atmosphere, I kept quiet and looked at the paper. I just stood by the bed just standing" (Participant 9).

Many felt that the forms were given to them to sign rather than to read:

"No form was given to me to read, I was just told to sign" (Participant 10).

"I don't know how I can explain it to you because they don't give you the form to say you know here is the form – like maybe you'll see in the banks and things like that, they'll give you a form to say here's a form, read and understand. Sometimes they will even leave you and give you a cup of tea or water (R: ja) for you to read and familiarise – uhm I mean in hos- / in x [Name of Hospital] it was the doctor here, and the nurse with the form and all that was required was really my signature. Ja. So I can't really say what was on the form, ja, but what I do know is that I did sign" (Participant 15).

Some women expressed regret at not reading the form and noted that in hindsight they wished that they had read the form or had it read to them. Signing the forms was often described as a traumatic process:

"I took it myself, I went back with her (the nurse's) paper and sat on the bed. It's just that I won't speak lies and say I read it, maybe I told myself that, my mistake maybe was there in that I didn't read you see, because I just ran out of strength" (Participant 9).

"They said I was going to be sterilised. I was scared to die so they made me sign a form but I do not know how. At theatre I got a child and after that they sterilised me. I signed the form but I did not know much about what it was about, and soon they rushed me to theatre. Because I had given birth through an epidural, I could register everything" (Participant 19).

"Yes I was in pain. But they did not get enough information. No form was given to me to read, I was just told to sign and the sister would ask if I understood English and I would say yes. I signed without reading the form and I did not see the information in the form" (Participant 11).

Again, this study indicates that South African women had similar experiences to those in Namibia (Mallet & Kalambi, 2008) regarding their sense of disempowerment regarding the signing of consent forms. Furthermore, protections in the Sterilisation Act relating to the signing of specific consent forms have ironically not protected women as healthcare workers appear to have misunderstood the role the forms play in the informed consent process. It appears that healthcare workers saw the obtaining of a signature on the consent form as the only requirement for valid consent.

Forced Sterilisation

While most women in this study reported that they signed the consent form under coercive circumstances, a few respondents reported that they had no knowledge at all that they were sterilised nor were they aware they had signed any consent documentation:

"So she said the child was a girl and then she shows me, then she says that the doctor closed me up. And I asked he's closed me? Then she says the doctor made me sign a paper for my

consent. Then I asked why they hadn't told me? Because I mean I didn't even know about this" (Participant 1).

"Uh I was sterilised at (inaudible) without agreeing... they didn't say I should sign" (Participant 10).

In some cases women only discovered that they had been sterilised many years later. One respondent described finding out that she was sterilised when she was accessing treatment for cervical cancer. Others reported that they were informed of the sterilisation some years later when they were trying to fall pregnant:

"I tried getting a baby, I went to the clinic because I was, I was (inaudible) now that I'm taking medication and they said no you can still have a baby but now I wasn't getting one... went back to the clinic and they said it means I won't get any more children, it seems I was closed" (Participant 10).

"I was going for a caesarean section. That was the only thing I had signed for. I don't know the rest, I found that out later when I had gone to the doctor who said, just a normal gynaecologist, I had asked if it is possible for me to have a baby. He said no, you were closed up. In which way, is my womb there? He said no, the womb is there, you did a tubal ligation. And that is complicated because the tubes were burned" (Participant 4).

While some women described not having been told that they were to be sterilised and did not have the opportunity to refuse the sterilisation, none of the women in this study described refusing the sterilisation but being sterilised any way.

Stigma and discrimination

Since HIV in Southern Africa is predominantly transmitted via sexual intercourse and to a lesser degree through injection drug use, it is highly stigmatised and associated with deviance and disease, including notions of indiscriminate promiscuity and irresponsible behaviour (Lawless, 2006). HIV-positive women in particular, are subjected to intense stigma and discrimination, which may lead to abuse and violations of their rights. Many participants in this study described experiences of discrimination in the healthcare setting as well as from their partners, families and communities.

Stigma, discrimination and abuse in the healthcare setting

Participants in this study reported a pervasive stigma on the part of healthcare providers that HIV-positive women should not engage in sexual relationships or reproduce. Women reported that they were discriminated against by healthcare workers because of their HIV status: *"as women living with HIV we are always undermined and discriminated against"* (Participant 10); their race: *"He said all black people are careless"* (Participant 3); their age and marital status. Women reported being verbally abused, humiliated and embarrassed: *"He was shouting at me while all were listening"* (Participant 3) and being called *"dumb"* for having children when they are HIV-positive (Participant 9). This is similar to reports in the literature on women accessing abortion services where they experience routine negligence as well as verbal and physical violence (d'Oliveira et al., 2002).

