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

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

Keywords: sterilization abuse, involuntary sterilization, informed consent, HIV-positive women, South Africa

There has been a radical transformation in the framework for provision of reproductive health care in post-apartheid South Africa. Flowing from the right to bodily and psychological integrity, including the right to “make decisions concerning reproduction” found in Section 12(2) of the 1996 Constitution,¹ a plethora of new laws and policies have been introduced that create a legal framework of rights in relation to termination of pregnancy,² sterilization,³ and sexual and reproductive health services for adolescents, among others.⁴ Despite this progressive legal framework, the gains for women’s health have been slow in coming, not least because of the low socioeconomic status of women with poor health and setbacks created by the HIV epidemic.⁵

Involuntary female sterilization is an example of the gap between policy and practice. The 1998 law regarding contraceptive sterilization is clear: there should be access to sterilization with the

informed consent of the person wishing to be sterilized and without any requirement of spousal consent.³ Despite the law, access to sterilization has remained limited and long waiting lists exist.⁶ At the same time, contraceptive use by women living with HIV is significantly higher than among uninfected women.⁷ Within this context, there have been anecdotal reports of sterilization abuse both prior to 1998⁶ and in subsequent years, including of HIV-positive women.^{8,9} However, there is no published evidence of the extent of the problem.*

*This is not only a South African issue. In 2012, for example, a Namibian court found that three women had been sterilized without their consent. All three women were HIV-positive, but the court dismissed the claim that they had been sterilized simply because they were HIV-positive. Source: *LM and others v Government of the Republic of Namibia*, case number 1603/2008.

There are allegations that sometimes when services are provided to HIV-positive women they are discriminatory and violate women's rights to dignity and bodily integrity. Accordingly, women's sexual and reproductive rights are not being fully realized as they struggle to access sterilization and other such services.

Informed consent and sterilization in South African law

The right to only receive medical treatment with informed consent is founded in the Constitution,¹ health laws^{3,10} and the common law.¹¹ Legally, consent operates both positively as a patient's right and negatively as a defense protecting health care workers (*volenti non fit injuria* – to one consenting no wrong is done).¹²

Consent as a positive right emanates from Section 12 of the Constitution, which provides for the right to freedom and security of the person, and includes the right to make autonomous health-related decisions concerning reproduction.¹ Consent can only operate negatively as a defense if the following criteria are met,¹¹ namely, the patient must:

- have the capacity to consent;¹³
- have knowledge of the nature and extent of the harm or risk involved;¹⁴
- understand or appreciate the nature and extent of the harm or risk;¹⁴
- be informed of the benefits, risks, costs and consequences of the proposed treatment in a language the patient understands and in a manner that takes into account the patient's level of literacy;¹⁰ and
- voluntarily consent to the procedure without being induced to do so by fear, force, threats, duress, coercion, compulsion, deceit, fraud, undue influence, perverse incentive or financial gain.¹¹

The South African Sterilisation Act of 1998 limits the circumstances in which sterilization may occur. It prohibits sterilization of persons under the age of 18, creates procedural protections for persons without the capacity to consent, only allows authorized institutions to perform a sterilization and requires such institutions to keep records of the procedures.³ Furthermore, it requires that those electing to undergo sterilization must consent to it. Section 4 of the Sterilisation Act says that consent must be given freely and volun-

tarily and may only be given if the person giving it has:

“(a) been given a clear explanation and adequate description of the proposed plan of the procedure; and consequences, risks and the reversible or irreversible nature of the sterilization procedure; (b) been given advice that the consent may be withdrawn any time before the treatment; and (c) signed the prescribed consent form.”³

Because there is limited in-depth evidence about the circumstances in which sterilization abuse occurs,^{8,9} we conducted a qualitative study in two provinces of South Africa with the following aims: documenting the subjective experiences of HIV-positive women who indicated that they had been sterilized without their informed consent; identifying the social, psychological and financial impacts of such sterilizations on these women; identifying the women's immediate and long-term support needs; and using the findings to inform an advocacy strategy for increasing awareness of sterilization abuse of women living with HIV and pressuring the government to bring about an end to the practice.

