

Experiences of forced sterilisation and coercion to sterilise among women living with HIV (WLHIV) in Namibia: an analysis of the psychological and socio-cultural effects

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Abstract: *The forced and coerced sterilisation of women living with HIV (WLHIV) is a phenomenon reported in several countries. In Namibia, litigation efforts for cases of forced and coerced sterilisation were successful, yet the psychological and socio-cultural well-being of those affected has not been adequately investigated and addressed. To determine the psychological and socio-cultural effects of involuntary sterilisation on WLHIV in Namibia, qualitative data from seven WLHIV were collected through face-to-face interviews. Our analysis showed that, firstly, there are negative psychological effects manifesting in psychological symptoms associated with anxiety and depression. Secondly, there are negative socio-cultural effects including discrimination, victimisation and gender-based violence. Patriarchal cultural values regarding reproduction, marriage and decision-making contribute to negative psychological and socio-cultural effects. Finally, negative psychological and socio-cultural effects of involuntary sterilisation are long-lasting. For participants, coping remains difficult, even over a decade after the sterilisations. Given the considerable long-lasting negative psychological and socio-cultural effects, psychological interventions to expedite positive coping and well-being must be prioritised.* DOI: 10.1080/26410397.2020.1758439

Keywords: forced and coerced sterilisation, women living with HIV (WLHIV), Namibia, psychological symptoms, socio-cultural effects, discrimination

Introduction

Forced and coerced sterilisation is a violation of fundamental human rights that occurs when a medical procedure eliminating an individual's ability to bear children is performed without informed consent, in instances where the individual is unaware of the fact that they will be sterilised and only learns of the sterilisation after the surgery.¹ Coerced sterilisation involves the use of coercion in obtaining the consent for the sterilisation procedure. It encompasses "emotionally coerced sterilisation, in which a patient is pressured into consenting to sterilisation in a way that diminishes his or her autonomy in making the decision".^{1,p.223} Coerced sterilisation happens when misinformation, intimidation tactics, financial incentives, access to health services or employment are used to compel individuals to agree to the procedure.²

Forced and coerced sterilisation is often targeted at vulnerable groups, such as women living with HIV (WLHIV). The forced and coerced sterilisation of WLHIV is a global phenomenon that has been documented by the International Community of Women Living with HIV (ICW) in Bangladesh, Brazil, Botswana, Cambodia, Chile, China, Democratic Republic of Congo, Dominican Republic, El Salvador, Fiji, Honduras, India, Indonesia, Kenya, Malawi, Mexico, Mozambique, Namibia, Nepal, Nicaragua, Pakistan, Philippines, South Africa, Sri Lanka, Swaziland, Tanzania, Thailand, Uganda, Ukraine, Venezuela, Viet Nam and Zambia.³ Despite the availability of international, regional and national legislation in the form of the various human rights conventions, protocols, policies and constitutions that seek to protect individuals from such violations, the occurrence of this

practice is widespread and so is the negative impact on the rights of those affected.

Forced and coerced sterilisation undermines individuals' rights that are protected in several international and regional human rights instruments (to which Namibia is also a signatory). These rights include the right to health, the right to information, the right to dignity, the right to bodily integrity, the right to privacy, the right to decide on the number and spacing of children, the right to found a family, the right to be free from discrimination, the right to autonomy, the right to privacy, the right to liberty, the right to security of person and the right to be free from cruel, inhumane and degrading treatment.⁴ These rights are guaranteed in United Nations human rights instruments such as the Universal Declaration on Human Rights, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. Provisions that prohibit involuntary sterilisation are also outlined in regional human rights instruments such as the African Charter on Human and Peoples' Rights, the African Charter on the Rights and Welfare of the Child, and the Protocol to the African Charter on the Rights of Women (Maputo Protocol). Furthermore, in 2013 the African Commission adopted Resolution 260 on Involuntary Sterilisation, a resolution which condemns involuntary sterilisation as a gross human rights violation.⁴

Historically, forced and coerced sterilisation has occurred around the world for diverse reasons. In the United States of America (US), 7600 people in North Carolina were sterilised between 1929 and 1974 for a range of reasons, including findings by authorities that they were lazy, promiscuous or poor.⁵ In other parts of the world, forced sterilisations have occurred in large numbers. For example, eugenics programmes, which focused on manipulating heredity to produce "better" people and on eliminating those deemed biologically inferior, prompted involuntary sterilisation in Nazi Germany (400,000 men and women), Sweden (63,000, mostly women), Japan (over 800,000 men and women) and Finland (11,000 women).⁶