As described above, women in this study also described being instructed by healthcare providers to sterilise because they are HIV-positive. Some women reported that healthcare workers saw the women's HIV status as a key reason for them needing to be sterilised and to stop reproducing:

"I (pause) sort of refuse to think that it's an attitudinal problem. Uh I mean we know, I mean want to generalise here, but we know that, I mean at least in South Africa, I don't know about countries, that I mean generally public maternal services are very violent towards women for the reasons I don't know, like I'm not sure whether this was about discouraging women to reproduce" (Participant 15).

One respondent contended that despite a protective legal framework, forced sterilisations “*find fertile ground*” in systemic violence against women in the maternal health sector. Rather than reflective of attitudes of individual healthcare workers, she believes that there may be a covert policy from government that supports coerced and forced sterilisations of HIV-positive women:

“... Uhm I want to remove it from the perceptions and actions of individual doctors and or nurses and think that it’s part of a particular system... Uhm I think(.) I think it’s systematic, it might be coming from apartheid South Africa, but it might also be coming from the global movement of eugenics because if you look at where the AIDS money’s coming from, particularly the AIDS money around reproduction, you know it’s coming from you know sources where reproduction of certain people is not encouraged. Uhm you know and it becomes very difficult for me to believe that the doctors don’t account for the time they spend sterilising women, because they’ve got to account for each and every minute that they spend, you know, which makes me think that there’s actually some government policy that is being followed, it may not be a written policy, uh you know but uh ja” (Participant 15).

It is also possible that coerced and forced sterilisations are carried out in some contexts as an ill-advised method of preventing vertical transmission of HIV (Nair, 2010). However, there are no public reports of HIV-positive men being targeted for sterilisation in order to prevent pregnancies. While incongruent with the perception of healthcare workers as “caring” (d’Oliveira, Diniz & Schraiber, 2002), HIV-positive women often experience stigma and discrimination in healthcare settings (de Bruyn, 2004; Lawless, 2006). HIV-positive women who are pregnant or who wish to have children are judged harshly, stigmatised and discriminated against for harming their (potential) children by infecting them with HIV, or leaving them as orphans when they die (de Bruyn, 2004).

A key way in which stigma and discrimination play out in the healthcare setting is by prohibiting HIV-positive women from exercising their rights. Respondents described being bullied and humiliated by healthcare workers, not receiving medical attention, feeling a lack of compassion and experiencing gross neglect:

“At times I did not understand because I would hear others saying you just enter and open, I didn’t know very well what was going on but I nearly died. After being sterilised I didn’t even pay attention to this baby I just arrived alive. The nurses didn’t wash my baby for me I was eventually helped by some other lady” (Participant 14).

“When I got X [name of baby] they put a peg and told me to lie on my stomach. I lay on my belly, I remember shouting for the nurse she says no, after like I don’t remember maybe about 5 minutes 10 minutes after I had lain on my stomach. I’m like sister there’s something that hurts beneath. She says to me what’s sore underneath? Probably it’s bleeding. I keep quiet a bit and I say no sister this thing is killing me beneath. She doesn’t pay attention to me up until the entrance of another through the door. I said no please help me, it’s so painful underneath I can’t bear it maybe the (inaudible) mine is full or something, I’m begging you please check me. She you know what maybe you need to urinate. She comes with that potty from there and she says turn over. When I turn she finds the left hand side of my vagina swollen you know it was big. She says sis she’s got a third degree (inaudible). Come, come. There were those that rushed to her, they pushed me, they did an operation on me, they sent me to the theatre, they cut me underneath, out comes something that healed after like/ I left X [name of Hospital] after some time and it hadn’t healed. Still the sisters told me to clean underneath up until another doctor saw. The doctor there said no it’s pus which means it’s not healing underneath. They sent me home, they gave me pills saying I should wash beneath but still I wasn’t becoming alright, I just got seriously sick” (Participant 9).

Some respondents also reported breaches of confidentiality in the health setting:

"They'd (the doctors and nurses) even discuss about you as they passed... Because there was a lady they were talking about, she's HIV-positive... I too at that time, I felt that the whole hall like knew that [I was HIV-positive]" (Participant 9).

"In the ward, they would talk about the fact that I was HIV positive and that therefore I needed the procedure done, but they were not even talking privately, so everyone in the ward could hear the conversation" (Participant 19).

It was also argued that discriminatory attitudes of healthcare workers may be perpetuated further by the lack of accountability of doctors in the public healthcare sector. However, not all healthcare providers that the respondents described were abusive:

"... the one (woman who was almost involuntarily sterilised) that I know, she was lucky in that she was warned, the nurse that was on duty told them when they came for their check-ups that when they arrive there (at the hospital to deliver) they will talk about such a thing (sterilisation). They will state, they won't even tell them, they will state that they should be sterilised and they shouldn't take that. That's how she was saved from it..." (Participant 16).