This article presents the experiences of 22 HIV-positive women who said they were involuntarily sterilized between 1996 and 2010 and explores the extent to which their consent to sterilization was or was not autonomous and/or informed. Details of the longer-term impact of sterilization on these women have been published elsewhere.¹⁵

Methodology

The term *sterilization abuse* has been used to describe situations where consent to a sterilization was not obtained because the patient was regarded as incompetent or situations where the sterilization was performed in the patient's perceived best interests as established by a third party.¹⁶ This study focused on the latter aspect of sterilization abuse, documenting involuntary sterilizations that involved the use of incentives, misinformation or intimidation to compel women to undergo sterilization as well as cases where women were sterilized without their knowledge or the opportunity to consent.

This exploratory descriptive study employed a qualitative approach. It was conducted among a small, purposive sample of HIV-positive sterilized women age 18 or older in KwaZulu-Natal and Gauteng provinces. Women who had been

sterilized during a caesarean section, shortly after childbirth or in exchange for another health care service such as an abortion were recruited at community-based support groups using purposive and snowball sampling strategies.¹⁷ Six trained field workers attended 11 support group meetings for HIV-positive women for the purpose of introducing the study and inviting all women who believed they had been involuntarily sterilized to complete a screening questionnaire. Thirty-two women completed the questionnaire, which addressed the informed consent requirements for sterilization.

The questionnaire indicated that 27 of the 32 women believed they had been sterilized without their voluntary and informed consent. These women were invited to participate in semi-structured interviews intended to gather in-depth information about their experiences of sterilization. All women provided informed consent for participation in the screening questionnaire, and the women who were invited to participate in semi-structured interviews provided informed consent for this activity as well. Women were paid US\$ 4 for completing the screening questionnaire and US\$ 10 for participating in the study to compensate them for their time, inconvenience and expenses.¹⁸

Data were collected between June 2010 and June 2011. The semi-structured interview included both closed- and open-ended questions regarding the circumstances surrounding the sterilization, the information provided to women as required by law, their perceptions of the voluntariness of their decision, the impact of the sterilization on their lives, and their thoughts on potential measures for redress. Interviews were completed by trained research assistants from partner organizations, and were 30 to 60 minutes long.

Interviews were audio-recorded, transcribed and translated from isiZulu or Xhosa into English (when necessary). Five interviews were excluded from the analysis because the women had been sterilized as part of treatment for cervical cancer. The final sample thus consisted of 22 participants. Transcripts were coded using NVIVO 8 (qualitative data management software). Data were analyzed using hybrid inductive-deductive thematic analysis to identify issues as they related to the research questions¹⁹ and were coded to identify key emergent issues. All key issues were discussed among the research team, with the aim of consolidating themes relevant for local, provincial and inter-

national advocacy. Key issues presented in this paper include autonomy, knowledge, voluntariness and agreement to sterilization.

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

Findings

Study sample

Fifteen study participants were recruited in KwaZulu Natal and seven in Gauteng. Four participants reported being sterilized without their knowledge and 18 reported being involuntarily sterilized. Furthermore, four were sterilized before 1998, when protective legislation was introduced, and 18 after the introduction of protective legislation: one between 1998 and 2000; seven between 2000 and 2005; and 10 between 2005 and 2010. Most participants were unemployed and unmarried. Twenty-one participants reported being sterilized at public health care facilities and one participant reported being sterilized at a private facility.

Autonomy

South African law respects the rights of all patients to make autonomous health choices.^{1,3,10,11} The decision of whether or not to undergo medical treatment is one for the patient, even if he or she is advised of its importance by the health care provider.²⁰ According to the interviews, none of the 22 women felt that they had made an autonomous decision to be sterilized. Their accounts reflect the perception of consent to sterilization as a decision made by health care workers rather than an expression of their right to autonomy.

“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)

Study participants reported that health care workers presented sterilization as a birth control option because of the women's HIV-positive status.

“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 sterilize me because I was HIV-positive and I was never supposed to get another child.” (Participant 19)

Some women reported being informed by health care workers that being sterilized would prevent the birth of more babies with HIV. Others recalled

being informed that sterilization would mean that they would not leave orphaned children.

