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“I feel like half a woman all the time”: The impacts of coerced and forced sterilisations on HIV-positive women in South Africa

Zaynab Essack and Ann Strode

abstract

HIV-positive women are entitled to sexual and reproductive health rights, including access to contraceptives of their choice. One such option is sterilisation. Given its permanency, a woman's decision to sterilise should be voluntary and fully informed. However, there have been multiple reports that HIV-positive women are being sterilised without their informed consent, and sometimes without their knowledge, in southern Africa and elsewhere.

The *Article* explores the socio-cultural, physical and emotional/psychological impacts of coerced and forced sterilisations on HIV-positive women. It is part of a larger qualitative study, conducted in South Africa, which explored the experiences of 22 HIV-positive women who reported being sterilised without their informed consent.

Involuntary sterilisation has devastating impacts on women, affecting them mentally and physically, and impacting on their relationships with their partners, families and the wider community. Many interviewees reported that being sterilised profoundly affected their perceptions of themselves as women. Involuntary sterilisations have grave social and emotional implications for already marginalised HIV-positive women. Therefore efforts should be made to address human rights violations in South African healthcare settings and to prevent further gender-based abuses.

keywords

HIV-positive women, coerced sterilisation, forced sterilisation, stigma and discrimination

Introduction

Sub-Saharan Africa remains the region most profoundly affected by HIV and AIDS (UNAIDS-WHO, 2009). In this region, HIV infections are disproportionately skewed toward women who account for nearly 60% of all infections (*ibid*). The feminisation of the 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 (Quinn and Overbaugh, 2005). In South Africa, the highest prevalence rates are among women of reproductive age (Cooper *et al*, 2009), estimated at approximately 20% compared to a 10.6% prevalence in the general population (Statistics South Africa, 2011).

High rates of HIV infection amongst women of child-bearing age have several implications for the public healthcare system.

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HIV can be transmitted vertically from mother to child (Abdool Karim *et al*, 2010), it may impact negatively on the fertility of HIV-positive individuals (Segurado and Pavia, 2007) and multiple pregnancies within a short period of time may undermine other health gains (London *et al*, 2008). However, the availability of antiretroviral therapy (ART) and prevention-of-mother-to-child-transmission (PMTCT) programmes mean that HIV-positive women can live long productive lives and that the chance of transmitting HIV from mother to child is negligible (Open Society Foundation, 2011). Research in both developing and developed countries suggests that many HIV-positive individuals may continue to engage in sexual relationships and that some have expressed strong desires to have children (Cooper *et al*, 2009; Harries *et al*, 2007; Nduna and Farlane, 2009). Still, the social context may pose significant challenges for women's reproductive decision making (Nduna and 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). Consequently, HIV-positive women have to grapple with complex sexual and reproductive decisions regarding whether and when to have children (Cooper *et al*, 2009).

Sterilisation as a reproductive health issue

Sterilisation is considered a highly effective permanent contraceptive option for all women, including those who are HIV-positive (Mitchell and Stevens, 2004). Generally, it is a safe, procedure with fewer side effects than other contraceptive options (Stovall and Mann, 2010). Sterilisation can take multiple forms, including a hysterectomy, where the uterus is removed, or bilateral tubal ligation, where the fallopian tubes are restricted to prevent fertilisation (Mallet and Kalambi, 2008).

Legal and policy framework for sterilisations

Racist apartheid population control policies aimed at reducing the fertility rate of Africans and encouraging white births (Department of Health, 2004). Current reproductive

policies are based on human rights principles and framed in accordance with section 12(2)(a) of the Constitution which provides that everyone "has the right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction" (Republic of South Africa, 1996). Accordingly, the current population policy focuses on "the quality, accessibility, availability and affordability" of reproductive health services (Department of Social Welfare and Development, 1998:17). Likewise, the current contraceptive policy aims at improving sexual and reproductive health and facilitating "informed choices" (Dept of Health, 2004:15).