Similarly to reports of abuse from healthcare workers by respondents in this study, d'Oliveira et al. (2002) reviewed data from different countries where women described healthcare providers as unkind, rude, brusque, unsympathetic, and uncaring and who often shouted at or scolded their patients. In South Africa, violence, abuse and neglect are seen to be weapons by nurses to assert a sense of superiority over their patients. The lack of accountability further serves to establish abuse as normal practice (Jewkes et al., 1998). It has been suggested that coerced and forced sterilisations may be perpetrated by health professionals as punishment for women who are not adhering to prevention messages and falling pregnant (Mthembu, 2009). Moral instruction is also perceived as an important part of being a good nurse, and, therefore, some women are singled out for punishment because they are believed to have transgressed moral codes, for example, women who have had abortions (d'Oliveira et al., 2002), and possibly HIV-positive women who decide to have children.

Social stigma and discrimination

Despite the fact that there is significant stigma around HIV and that HIV is a potentially life-threatening disease, some respondents even reported that it is easier for them to be HIV-positive, than to be sterilised:

"It's better to have HIV because everyone sees HIV and everyone is affected by HIV even if they deny it, you know. So you can live with the fact that they said 'ingculaza' you have AIDS. You know it's like, who doesn't have it, but inyumba it's like at the centre of you being a woman, it's the core. So it really hurts" (Participant 15).

Experiences of being socially stigmatised and feelings of isolation as a result of being sterilised were also reported:

"[After I was sterilised and my boyfriend left me] I'd get SMSs from his [new] girlfriend saying, 'I got his child,' you see things like that, 'you barren thing'" (Participant 9).

"This woman called me 'inyumba' and 'inyumba' is like you are like a used, a worthless woman because you can't bear children" (Participant 15).

It is evident that women who are HIV-positive and sterilised face a double stigma (Mamad, 2009) and it appears that for some, the stigma may be more pronounced when they are sterilised compared to being HIV-positive. This appears to be related to cultural conceptions of womanhood

(discussed below) to the extent that “in African culture, if you are not able to have children, you are ostracized. It’s worse than having HIV” (Jennifer Gatsi in Open Society Foundations, 2011, p. 5).

Disclosure of sterilisation to others

Many respondents described disclosure of sterilisation as intensely difficult. Only one woman reported publicly disclosing that she was sterilised. For her, this was with the intention to raise awareness of the injustice and to help connect with others who have had similar experiences:

“And when I came out I (pause) I also began to talk about it publicly – you know the fact that this has happened to me, I know it was an injustice but there isn’t anything that I could do about it. And I also thought that if it happened to me (pause) surely it happens to other women as well” (Participant 15).

A few respondents reported disclosing to their mothers, sisters and partners:

“The only person I have discussed this issue with, is my mom. We have talked about disadvantages of sterilisation especially about how sometimes I get sick and also about times when I have to be admitted to ICU. She said that it was wrong that I got sterilised” (Participant 19).

Most respondents had told no one that they were sterilised, not even their partners:

“Generally, we [involuntarily sterilised women] all agreed that we have to get into marriage without telling a man you are sterilised” (Participant 9).

“I did not tell him too as it is difficult to tell a man that you cannot bear children” (Participant 3).

“Once you tell someone about your sterilisation they start to compare you. If they have another girlfriend they tell themselves that the other woman can bear children and you can’t. That is why I don’t tell them” (Participant 20).

One woman expressed the difficulty of carrying the burden of secrecy:

“If you’re a female and facing the problem of being positive you must take care of yourself, and here now you’re facing the fact that you have a secret. Now it’s eating at you and your conscience even if there are things that are good reports” (Participant 16).

Some respondents found telling others that they had been sterilised was more difficult than disclosing their HIV status:

“I can understand being HIV-positive but telling your partner that you cannot have children is too much” (Participant 20).

There was also some concern of abandonment and extramarital relationships if partners were informed of their sterilisation:

“He has choices, he can go anywhere and have children with whomever he chooses, and I, I can’t” (Participant 15).

Disclosure of sterilisation is particularly problematic in a cultural context that values women based on their ability to conceive. In fact, many women in this study reported that their partners would like to start a family or would want to start one in the future:

“Oh my goodness, no. I don’t feel well at all. It doesn’t make me happy [that he wants to start a family] because of the things that are happening and which I see heading my way.

There are problems that I foresee coming pertaining to the closing of my womb. If I could elucidate there: I'm still young, I'm in a serious relationship, the person I'm with doesn't have children and he's serious about me. I'm foreseeing a problem with this person because I didn't tell him and I don't see myself telling because it means my hopes would vanish and his dreams would've vanished because he doesn't have a child and by him choosing me I will not be able to give him one" (Participant 16).

"Yes it affected it badly as I did not tell my family. My husband keeps saying I must reverse and does not believe that the doctor keeps rejecting my requests" (Participant 21).

Desire to have children

Most women interviewed expressed a strong desire to have more children for various reasons including that some women had lost the children they had when they were sterilised either because the children were stillborn or died subsequently. Some women wanted to have children because it's an expression of life, because they had started new relationships, or for marital reasons:

"... [H]e doesn't have a child like you know and he had just paid lobola... So he wants a child" (Participant 9).