“They said if I were to have a child again, who would raise it because I was going to die soon.” (Participant 11)

Some women reported being told that being HIV-positive and pregnant was a potentially fatal health risk.

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

“He [the doctor] asks how many kids I have. I say it’s the second one. Do I have any knowledge about how risky it would be for me to get another child being HIV-positive?... Then he said the way he sees it I must be sterilized because it’s a risk.” (Participant 16)

Knowledge

Before patients make health-related decisions, according to South African law, they must be given information about their health status; the range of treatment options available to them; the benefits, risks, costs and consequences of each option; and their right to refuse treatment.^{10,20} The Sterilisation Act stipulates that patients should be informed of the nature of the procedure; its consequences and risks; the permanence or reversibility of the outcome; and their right to refuse sterilization.³

Most of the women in this study became aware of their HIV status while pregnant, through prevention of mother-to-child transmission programs intended to benefit their children. Nevertheless, many women felt that they had been branded as unworthy mothers simply because of their HIV status. None of them reported being told that sterilization was simply one of a range of birth control options.

“I was young. I did not get... options.” (Participant 21)

Most study participants reported being told that they would benefit from being sterilized because they were HIV-positive. Only a few participants reported being informed of the risks or consequences for fertility of being sterilized. Most reported not being informed about the type of sterilization they would undergo.

“I do not know anything, even what form of sterilization was performed.” (Participant 17)

Only one woman recalled being shown a picture of a uterus and fallopian tubes, and being told

by the nurse how the tubes would be tied. Another woman was shown physically on her body how the procedure would be performed.

Some women reported being given so little information about the nature of the sterilization that they did not even know that it was a surgical procedure until they arrived at the operating theater.

“I was told to be sterilized. They said it was a simple procedure. Only when I went to the theater did I begin to realize the seriousness of my situation. They had not told me that I would be taken to a theater.” (Participant 21)

From participants’ descriptions, it appears that the implications of sterilization were downplayed and that information about consequences was imparted in a biased manner in order to encourage sterilization. Women were seldom told that they would no longer be able to bear children, and most reported being 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 sterilize me and I would be able to reverse it one day.” (Participant 11)

The power differential between patients and health care workers appeared to make women fearful of asking questions and inclined to do what they were told.

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

“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)

None of the women reported being informed of their right to refuse the sterilization.

Voluntariness

Patients have the right to voluntarily choose or refuse a medical procedure.^{3,10,11} In *LM and Others v Government of the Republic of Namibia* the court held that obtaining consent for a sterilization while

a woman is in active labor impacted on voluntariness and was inappropriate as it would need to be hurriedly obtained.²¹ Most study participants recalled signing consent forms indicating their agreement to sterilization. However, they felt coerced to consent by a range of overt and subtle factors.

Many participants made the decision under duress. For example, some were asked to consent when they were already in labor and enduring great pain.

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

“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 labor.” (Participant 17)

Others were asked to sign consent forms on the way to the operating theater for caesarean sections. One participant described how she was already in the theater for another procedure when health care workers told her that she was to be sterilized.

A number of women felt compelled to make the decision to be sterilized in order to access another service such as an abortion.

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

Subtle factors such as a fear of health care providers or perceptions of being powerless to control decision-making also influenced women’s acceptance of sterilization.

“I went back and she gave me a pen... If she wanted to give me an option she wouldn’t have to give me a pen. You understand? She would’ve [asked] me if I had thought about it... Or she could’ve said, ‘Have you read it?’ ” (Participant 9)

Many study participants described feeling so disempowered by how health care workers treated them that they were compelled to agree to the sterilization. For example, a participant reported that her opinions on the sterilization were of little value as health care workers had not “asked... politely.” Another woman recalled needing to decide while her doctor was angrily rebuking her.

“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)

Others felt alienated from the decision-making process. One woman reported that the decision was made by health care workers who spoke about it in front of her, but did not include her in the conversation. Some women felt they should defer to health care workers who knew better than they did.