As part of this new policy framework, legislation has been passed on a range of sexual and reproductive issues (Department of Health, 2011), including the Sterilisation Act (No 44, 1998), which promotes autonomous decision making and protects patients through, for example, requiring voluntary, informed and written consent before a sterilisation (Sterilisation Act, 1998). The legal and policy framework does not promote sterilisations of a particular sector of society. Instead the Act aims to protect against coercion and for example, includes special protection to prevent arbitrary sterilisations of disabled persons.

Involuntary sterilisations of HIV-positive women

Despite this protective legislation, HIV-positive women make contraceptive choices within the context of widespread stigma and discrimination, including the perception that HIV-infected women should not engage in sexual relationships or have children (Paiva *et al*, 2003). Resultantly HIV-positive women may experience difficulty in accessing information on HIV and pregnancy, and on contraceptive options (de Bruyn, 2004). Further, if HIV-positive women decide to become pregnant, they may be subjected to negative attitudes and discrimination from their communities and healthcare providers (de Bruyn, 2004).

There are increasing reports that HIV-positive women in various contexts are being coerced or forced into submitting to sterilisation (Gatsi *et al*, 2010, Gatsi-Mallet, 2008; Mthembu, 2009; Patel, 2008; Mthembu *et al*, 2011). Cases of alleged

coerced and forced sterilisations have been documented in Namibia, South Africa (Gatsi-Mallet, 2008; Mthembu, 2009; Patel, 2008), Chile (Nair, 2010) the Democratic Republic of Congo and Zambia (Satande and Strode, 2010). It appears that a number of HIV-positive pregnant women have been compelled or deceived into having sterilisations in order to prevent future pregnancies simply because they are HIV-positive (ARASA, 2008; Patel, 2008). In southern Africa, women accessing PMTCT or abortion programmes are disproportionately likely to experience involuntary sterilisations (Mthembu, 2009). In Namibia and South Africa, women report being compelled to sign consent forms without explanation under highly stressful circumstances such as while they were already in labour or being wheeled into theatre (Mthembu *et al*, 2011; Open Society Foundation, 2011). Some women even reported being sterilised without their knowledge and only becoming aware of the sterilisation some time after it was performed (Mthembu *et al*, 2011; Open Society Foundation, 2011).¹

women report being compelled to sign consent forms without explanation under highly stressful circumstances

The impact of coerced and forced sterilisations on women living with HIV

There is some literature on the impact of coerced or forced sterilisations on HIV-positive women. However there are limited in-depth accounts from South African women on the social, psychological and financial implications of such sterilisations. This *Article* argues that the impact of coerced or forced sterilisation can be framed in terms of vulnerability (the power, opportunity or ability, or lack thereof, to make autonomous decisions). This contextualises impacts of coerced or forced sterilisations within a broader political framework of the marginalisation of HIV-positive women. Mann and Tarantola (1996) describe three inter-linked sources of vulnerability in the context of HIV, namely, personal, programmatic and societal vulnerability. Mann and Tarantola (1996) describe personal vulnerability, as behavioural and biological factors that place individuals at risk; programmatic

vulnerability as vulnerability which flows from programmatic responses to HIV by the state and other stakeholders; and societal vulnerability as emanating from the broader socio-economic and political context, and the individual's position in society.

At the level of personal vulnerability, involuntary sterilisation undermines a woman's perception of herself. The inability to reproduce may threaten a woman's feminine identity – particularly in contexts in which motherhood is perceived as the norm (Sandelowski in Rochon, 2008). South Africa remains a pro-natal society and motherhood forms a central feature of women's social identities (Dyer *et al*, in Cooper *et al*, 2007; Nduna and Farlane, 2009). The eroding of individual self-esteem increases personal vulnerability. The programmatic response to sterilisations is reflected in part by the nature of the legal framework described above. In South Africa, although highly protective, the legal framework appears to be failing HIV-positive women. The impact of poor implementation of legal norms is not detailed in the literature and there is limited in-depth data on the circumstances in which such violations of the law occur (Strode, Mthembu and Essack, under review). An analysis of the failings of the programmatic response and the need to reform the legal framework is set out elsewhere (*ibid*).