"Well... life goes on, the years pass by. But even if that is so I was looking forward to having another child. There would have been four children. I have three" (Participant 1).

Many expressed a sense of devastation because the option to decide whether or not to have children was denied them:

"Because I do feel that even, I do want to make that decision that I want a child, I don't want a child. I want a child, I don't want a child. I don't choose to [inaudible] to choose my options for me you understand? ... I want it to be a thing of I can make my own decision" (Participant 9).

"I didn't have the immediate desire of having a child, you know but I sort of kept thinking that it would be nice if I had the option of what is it that I want to do with my future" (Participant 15).

Only a few women suggested that they did not wish to have more children, some because of their age:

"I don't want to and I'm old now" (Participant 10).

Some women have tried to have their sterilisations reversed. For some, attempts to reverse the procedure appeared heightened when starting a new relationship:

"I didn't know what is it that they'd done. I became aware of that much later, when I was trying to have the sterilisation reversed. That's when I was taken to theatre because they wanted to see what is it that they'd done. And then they took pictures and then they said that my tubes had been cut and burned" (Participant 15).

For other participants, while they wished to reverse the procedure, they did not have the financial resources to do so:

"What steps will I take because I do not work? You have to pay for hospitals you see, everything is money. I do not have money" (Participant 16).

Others were unsure about how to initiate the process of reversal:

“Because I am not married and I want to have a baby girl but have no clue where to begin to reverse this condition” (Participant 17).

None of the women in the study had successfully reversed the sterilisation to the extent that they were able to conceive again. Most women were told by healthcare workers that sterilisation was reversible, which is rarely the case. Additionally, some women were sterilised in such a manner that reversal was absolutely impossible, that is, rather than being tied, their tubes were cut and burned. Some women only learned of the permanency of sterilisation when they attempted have it reversed:

“That’s when I found out that I can’t reverse it. It can’t be done. This is a permanent thing” (Participant 9).

One of the women succeeded in getting one of her tubes rejoined but had not yet conceived.

Apart from attempts to reverse the procedure, some women had attempted in-vitro fertilisation (IVF). None of these attempts was successful. One woman reported trying traditional medicine to conceive, but again these attempts were futile. Some of the women were hoping that with time the tubes would rejoin naturally so that they might be able to conceive.

Fertility desires and needs of women living with HIV are the same as those of the general population (Cooper et al., 2007). Women living with HIV want to have children for personal as well as socio-economic reasons. These include starting and completing families, marital responsibilities, an expression of life as well as creating social security for later in life. A study exploring the reproductive intentions of HIV-positive men and women in South Africa found that “reproductive desires and intentions were modified, but not removed, by being HIV positive” (Cooper et al., 2007, p. 280). Further, data indicated that being HIV-positive could either promote or limit desires to reproduce (Cooper et al., 2007).

The impacts of sterilisation

Forced and coerced sterilisations have severe negative impacts on victims' lives. These include severe emotional distress, dissolution of romantic and family relationships, ill-health, and some have reported financial costs as a result of sterilisations.

Emotional and relational impacts

Most respondents reported ongoing and significant emotional distress because they can no longer bear children with a few women even reporting clinical depression and the use of anti-depressants:

“After discovering that I had been sterilised I became depressed and started taking anti-depression medication. I had discovered that I could have had a child had they not sterilised me because I was HIV positive” (Participant 2).

“... for a long time I relied on anti-depressants but uh this year I decided that I will take them for a short period of time and seek sort of ongoing therapy” (Participant 15).

Respondents also reported feelings of trauma, isolation, helplessness, stress and long-term humiliation that extended far beyond their time in hospital.

“I feel alone. You feel scared as to who you will talk to because once you tell them then they will tell others” (Participant 20).

Experiencing an involuntary sterilisation left some women with a sense of loss:

"[S]ometimes I would wake up and say, 'you know what, she (the nurse) snatched something that I wanted,' you know? She made up a choice. She made up a choice for me" (Participant 9).

Some women also described that being sterilised profoundly affected their sense of womanhood:

"I no longer feel like the person I was" (Participant 12).

"I feel like half a woman all the time" (Participant 15).

"It makes me feel incomplete that I am not a proper woman first that I'm HIV Positive and secondly I cannot bear children. Men don't want HIV Positive women but the inability to have a child is an added problem" (Participant 4).

Respondents also expressed feelings of inadequacy because of their involuntary sterilisation. One woman described that she wanted a baby of her own and was unhappy with the option to adopt after she was sterilised:

"Adopting and filling in forms make you feel like are not right in your mind" (Participant 21).

Sterilisation has also had negative impact on most women's relationships with their partners:

"Then I returned (home), when I arrived at the flat I tried telling this (that I was sterilised) and the man just chased me out" (Participant 10).