Many also felt pressured by a fear of disappointing health care workers who were assisting them under difficult circumstances, for example, by providing an abortion when other doctors would not do so, or by delivering a baby when health care staff were on strike.

“To 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 doing a favor for me.” (Participant 9)

Agreement to sterilization

Although none of the 22 women said that they had refused sterilization, this does not necessarily mean that they had been in agreement. The Sterilisation Act requires that the patient sign a written consent document before undergoing a sterilization.³ Most women said that they had signed consent forms, but many felt that the forms were given to them with the expectation that they would sign, rather than being presented as information for them to read and consider.

“[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)

“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. In [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)

Four women reported neither having knowledge that they were going to be sterilized nor being aware that they had signed consent forms.

"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 [a] gynecologist. 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)

Three women only discovered that they had been sterilized many years later. One described finding out about the sterilization when she was having treatment for cervical cancer. Two others reported that they were informed of the sterilization some years later when trying to become 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... I went back to the clinic and they said it means I won't get any more children, it seems I was closed." (Participant 10)

Discussion

South African law prohibits sterilization without informed consent.³ Although consent was generally obtained from participants in this study, women felt that their "consent" did not reflect an informed, autonomous reproductive choice. Sterilization was presented to them or took place without their knowledge because they were HIV-positive, and their right to autonomous decision-making was undermined or ignored by health care workers who carried out the procedure.

Previous research has shown that health care workers play a critical role in shaping the reproductive choices available to women, and that health care workers may project their personal feelings and stigmatizing attitudes onto patients.²² Health care workers also tend to locate decisions within medical parameters; many of the cases of sterilization reported by study participants occurred before antiretroviral treatment was widely available in South Africa. It can therefore be theorized that sterilization was promoted

because of the perceived impact of HIV on the health of women and their children, as a misguided attempt at reducing mother-to-child transmission and embedded in perceptions that those with HIV should not have children.^{22,23} It appears that the women were not seen as fit mothers who could live long and productive lives.

The World Health Organization has identified six aspects of sterilization that patients should be informed of: sterilization is a surgical procedure; it has risks and benefits; it will prevent future pregnancies; it is considered permanent; refusing the procedure will not result in the loss of any benefits; and non-permanent contraceptive alternatives are available.²⁴ For the women in this study, the World Health Organization standards were not fulfilled. A previous South African study found that medical professionals discourage HIV-positive women from becoming pregnant and have very different perspectives on reproductive choices from their patients. Overt coercion and more subtle forms of pressure and intimidation clearly violated the legal rights of our study participants. Health care workers are in a privileged and powerful position compared to their patients, and some may abuse this power to obtain patients' cooperation.²³

In this regard, our findings corroborate those from Namibia where in 40 documented cases women reported that they signed consent forms while in labor or when trying to access another health care service.⁸ However, despite the concerns raised by study participants, it is unclear whether a court would perceive all reported levels of coercion, particularly subtle pressure, as having undermined and vitiated a woman's ability to make a voluntary decision.

Although the 1998 Sterilisation Act was intended to ensure informed decision-making regarding sterilization, these protections failed the HIV-positive women in this study. Our findings suggest that some health professionals may consider a signature on a consent form as sufficient regardless of how it was obtained. However, the recent case of *LM and Others v Government of the Republic of Namibia* shows that health care workers cannot rely on consent documents alone, as the court held that there was an onus on providers to show that the consent was informed. This confers a duty on health care workers to document the reason for the sterilization, the information provided to the patient (including whether contraceptive alternatives

were identified) and how it was provided, for example, during group counseling.²¹

This study had a number of limitations. Firstly, we had originally planned to interview women in four provinces, but due to a lack of resources and time, women were interviewed only in KwaZulu-Natal and Gauteng. Secondly, resources did not permit including interviews with HIV-negative women who had been sterilized, health care providers or Ministry of Health staff.

This study was exploratory and descriptive in nature. The cohort of 22 women was carefully selected, and the findings cannot be generalized. Nevertheless, the themes identified were confirmed as an accurate reflection of women's experiences at a feedback consultation with some of the study participants, as well as by members of HIV-positive women's support groups and civil society organizations.