In terms of societal vulnerability, the inability to have children due to coerced or forced sterilisation places women at risk for a range of negative outcomes, for example, stigmatisation, isolation and the loss of access to other socio-economic spaces and opportunities (Mthembu, 2009; Mamad, 2009; Nair, 2010). Sterilised women also risk losing access to marriage as in many cultures and contexts (including many parts of South Africa) there is a pervasive stigma facing childless women (Mamad, 2009). Being unable to conceive children could thus inadvertently serve to further marginalise and erode the power of HIV-positive women (Mthembu, 2009) and may diminish their social status in the community (Dyer *et al*, in Cooper *et al*, 2007).

Methodology

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. This study was exploratory and descriptive in nature and adopted an interpretive approach – it aimed to understand how women make sense of their experiences of being involuntarily sterilised and the meanings they attach to these experiences. This *Article* describes and discusses findings on the impact of coerced or forced sterilisation on HIV-positive women. Both coerced and forced sterilisations are considered involuntary and were defined in the study as follows (Open Society Foundation, 2011: 2):

- “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.”

Sample, procedure and instruments

HIV-positive sterilised women, 18 years and older, were recruited at support groups for HIV-positive women and via snowball sampling where interviewees were asked to identify other potential participants (Silverman, 2005). A total of 32 women volunteered to complete the screening questionnaire of which 27 were identified as having undergone an involuntary sterilisation. All 27 women participated in in-depth semi-structured interviews to discuss their experiences of sterilisation. 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 only because they were HIV-positive. Sample size was determined by women's willingness to be interviewed. Interviews were conducted by trained research assistants from HRI and partner organisations. Most of the women in the sample were unemployed and unmarried and most reported that sterilisation occurred at public health-

care facilities with one participant being sterilised at a private facility. The data were collected between June 2010 and June 2011.

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) and analysed using hybrid inductive-deductive thematic analysis (Fereday and Muir-Cochrane, 2006). While 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. One member of the research team was responsible for coding the data. Selected transcripts were co-coded by three researchers. Discrepancies in coding were resolved through discussion. 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. Findings were presented to stakeholders, including some study participants, at a feedback consultation. Consultation with participants helped develop an advocacy strategy aimed at stopping involuntary sterilisations of HIV-positive women.

Ethical considerations

Ethical approval for this study was obtained from the University of KwaZulu-Natal, Human and Social Sciences Ethics Committee.² Prior to research implementation, a consultation was held with key stakeholders to inform them about the study and get their inputs and feedback. During study implementation, all participants provided written informed consent for participating in the screening questionnaire and individual interviews, and for audio-recording of 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 legal advice following the interviews were made. All participants took up this opportunity and the results were documented by the attorney who provided the service.

Results

HIV-positive women in our study reported that forced and coerced sterilisations, apart from infringing several of their fundamental rights, had severe negative consequences for themselves and their lives. These included severe emotional and psychological distress, dissolution of romantic and family relationships, ill-health, and financial expenses.

(1) Personal vulnerability

Desire to have children

Most women interviewed expressed a strong desire to have more children despite their sterilisation. The reasons given included that some had lost the children they had when they were sterilised either because the children were stillborn or died subsequently. Some wanted to have children because it is an expression of life, because they had started new relationships, or for marital reasons. Further, many participants reported that their partners would like to start a family or would want to start one in the future. Participants' comments reflected the impact of the social pressure on women to have children:

"...[H]e doesn't have a child like you know and he had just paid *lobola* (the bride price)... 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).

Emotional and psychological impacts

Most participants reported ongoing and significant emotional and psychological distress because they can no longer bear children. A few women even reported that they were clinically depressed and used anti-depressants.

Participants described feelings of trauma, isolation, helplessness, stress and long-term humiliation that extended far beyond their time in hospital, for example: "It impacted badly on me, it impacted very badly on me" (Participant 18). These feelings were so powerful that some women described

avoiding social situations, like conversations about babies because they are extremely distressful:

"I avoid conversations about children because they hurt me.... Uhm you avoid going to baby showers at all costs" (Participant 15).