Internationally, studies of forced and coerced sterilisation have highlighted that the practice is not only discriminatory but negatively impacts

physical and emotional well-being. Kendall and Albert investigated the experiences of coercion to sterilise and forced sterilisation among WLHIV in Latin America, finding that HIV-related stigma and discrimination by healthcare providers were a primary driver of coercive and forced sterilisation and that WLHIV are most vulnerable to forced sterilisation when they seek maternal health services.⁷ Twenty-three per cent of the participating WLHIV experienced pressure to be sterilised after they were diagnosed as HIV positive. Those whose HIV status was known were six times more likely to experience forced and coerced sterilisation, compared to women whose HIV status was unknown during pregnancy. Apart from the physical effects of the sterilisation procedure, this study found that psychological effects included stress, depression, loss of self-esteem and self-worth, fear and anxiety.⁷

In Africa, a study in South Africa on forced and coerced sterilisation of WLHIV reported issues of stigma and discrimination, ineffective legal frameworks, lack of policies to protect individuals and negative attitudes of health professionals towards these women.⁸ A legal analysis of involuntary sterilisation in South Africa found that the practice was rooted in a systemic problem of HIV stigmatisation that is prejudicial, especially regarding reproductive health rights, extending involuntary sterilisation beyond the notions of medical malpractice or negligence.⁹ The analysis concluded that radical and gendered responses are required to address such a systemic practice, with more attention paid to educating women on their reproductive health rights and reproductive autonomy, empowering them to explicitly demand and claim their rights.⁹

Other investigations on the effects of forced sterilisation on the mental well-being of WLHIV in South Africa found that "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 ... feelings of trauma, isolation, helplessness and stress".^{10,p.25} WLHIV who experienced involuntary sterilisation in South Africa highlighted that they were affected mentally and physically and that relationships with partners, families and the wider community were impacted.¹¹ In patriarchal cultures, where the value of a woman is placed on her ability to bear children, the socio-cultural effects of sterilisation may be intense,^{11,12}

including abusive behaviour from spouses who were not consulted about the sterilisation decision.^{3,11} If a woman marries again after sterilisation, her new husband might be displeased with her inability to bear him children, causing tumult in the marriage.³

Cases of forced and coerced sterilisation of WLHIV in Namibia were discovered in 2008, during a “Young Women’s Dialogue” discussion on sexual and reproductive rights conducted by Namibia Women’s Health Network (NWHN), a local NGO that focuses on the rights and well-being of WLHIV, and the ICW. During this meeting, a young woman mentioned that with all the issues surrounding pregnancy and HIV she was “grateful” that the healthcare facility had insisted that she be sterilised.¹³ When three other women in the group reported similar experiences, it became clear that a violation of women’s rights had occurred.¹³ Further investigations by the ICW and NWHN resulted in the documentation of 40 cases of WLHIV who had been sterilised in state hospitals between 2004 and 2007, apparently because of their HIV statuses, with some women only learning of the sterilisation after surgery and others being coerced in order to obtain the required informed consent.^{1,2,13,14} Two civil claims were instituted against the Government of Namibia.¹⁵ The first claim, grounded in civil law, was for damages as the surgical procedures were unlawful due to having been performed without the women’s informed consent.¹⁵ The second claim was due to the discriminatory nature of the practice as it was deemed to be targeted at WLHIV.¹⁵ In 2014, the Supreme Court of Namibia ruled that the WLHIV were sterilised without informed consent, and the government was ordered to compensate them financially.¹⁶ However, the judgement failed to address the issue of the forced or coerced sterilisation of WLHIV as a form of discrimination.¹⁵

While the major focus in assisting the survivors of forced sterilisation in Namibia has been to provide litigation services to facilitate compensation,¹ it is now also addressing effects on the psychological and social well-being of the women involved,¹⁷ since forced sterilisation may be considered a traumatic or stressful event,⁴ due to both its negative effects on the body and the possible psychological shock experienced. Matsumoto postulates that a traumatic event inflicts physical damage on the body, severe shock to the mind, or both.¹⁸ Thus, mental well-being should be highly prioritised since there could be a risk for mental health

problems. In addition, WLHIV who experienced forced and coerced sterilisation in Namibia are of low socio-economic status which adds further stressors to the additional stigma and discrimination that comes with being HIV positive. Many women remain silent about their sterilisation, fearing negative social and cultural consequences such as limited marriage prospects, stigmatisation, prejudice and social isolation.^{3,17}

The research described above shows that forced sterilisation may result in mental health effects including psychological symptoms of anxiety, depression, isolation, stress, psychological distress, feelings of worthlessness and helplessness. Additionally, negative effects of discrimination and disrupted interpersonal relationships were noted. The purpose of this study was to explore and obtain an in-depth understanding of the psychological and socio-cultural effects of forced and coerced sterilisation in HIV positive women in Namibia, to determine the implications for intervention.