This study has been used to develop an advocacy strategy for the Her Rights Initiative. The aims of the Her Rights Initiative include raising awareness of the rights of women electing to be sterilized, publicizing documented cases of sterilization abuse, facilitating access to remedial legal services and ensuring that the national Department of Health addresses the need for training of health care workers on how to implement the Sterilisation Act in a way that is consistent with constitutional values.

Even this small number of cases of involuntary sterilization of HIV-positive women raises significant concerns when juxtaposed against the background of a protective legal framework, a resource-constrained environment and an increas-

ing focus on providing a comprehensive package of HIV care. New strategies are needed to address the implementation of the Sterilisation Act. These should include work on the attitudes of health care workers towards patients living with HIV, more detailed operational policies on the process of obtaining informed consent and ensuring that state institutions provide appropriate oversight. Additionally, law reform is needed to enhance current protections. For example, legally mandated counseling before the sterilization or time between the information provided and the sterilization could be more effective in protecting the rights of women to make informed choices. Gazetted minimum standards on the information to be provided to patients may also ensure more consistency relating to this aspect of consent.

Finally, further research is required to explore whether involuntary sterilizations are still happening, and if they are, the underlying reasons for them, the extent of the problem, and health care provider perceptions regarding solutions.

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Résumé

Depuis 1998, la loi sud-africaine garantit l'accès des adultes de plus de 18 ans à la stérilisation, mais seulement avec leur consentement éclairé. Néanmoins, le droit à la stérilisation et d'autres droits génésiques ne sont pas pleinement réalisés puisque les femmes luttent pour accéder à des services limités et que certaines se plaignent de discrimination et de stérilisations abusives. Cette étude qualitative menée dans deux provinces analyse l'expérience de 22 femmes séropositives qui ont indiqué avoir été stérilisées sans leur consentement éclairé (n=18) ou à leur insu (n=4). Les principales questions citées par les participantes concernaient le non-respect de leur autonomie, le manque d'informations sur les conséquences de la stérilisation et les pressions subtiles ou manifestes exercées pour leur faire signer le formulaire de consentement. Même si le cadre juridique avait pour but de garantir une prise de décision éclairée sur la stérilisation, les garanties ne semblent pas avoir protégé les femmes séropositives de l'étude. Il apparaît que

Resumen

Desde 1998, la ley de Sudáfrica dispone que toda persona adulta debe tener acceso a esterilización pero solo con su consentimiento informado. Sin embargo, el derecho a la esterilización y otros derechos sexuales y reproductivos no se han realizado plenamente, ya que las mujeres luchan por tener acceso a servicios limitados y existen alegaciones de discriminación y abuso de esterilización. En este estudio cualitativo se exploran las experiencias de 22 mujeres VIH-positivas en dos provincias, quienes relataron haber sido esterilizadas sin su consentimiento informado (n=18) o sin su conocimiento (n=4) entre 1996 y 2010. Los asuntos clave mencionados por las participantes fueron: falta de respeto por su autonomía, falta de información respecto al procedimiento de esterilización y presión sutil o explícita para firmar el formulario de consentimiento. Aunque el marco legislativo fue creado para garantizar una toma de decisiones informadas respecto a la esterilización, estas protecciones parecen haberles fallado a las

certaines professions de santé considèrent comme suffisante une signature dans un formulaire de consentement, quelle que soit la manière dont elle a été obtenue. De plus, l'impression des femmes qu'elles ont été orientées vers la stérilisation simplement du fait de leur séropositivité doit être examinée plus attentivement. Davantage de recherches sont nécessaires sur la nature du problème et les perceptions d'autres parties prenantes.

mujeres VIH-positivas en este estudio. Los hallazgos indican que algunos profesionales de la salud consideran que basta con tener una firma en el formulario de consentimiento, sin importar cómo se obtuvo. Más aún, las percepciones de las mujeres de que fueron señaladas como que necesitaban ser esterilizadas simplemente porque era VIH-positivas, merecen una investigación más a fondo. Se necesitan más investigaciones sobre la naturaleza del problema y sobre las percepciones de otras partes interesadas.