The inability to bear children due to forced or coerced sterilisation was devastating for many participants. Some women described that being sterilised profoundly affected their sense of womanhood and they expressed a sense of loss of their identity:

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

"I feel like half a woman all the time. I can identify with other women but I know that I'm different in a very sort of unusual way" (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).

Being unable to bear children can create feelings of isolation, which may be amplified when women are discriminated against because they are sterilised. Some women described experiencing social stigmatisation due to sterilisation, which served to further erode their sense of self-worth, for example:

"[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).

Physical impacts

Participants described the physical impacts of involuntary sterilisations including that for some the wounds took a long time to heal. A few women described complication

with their menstrual cycles, for example: “My periods are irregular and sometimes I bleed a lot” (Participant 11).

Some participants reported experiencing physical pain, including backache. One woman described her frustration that she was never told what was wrong with her when she queried her post-sterilisation ailments. She tended to tolerate this lack of information and the inefficiencies at 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

In addition to the potential revocation of *lobola*, some participants described other negative financial implications as a result of sterilisation. Women reported spending money 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 in vitro fertilisation (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).

While others wished to reverse the procedure, they did not have the financial resources to do so. One woman shared her experience of losing a partner and income support for her children as a result of her involuntary sterilisation:

“He did not provide for those children, he did nothing, he just dealt with those who do give birth...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).

Participants 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. Post-sterilisation, women also expressed disinclination towards using public healthcare facilities and as a result have to find money to access care in the private healthcare sector:

“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” (Participant 9).

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 opportunities were absolutely impossible, that is, rather than being tied, their tubes were cut and burned (ie diathermy was used). Some women only learned of the permanency of sterilisation when they attempted to 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).

(ii) Social Vulnerability

Relational impacts

Many participants described disclosure of sterilisation as intensely difficult with only a handful of participants reporting having disclosed to their mothers, sisters or partners. The majority of participants had not disclosed their sterilisation to anyone, not even their partners due to fears of abuse and abandonment:

“Generally, we [involuntarily sterilised women at support group] 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).

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

While acknowledging the difficulty of disclosure, one woman expressed the personal struggle 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...” (Participant 16).

Disclosure of sterilisation is particularly problematic in a cultural context that values women based on their ability to conceive. Some participants found that disclosing their sterilisation 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).

Generally, sterilisation negatively impacted on women’s relationships with their partners. When husbands/partners learn of a woman’s sterilisation, there are negative consequences and social costs, including but not limited to abandonment, withholding of financial resources, violence, divorce and stigma, for example:

“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).

“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* could be lower or non-existent. Those already married expressed fear that their *lobola* could be revoked. This would cause cultural humiliation and may lead to the woman being disowned by her family and the marital family, potentially leaving 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 [sterilisation]...” (Participant 16).

“And also when you consider the *lobola*, the *lobola* that people pay – 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).

Discussion

It has been argued that involuntary sterilisation can have devastating impacts on women, affecting their mental and physical health as well as their relationships with their partners, families and communities (Gatsi *et al*, 2010). Furthermore it increases their vulnerability through eroding their personal and societal power. Indeed women in our study reported emotional and psychological distress, negative implications for their physical health and financial costs, as a result of involuntary sterilisations. However from their reports, it appears that the most severe impacts are at the level of a women's identity and self-worth, and on her relationships with others. Given the central role that children play in a woman's cultural conception of herself, the impact of sterilisation on women's self-esteem and self-worth was profound. This further impacted on their ability to form relationships and to be economically self-sufficient. It appears that these psycho-social impacts far outweighed the physical distress caused by the procedure. Together, this undermined their ability to act as autonomous women, with a strong sense of self, as generally, the women in the study felt powerless and marginalised by their inability to reproduce.

Previous literature has articulated that the fertility desires and needs of HIV-positive women are similar to the general population (Cooper *et al*, 2007). 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: 280). Similarly most women in this study reported an intense desire to have more children. They were illegitimately deprived of the decision to be able to do so however, when they were sterilised without their informed consent.