Methods

Study design

A qualitative approach was adopted to discover individuals’ perceptions and explore the complexity of their understanding.¹⁹ Data were collected with a semi-structured interview schedule, developed by the researchers based on available literature on forced and coerced sterilisation. The instrument included a structured section aimed at collecting socio-demographic information including age, marital status, number of children, sterilisation date, type of sterilisation performed, level of education, employment status and occupation. The interview schedule also covered the following content areas: experiences with sterilisation (e.g. how do you think sterilisation changed your life?), coping and establishing the meaning of being sterilised, (e.g. what does the fact that you were sterilised without your knowledge mean to you now at this moment?), sterilisation and mental health problems, and consequences of forced sterilisation (e.g. do you think someone who is sterilised wishes to have more children?).

To explore psychological symptoms, questions on commonly reported symptoms in literature, namely mood, anxiety and trauma and stressor-related disorders, were asked. Both open-ended and closed questions were used, giving participants the opportunity to elaborate on their experiences and symptoms.

The research instrument was translated into Oshiwambo, since all the members of the target population were primarily Oshiwambo speaking.¹⁷ To enhance the quality of translation, two independent translators were used, the first to translate the instruments from English to Oshiwambo and the second to review the translated documents for consistency in meaning. A pilot study was done and results recommended simplification of language used and wording in some sections of the interview guide. The pilot study informed the editing and finalisation of the research instrument. Ethical approval for the study was obtained from the University of Namibia Research Ethics Committee (UREC).

Sampling and recruitment

The target population for this study was the 40 women (22 from the Khomas Region and 18 from the northern regions) who experienced forced and coerced sterilisation in Namibia, and whose cases were documented. The population data were obtained from NWHN, the NGO that has been spear-heading advocacy initiatives pertaining to the forced and coerced sterilisation cases in Namibia. Resource constraints meant that the study could only accommodate seven participants. With the assistance of NWHN, convenience sampling was used to select participants, based on availability and proximity to the researcher. Therefore, only participants residing in the Khomas Region of Namibia participated in the study, although five were originally from the northern regions of Namibia.

Prospective participants were briefed by telephone about the research, its aims and objectives. Those interested were invited to the NWHN office, where the researcher explained in detail all aspects of the study before obtaining consent. Participants were approached until the predetermined number of seven participants was obtained. We acknowledge that the convenience sampling employed in this study can be marred with sampling bias and lack of representativeness of the target population, however, a sample of seven participants can provide sufficient data saturation for qualitative analysis,²⁰ especially as the overall target population was only 40.

Data collection

Data were collected through face-to-face individual interviews conducted between August and September 2017 by three trained, Oshiwambo-speaking

research assistants. Interviews took about one hour and were audiotaped, transcribed and translated into English for analysis. This research took into consideration ethical issues of confidentiality, anonymity, privacy, informed consent, deception, debriefing, mental and physical stress and discomfort, recognition of participants' rights to withdraw, and problems with involuntary participation and intervention.²¹ There were no refusals or withdrawals in the study and pseudonyms were used to protect the identity of participants.

Data analysis

A content analytic approach was used to analyse the data, to interpret meanings and derive themes. The following steps were applied: familiarisation and immersion, including themes, coding, elaboration, interpretation and checking.²⁰ The first author led these steps, with codes and interpretation discussed with the second author to provide an external check on the research process. Atlas ti 7 was used to assist with analysis, specifically during the coding process.

Results

Demographic characteristics

All participants were either unemployed or working in traditionally low paying jobs (Table 1), highlighting potential vulnerability of participants. Participants were aged between 38 and 44 years and at the time of the interviews, between 10 and 13 years had passed since the sterilisations occurred. Participants were sterilised when they were in their late twenties to early thirties.