"... and sometimes if you (.) if you chose to talk about it in relationships you see that it changes the way you are perceived, uh, you know, because it takes time for partners, I suppose male and female to sort of understand, reproductive you know issues. Sometimes you feel that even if he's on your side, he's probably feeling that it was the best decision that they did because you had transgressed so much (.) (R: ja) you know so maybe they were helping you in a way. And that breaks your heart because you expect everyone to sort of say 'that was horrible, they shouldn't have done that (R: done that, ya) to you', yes" (Participant 15).

When husbands/partners learn of a woman's sterilisation, there may be serious negative consequences and social costs, including but not limited to abandonment, withholding of financial resources, violence, divorce and stigma:

"There's been a lot of impact [inaudible] my husband has even gone outside [inaudible] he got another girl pregnant. This is really treating me badly. Isn't it he will continue to do shenanigans outside of us?" (Participant 14).

Some of the women in this study feared that being sterilised would mean that their lobola (the bride price) could be lower or non-existent. Those who were already married expressed fear that their lobola would be revoked. This would cause cultural humiliation and may lead to the woman being disowned by her family and the marital family, and could leave her destitute:

"Now you see I've found someone, he's the right person, it's so nice but there is this thing that will disappoint in the end. What could happen is even this marriage I'm looking towards could dissipate because of this, the way they handled it at the hospital" (Participant 16).

"And also when you consider the lobola (bride price) (R: mm), the lobola that people pays – I mean it's like buying a woman and the chances are that if you can't bear children they wouldn't pay lobola for you. So (.) I mean within my networks there are young women, and one of them is actually married and she wouldn't dare tell her husband that she is sterilised because her husband will go back to the family to (R: claim the money back) the money back,

so that's a risk she'll never take" (Participant 15).

Involuntary sterilisation can have devastating impacts on women, affecting their mental and physical health as well as their relationships with their partners, families and their communities (Gatsi, Kehler & Crone, 2010). The literature describes that while traditionally lobola was paid in cattle as a gesture of respect reflecting that the man had wealth and could support his wife, today lobola is paid in cash "for a bride" which means that the husband and his family have "bought" the woman, including her future children (LaFonte & Hubbard, 2007). Thus, a women's value is linked to her ability to have children, and infertility can be grounds for divorce and result in the husband's family demanding that their lobola be returned (Wood, Lambert & Jewkes, 2008; LaFonte & Hubbard, 2007).

Physical impacts

Respondents described the negative physical impacts of involuntary sterilisations. Some described that the sterilisation operation took a long time to heal. A few women described that the sterilisation affected their menstrual cycles, with menstruation non-existent or irregular:

"My periods are irregular and sometimes I bleed a lot" (Participant 11).

"I do not menstruate. I keep taking pills and get my periods through taking these pills, but now I do not take them" (Participant 21).

Some participants reported experiencing physical pain, including backache:

"I experience pain in my pelvis when it is cold" (Participant 20).

One woman reported frustration that she was never told what was wrong with her when she asked about the post-sterilisation ailments, but she tended to tolerate this lack of information and inefficiencies at the public health hospitals because she expected no better:

"They cleaned me up, but they did not explain what the problem was. I had gone about three times to another hospital and even in this hospital I went to theatre but still with no luck. I also did not get any information about my problem because all the hospitals I attended were public hospitals" (Participant 19).

Financial impacts

Some women in the study described that being involuntarily sterilised had negative financial implications for them in addition to the potential revocation of their lobola. Women reported spending money that they would otherwise not have spent consulting doctors on reversals or alternative methods of conception:

"I went to another doctor who said I could get a child. I kept paying and I thought I would eventually conceive. At 8 months I went to the clinic and they said the pills I had been taking were poisonous" (Participant 21).

There were also reports of women considering taking loans in order to finance sterilisation reversals and IVF treatments:

"You know it was to a point that I have wanted like to take out a loan" (Participant 9).

Some women reported having used their savings to finance repeated IVF procedures or in attempts to reverse the sterilisation:

"... [S]o my work life has somewhat become a circle. It's like you know, each year (.) you have your savings (.) and you know when you get your savings you go back [for IVF] and you can't

just save for one because you give yourself the little doubt to say if it does not work I should be able to try immediately because that's what the doctors advise" (Participant 15).

"I had to pay the doctor R7 000 for the reversal procedure. I also had to pay R15 000 for the hospital. These were all paid in cash; I do not owe anything... No. Physically, I have no problems. My problem is financial. Since the reversal, I have paid a lot of money, it's not only R22 000 I have paid but it goes on since I have not conceived to this day" (Participant 20).

One woman shared her experience of losing a partner and income support for her children as a result of her involuntary sterilisation and resultant infertility:

"He did not provide for those children, he did nothing, he just dealt with those who do give birth [those who are fertile]... since I'm not working, I have no one to provide for these children of mine because that man threw me out with the child I had just delivered" (Participant 10).