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 of being sterilised and unable to bear children may be more pronounced than being HIV-positive. In addition, affected women may not be valued by their families or may be looked down upon by women who are able to reproduce. This appears to be related to cultural conceptions of womanhood to the extent that "in African culture, if you are not able to have children, you are ostracized. It's worse than having HIV" (Gatsi in Open Society Foundation, 2011:5). Similar to one participant's description that *lobola* is "like buying a woman", 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 (LaFont and Hubbard, 2007). Thus, a woman'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 *et al*, 2008; LaFont and Hubbard, 2007). This further reflects the impact of coerced or forced sterilisations on the personal and societal vulnerability of HIV-positive women. Accordingly, disclosure of sterilisation is problematic in a culture that values a woman based on her ability to conceive.

the women in the study felt powerless and marginalised by their inability to reproduce

This study revealed that HIV-positive women undergo a vicious cycle of discrimination. Pregnant HIV-positive women face AIDS-related stigma and are considered as "dirty, diseased and undeserving" (Lawless *et al*, 1996:1371). Restricting HIV-positive women's reproductive choices reinforces erroneous public discourse that they are not deserving of bearing children, that they are vehicles for transmission of the virus, and/or that they are promiscuous (Lawless *et al*, 1996). Therefore, being sterilised results in the further marginalisation of this already vulnerable group who are then subjected to various forms of social discrimination and social exclusions

(Mthembu, 2009). Discrimination at all these levels has consequences for a woman's psychological health, emotional well-being, familial relationships and financial position.

It is argued that forced and coerced sterilisation of HIV-positive women is gendered HIV-related discrimination. Women face layers of stigma and discrimination for being female, HIV-positive, and for expressing their sexual and reproductive rights. This is rooted in perceptions that HIV-positive women should not reproduce and that as a corrective measure sterilisation should be mandated for all HIV-positive women (van de Wal, 1998). There have been no reports of coerced or forced sterilisations of men which may reflect a lack of opportunity or that it is HIV-positive women who disproportionately bear the burden of stigma and discrimination.

The involuntary sterilisation of HIV-positive women in South Africa may have grave consequences for the public healthcare system and the programmatic response to HIV. Participants in our study reported an unwillingness to use public healthcare services as a result of being involuntarily sterilised. In addition, fear of coerced/forced sterilisation and other rights violations, may prevent HIV-positive pregnant women from seeking PMTCT services which may consequently exacerbate maternal mortality. Such stigmatising practices may also prevent women from testing for HIV. Together violations of sexual and reproductive rights only serve to "severely undermine government's public health initiatives on HIV and reproductive health" (Gatsi *et al*, 2010:12).

This qualitative study was exploratory and descriptive in nature and aimed to explore a sample of HIV-positive women's experiences of forced and coerced sterilisations in South Africa. While it was originally planned that data would be collected in KwaZulu-Natal, Gauteng, Eastern Cape and Western Cape, due to a lack of resources and timeline concerns, data was only collected in KwaZulu-Natal and Gauteng. Therefore, this study has limited generalisability. However, themes identified in the data analysis were identified as an accurate reflection of women's experiences at a feedback consultation with some study participants, members of support groups of HIV-positive women and civil society orga-

nisations. In addition, we acknowledge the need for further qualitative and quantitative research on the wider implications of this problem for the health of HIV-positive women, including its impacts on their mental health, and willingness to get tested for HIV and enrol in PMTCT programmes.

Conclusions

Despite a protective legal framework in South Africa which 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, HIV-positive women report having been coerced, and sometimes forced into sterilisation procedures (Mthembu *et al*, 2011).

The discrimination of HIV-positive women in the form of coerced or forced sterilisation creates a vicious cycle that has profound consequences for their lives including their further marginalisation. This data calls 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 HIV-positive women. 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 common and where women's dignities are abused. Finally, the impact of sterilisations on women living with HIV should be addressed as a matter of urgency as it further contributes to their personal and societal vulnerability and violates women's legal rights to autonomy and to make reproductive choices.

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Notes

1. Litigation has begun against coerced and forced sterilisation at the Inter-American Commission for Human Rights in Chile and at the Namibian High Court (Nair, 2010).
2. Ethics approval number: HSS/1006/010.

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