Circumstances of sterilisation

All participants were coercively sterilised during childbirth, when C-sections were done. For example, Participant 1 stated that:

"I went to the hospital to give birth in 2007, I went there on the 7th of December, I was told that I am going to the theatre, but I was not told that by going to the theatre I am going to be sterilised also, I was just told that you are going to have surgery because you are living with HIV we just want to help your baby not get infected by the virus, you are just going to be operated so that we can remove the baby, nothing else is going to be done ... It was only in 2013 when I found out because of the sterilisation campaign ... I went to the office of Namibia Health

Table 1. Socio-demographic characteristics of participants

Participant Code	Age	Highest education level obtained	Employment	Marital status	Sterilisation date	No. of biological children	Age at sterilisation
P001	43	Grade 10	Unemployed	Previously married – separated	2007	4	33
P002	44	Grade 10	Volunteer	In a relationship – 6 years	2004	4	31
P003	43	Grade 12	Employed – night supervisor in catering	In a relationship – 2 years	2007	3	33
P004	41	Grade 12	Unemployed	Married – 5 years	2007	3	31
P005	39	Grade 9	Employed – security guard	Single	2006	2	28
P006	41	Grade 9	Employed – cleaner	Married – less than 12 months	2007	2	31
P007	38	Grade 6	Unemployed	Divorced	2005	3	26

Women Network, they saw on my health passport that I am sterilised.”

Four research participants only learnt that they were sterilised well after childbirth; two found out about the sterilisation when seeking postpartum care and family planning services, and two women only discovered they had been sterilised because of the Stop Forced Sterilisation campaign conducted by a local NGO. Three research participants found out about the sterilisation at or immediately after childbirth. Intimidating tactics were used to make them sign consent forms. As Participant 6 explained, doctors told her:

“We were told by our boss that we must sterilise all women who are positive, so if you don’t want then we can’t help you to deliver your baby ... I decided to sign as I was afraid that something might happen to my baby.”

All participants believed they were sterilised because of their HIV statuses. For instance, Participant 2 remarked:

“I think I was sterilised because of my HIV status, I already informed the nurse that I am HIV positive ... yes, it was because I am HIV positive.”

Themes

Five primary themes were identified, each consisting of several sub-themes (Table 2). Themes were selected based on the prominence with which they recurred throughout the data.

Psychological symptoms of forced sterilisation

As seen in Table 3, participants reported several psychological symptoms, most notably those related to anxiety and depressive symptoms. Anxiety and stress-related symptoms were common in all seven cases.

Physical effects or negative health effects of forced and coerced sterilisation

Participants reported that they continue to experience severe physical health problems as a consequence of the sterilisations. These included heavy

Themes	Sub-themes
1. Psychological symptoms	a) Anxiety, stress and fear
	b) Isolation
	c) Overthinking/ ruminating
	d) Feelings of helplessness
	e) Feelings of hopelessness
	f) Feelings of worthlessness
	g) Feelings of sadness
	h) Feelings of anger
	i) Change in sleep pattern
	j) Change in weight
	k) Loss of interest
	l) Self-blame/ blame
	m) Shame
2. Physical effects or negative health effects	a) Health effects/ physical symptoms
	b) Poor healthcare service provision
3. Sterilisation and culture	a) Expectations of marriage and reproduction
	b) Decision-making
4. Negative social effects	a) Effects on interpersonal relationships and gender-based violence
	b) Discrimination and victimisation
	c) Effects on occupational functioning
5. Support and coping	a) Support received after sterilisation
	b) Meanings attached to forced and coerced sterilisation and coping

menstrual bleeding, severe abdominal pain, severe back pain, weakness and problems with the lower limbs. The symptoms started soon after the sterilisation operation and persist to this day. As one participant explains:

“When I was sterilised that was in 2007 December, but since that year 2007, until now, I am just having severe pain almost every month. It is back pain, heavily bleeding and that is where I started being concerned ... the bleeding is too much, it takes about 2 weeks you are not even able to walk, not at all. When you go to the hospital you do not get any help, they will just tell you that is just how you will be.” (Participant 1)

Participant 5 mentioned that the “heavy bleeding” was so persistent that she “would fill three buckets a day” and “used and still uses pampers”. All participants indicated that these health problems increase financial difficulties, for example they need to purchase a lot of diapers and sanitary pads for the heavy bleeding. They are constantly ill and participants’ day to day and occupational functioning are affected. Participants link these health problems to stress, helplessness, hopelessness and fear.

These effects require the women to constantly seek health services and, since all are of low socio-economic status, they rely solely on state hospitals. Participants reported that due to sterilisation, they faced and still face discrimination and victimisation when accessing healthcare centres.

Sterilisation and culture

Expectations of marriage and reproduction

All participants reflected on the important expectations that Namibian culture has regarding reproduction and marriage. Firstly, they cited that their culture ascribes having children as very important for women. The value, worth and respect of women is mainly attached to their ability to reproduce.