Respondents felt that they now have to make financial plans and ration in a way that they would otherwise not have had to, if they were not sterilised. Women reported having to cut down on medical aid costs for their children in order to finance reversals:

"I look at my budget and check that okay fine I can send my kids to a public hospital, to a public clinic if they're sick and then be able to save their money for things like this, when things like this happen you know but now I'm like you know what I have to take medical aid because I don't want my kid to be treated like this. Like I took my medical aid just after all this ordeal had happened, only last year that you know what, I don't want my kids to experience the same thing. In the future if someth/ I don't want to go through the pain because I don't even know what I was sick with back then in 2000" (Participant 9).

Redress measures

While recognising that there is nothing that can be done to fully make up for what they endured: *"I don't know how I could be recompensed"* (Participant 10) and *"Ey I don't think that there's something that could make it better"* (Participant 16), the women in our study requested multiple redress measures. These included financial compensation, the provision of free psychological support, more information on the nature of the procedures they have undergone, pain relief for the physical side effects of the sterilisation procedure, and sterilisation reversal procedures where possible:

"I had just spoken just before to know how I can get to speak to the doctor to untie this big problem" (Participant 14).

"I think that they can help me a lot as I need counselling, about how in future I can deal with this I feel about having been sterilised" (Participant 18).

Some women may seek redress through the Courts:

"My boyfriend then said that if he had had money he would have taken this matter up in court" (Participant 18).

Recommendations from the women

Upon reflection about how the South African healthcare service might improve sterilisation services, the women suggested that anyone being considered for surgical sterilisation should be informed of the risks and benefits of the sterilisation, the fact that it is permanent and that there is little success in reversing the procedure. Respondents felt that they should have been given more time to consider whether to sterilise and that consent should not be sought when women are in labour or trying to access another healthcare service:

“I suppose the consenting process, it has to be a process not an event so that women are really able to choose what is good for them” (Participant 15).

Respondents suggested that anyone being asked to consider sterilisation should be provided with accurate information and allowed to make decisions independently:

“They lied to you when they told you can [reverse the procedure], it’s permanent. I sit down knowing that I do this it’s a choice I made. I decided to be half a person; I decided to be half a woman. Not somebody decided it for me” (Participant 9).

Other options for contraception should have been made available to women instead of being pressurised into sterilisation. The women recommended that the discussions about sterilisation should start early on in pregnancy and that women should be given sufficient time to properly consider their decision.

Many of these recommendations are consistent with requirements in the existing legal framework which suggests that there is significant disjuncture between policy and practice.

Study limitations

This study aimed to explore a sample of HIV-positive women’s experiences of forced and coerced medical sterilisations in South Africa. While it was originally planned that data would be collected in four South African provinces, KwaZulu-Natal, Gauteng, Eastern Cape and the Western Cape, due to a lack of resources and timeline concerns, data were only collected in KwaZulu-Natal and Gauteng. Therefore, this study has limited generalisability. However, given that women from both rural and urban areas across two provinces provided similar accounts of their experiences, it may be possible that HIV-positive women across South Africa may have experienced similar abuse.

While developing the capacity of study partners to undertake the research was an explicit aim of this study, there were challenges with regard to data collection. While the field workers were trained for a week on interviewing techniques and the use of recording results, interviews conducted by field workers were more superficial than in-depth and many did not probe as much as they should have. To address this, four additional interviews were carried out by trained researchers to supplement the data.

Conclusions

Despite a protective legal framework in South Africa that specifies that sterilisation should be voluntary and informed, in clinical practice across two South African provinces, in both rural and urban settings and in both public and private facilities, women report having been coerced, and sometimes forced into sterilisation procedures. Participants' accounts of their experiences have helped to identify areas where the informed consent process is inadequate or fails in practice. These include that:

- (i) Healthcare providers appear to have scant or no understanding on the informed consent process. Some healthcare providers tend to underplay the informational component of informed consent by providing women with little or no detail about the proposed procedure, the risks and benefits, and other contraceptive options. By misinforming women that sterilisation is easily reversible and by creating and exaggerating the reasons why sterilisation may be a preferred contraceptive option, information tended to be provided in a way that was biased towards encouraging women to sterilise. Healthcare workers generally did not see patients as rational, authoritative decision-makers about procedures to be performed on their bodies;
- (ii) Most women felt a sense of pressure and coercion during the consent process. This was reflected in a range of different ways and resulted in them feeling that they had no choice but to sign the consent form. The women were told to sign the form under duress, whilst in pain, and in some instances, while being bullied by health workers. Some expressed being fearful of health workers and an inability to reject the procedure. None of the women reported being told that they could refuse the sterilisation or that they could withdraw their consent; and
- (iii) In the majority of cases, healthcare workers equated signing the consent forms with valid informed consent. Given the potential for the signing of the informed consent form to be equated with valid informed consent, in the United Kingdom, a signed consent form is legally invalid unless it can be shown that the patient was given sufficient comprehensible information about any treatment (Kerrigan, Thevasagayam, Woods, McWelch, Thomas, Shorthouse et al., 1993). Despite the fact that the Sterilisation Act requires knowledge, voluntariness and written agreement, data from this study indicate that the signing of the consent form is seen as an end in itself.

This study indicated that information was rarely provided to women on the sterilisation procedure, and when it was, it was incomplete and sometimes inaccurate. Further, women's autonomy to decide voluntarily was severely restricted through a range of coercive practices or by performing the sterilisation without their knowledge. In South Africa, requiring written consent for surgical sterilisation has provided little or no protection for patients. This study has shown that procedural protections which require, for example, counselling before the sterilisation or time between the information provided on the sterilisation and the resultant procedure, would probably be more effective in protecting the rights of women than the current approach.

Forced and coerced sterilisation of HIV-positive women is gendered and HIV-related discrimination rooted in pervasive stigma that HIV-positive women should not reproduce. Rather than the case where such abuses are perpetrated by a few "bad" healthcare providers (cf. Jewkes et al., 1998), the results from this study suggest a culture where abuse of HIV-positive patients is systematised. In this context, women face stigma and discrimination for being female, for being HIV-positive, and for expressing their sexual and reproductive rights. These identities and expressions appear to be perceived as so socially unacceptable that they deserve violence as a corrective measure, the medicalised violence of involuntary sterilisation against women living with HIV. Further research is required to more fully understand this issue in our context.

These data call for more attention to be given to human rights violations in South African healthcare settings. There is an expressed need to focus on upholding the rights of marginalised people, in particular women living with HIV. There is an equal need to build the capacity of women to be aware of their rights and to be empowered enough to exercise them. Healthcare providers, like all people who hold public office, should be held accountable for their human rights abuses. There is a need for maternal healthcare services to be transformed so that they are no longer viewed and accepted as places where violence against women is endemic and women's dignities are abused.

Recommendations

Forced and coerced sterilisation of HIV-positive women in South African hospitals must end immediately. From the data it is possible to make a number of recommendations toward that objective, including:

- (a) *Law reform.* Although a protective legal framework exists it is failing to protect a highly vulnerable group, women living with HIV. Law reform is needed in order to place new procedural obligations on healthcare workers to require them to view informed consent as a process rather than a formality. South African laws and guidelines on surgical sterilisation procedures should be in line with the International Federation of Gynaecology and Obstetrics 2011 Guidelines on Female Contraceptive Sterilisation. These could include regulations to accompany the Sterilisation Act which contain a detailed and clear informed consent form in all official languages and an accompanying information sheet on sterilisations which must be read, comprehended and signed by all persons wishing to be sterilised two weeks before the procedure and/or as part of reproductive health education. The Act should provide further that this informed consent process is repeated on admission to hospital;
- (b) *Training.* It is clear from this study that healthcare workers at all levels have little or no understanding of the key elements of informed consent. Training is needed on patient autonomy and the ethical-legal principles of informed consent;
- (c) *Policies prohibiting unfair discrimination due to HIV status.* Women in this study reported being told they had to be sterilised because they were HIV-positive. This is a form of discrimination and national policy statements are required which clearly state that women living with HIV have the right to reproduce and cannot be sterilised simply because they are HIV-positive;
- (d) *Policies aimed at addressing patient perceptions of involuntariness.* This study provides insight into the many factors that women felt coerced them into signing the sterilisation forms. These should be taken note of and addressed through institutional policies that prohibit providing consent under conditions of duress, for example the signing of consent forms whilst in labour or in the operating room; and
- (e) *Further research.* Research on healthcare workers' perceptions of sexual and reproductive rights of HIV-positive women, as well as their understanding of why HIV-positive women should or should not be sterilised, needs further exploration as healthcare workers are key to ending this abuse. Research also needs to explore intersections between involuntary sterilisation and broader social issues (stigma, discrimination, and related forms of violence) that serve to further marginalise women who are HIV-positive and women living with AIDS.

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Appendix A: Semi-structured interview

1. Could you tell me about yourself?
 - *Prompts:*
 - i. How old are you?
 - ii. Are you in a relationship?
 - iii. What is your highest level of education?
 - iv. Are you employed?
 1. If yes, what work do you do?

HIV testing experiences

2. Please describe your experiences of getting tested for HIV?
 - *Prompts:*
 - i. Why did you decide to get tested?
 - ii. When did you get tested?
 - iii. Where did you get tested?
 - iv. Why did you go to the healthcare facility when you were tested? (Specifically to test for HIV or for some other reason, e.g. pregnancy?)
 - v. How did you feel about the service you received from the healthcare professionals when you were tested?
 1. Did they provide you with sufficient information about being tested?
 2. Did they maintain confidentiality about your test result?
 3. Did you receive any support (e.g. psychological, medical) after you received your HIV positive result?

Experiences of sterilisation

3. When were you sterilised (year)?
 - How old were you at the time?
4. What is the name of the facility where you were sterilised?
5. Why had you gone to the healthcare facility, when you were offered the sterilisation? (Birth of a child, termination of pregnancy, other – specify.)
6. How did you first hear about sterilisation?
7. Did you request the sterilisation yourself or was it recommended to you?
 - If recommended, by who?
8. What made you decide to get sterilised?
9. What was the reason for the sterilisation?
 - Did you understand these reasons?
 - Did you agree with these reasons?
10. What were you told about sterilisation by the healthcare workers before you underwent the procedure?
11. Were you informed of other alternatives to sterilisation (contraception, etc)?
12. What type of sterilisation did you get? (Tying of tubes, cutting of tubes, burning of tubes?)
13. What information were you given about this sterilisation?
 - What were you told about the risks of the procedure?
 - What were you told about the reversibility of the procedure?
 - What information were you given about other sterilisation options?
14. Were you able to ask questions about the sterilisation and how it would affect you?
 - Were these questions answered to your satisfaction?
15. What did you understand having a sterilisation would mean for you?

16. Who did you discuss having a sterilisation with before you underwent the procedure? (E.g. healthcare worker, partner, friend or parent.)
17. How did you feel about having a sterilisation?

Feelings of pressure or coercion

18. Did you feel that you were able to say 'no' to the sterilisation?
 - Can you explain why? (Or why not?)
19. Did you provide consent for the sterilisation to happen?
 - If not, who did?
 - i. Why did someone else provide consent on your behalf?
20. Did you (or the person consenting for you) give consent in writing?
21. Can you describe the circumstances at the time when consent was provided? (In the doctor's office, during labour, unconscious?)
22. What information were you given after the sterilisation?
23. Do you feel that you were given enough information to make the decision to be sterilised?
 - Why? (Why not?)

Impact of sterilisation

24. How has being sterilised impacted on you?
25. How do you feel about being sterilised?
26. How do you feel about your body and your fertility now?
27. How do you feel about not being able to have children?
28. What has been your experience of using the healthcare services after your sterilisation?
29. Have you experienced any medical complications as a result of being sterilised?
 - If so, please describe.
 - What kind of support have you received after your sterilisation? (Psychological support; medication.)
30. What kinds of support would have helped you cope better after the sterilisation?
31. How has being sterilised impacted on financial or economic opportunities?
32. Have you endured any financial consequences as a result of being sterilised?
33. How has being sterilised affected your sexual relationships? (Talking with your partner; pleasure; abuse.)
34. How has being sterilised affected your relationships? (Partner, family, community.)
35. Have you considered or enquired about possible ways to reverse your sterilisation?

Redress

36. Do you think it was wrong for the clinic to sterilise you? If so, why?
 37. Who have you told about the procedure/process?
 - What was their response?
 38. Have you heard of other women who went through similar experiences?
 - Can you tell us more about this?
 - Where did you hear about this? (E.g. support groups etc.)
 39. Why do you think it is (or could be) difficult for women to talk about being sterilised?
 - What do you know about reproductive health rights? (E.g. laws that protect women from being sterilised without their consent.)
 40. Why do you think that women get sterilised without their consent given that it is against the law?
- What would have made your experiences of being sterilised better?

Appendix B: Screening Questionnaire

Note: This instrument may be refined and adapted after it is piloted.

Her Rights Initiative (HRI) is working with the Health Economics AIDS Research Division (HEARD) of the University of KwaZulu-Natal on a research study that aims to understand the experiences of women living with HIV in South Africa who have been coerced into sterilisation.

We are looking for women to participate in this study. If you are interested in participating, we invite you to complete this screening questionnaire. We will use your answers to find out if you meet the criteria that we have set for participation in the study. If you meet the criteria, you will be invited to participate in an interview. If you do not meet the criteria, the information obtained from you during screening will not be included in this study and will be shredded to protect your privacy.

You will be paid R 20.00 (twenty rand) for the time it takes to complete this form.

Thank you for agreeing to assist us.

Instructions for completing the questionnaire:

Please read through the questions below and answer yes or no by placing an X in the correct box.

QUESTION	YES	NO
Did you approach a health care worker or doctor and ask for information on sterilisation?		
Did a health care worker approach you to tell you about sterilisation as a form of birth control?		
Did anyone give you any information on the procedure, how it would be done and what implications it would have for you in the future?		
Did you have an opportunity to ask any questions?		
Were you given time to think about the procedure?		
Did you understand what was told to you?		
Did you agree to the sterilisation verbally?		
Did you sign an informed consent form?		
Was the consent form in English?		
Do you read and understand English?		
Did anyone explain the form to you?		
Did you feel pressurised into signing?		
Were you trying to access a health care service (for example a termination of pregnancy, caesarean section or other) at the time?		