“What is important in our culture is having a baby, because even if the boyfriend says, I just want to stay with her, some families might say no we don’t want a woman who cannot conceive.” (Participant 2)

“In our culture there is no sterilisation. People are against it; they are not happy with it. For us we are 12 in our family, so I wanted to have many children as much as I can, now I cannot. In my culture people will go for many children they don’t know sterilisation.” (Participant 7)

Table 3. Psychological symptoms experienced by WLHIV due to forced and coerced sterilisation		
Psychological symptoms	Number of participants expressing symptoms	Quote examples
Anxiety, stress & fear	7	<p><i>“I don’t really think right, because sometimes I think, what if I became sick? What if I die? Maybe I will not be able to achieve most things. Mostly the only deep things I can think of is the sickness, that now that I am sick because of sterilisation, will I be able to walk, or maybe will I become unable to walk, such things.”</i> (Participant 1).</p> <p><i>“I don’t trust them anymore. That is why even the paper they gave my daughter at hospital, maybe they just want to look for way to sterilize her. I’m afraid of them.”</i> (Participant 7)</p>
Isolation	6	<p><i>“Physically you might be present together with people but mentally you are totally not there.”</i> (Participant 3)</p>
Overthinking/ Ruminating	5	<p><i>“It causes me to have headaches because I am always thinking too much about all those things ... this will not leave one’s mind; more especially when you are thinking that you will not have the number of children that you wanted anymore ... mind is always occupied by this problem.”</i> (Participant 3)</p>
Feelings of helplessness	7	<p><i>“If for example you ask them, to give you your file saying that I need my hospital file, maybe there is someone out there who might be able to help me, so I might need to take it there to see what kind of medicines I will be able to get, to help me feel much better. The file is not there”.</i> (Participant 1)</p>
Feelings of hopelessness	7	<p><i>“I thought it is over, I do not know what to do anymore.”</i> (Participant 5)</p>
Feelings of worthlessness	5	<p><i>“You will feel that you are no longer useful ... I was thinking that I am no longer a real woman.”</i> (Participant four). <i>“ ... to me it’s like I am not important ... ”</i> (Participant 5)</p>
Feelings of sadness	7	<p><i>“Yes, if it just comes to your mind you will start crying. I know I am a big person but if you just happen to think of your life before and your life now you will just start crying. Or if you see others being active and you will also want to do the same but you just can’t, because most of the times I feel so weak and without any strength and that is what makes me cry.”</i> (Participant 2)</p>
Feelings of anger	1	<p><i>“I do not know why they did this to me; they were supposed to let it in God hands, who gave them that permission? They caused problems in our lives, we are bleeding every time, and some of us are divorced, because man cannot stay with barren woman. They must know that whatever they did to us was very wrong; they were supposed to let us know. They cannot decide what is right for us. Who told them those women who are HIV positive deserve to be sterilised? I told them that I wanted help I do not want to be sterilised, but they did not listen to me, they forced me.”</i> (Participant 7)</p>
Change in sleep pattern	6	<p><i>“ ... before I used to sleep well because I did not have a lot of things to think about, but after I got sterilised, even though that day I am not in pain I am still thinking what to do while I am not sick, because I already know that after a few days I will start getting sick again. Even if I try to sleep, I won’t really sleep peacefully because I am just thinking of the pain.”</i> (Participant 1)</p>

(Continued)

Table 3. Continued		
Psychological symptoms	Number of participants expressing symptoms	Quote examples
Change in weight	5	<i>“Being sterilised, it brings changes in body weight, that day my weight was at 68Kg, now my weight is 30 Kg. It real changed me.”</i> (Participant 5)
Loss of interest	3	<i>“I remember during those years 2007 and 2008, I liked singing very much, singing songs with youths, but those two years I did not sing, I was just in the house, thinking that it is over.”</i> (Participant 5)
Self-blame	7	<i>“Yes, I blame myself because I ask myself why I came in this world to face this kind of things.”</i> (Participant 5)
Shame	3	<i>“... and I was kind of feeling ashamed because, I was thinking that I am no longer a real woman.”</i> (Participant 4)

All participants explained that, in their culture, marriage is highly valued, every woman wishes to get married, and the outcome of every marriage is children. Thus, when men marry, they immediately expect their wives to get pregnant and have children. According to Participants 1 and 7, they lost their marriages because of the forced sterilisation; their spouses did not understand and blamed them for being unable to have more children. Participant 7 stated that:

“I was still very young when this happened and I had hoped to have many more children. The stress was also because my husband blamed me and left me when he found out that I could no longer have children.”

Participant 6’s husband still expects and puts pressure on her to have children, even though he knows she was sterilised. According to participants, when a woman is unable to bear children for her husband, she faces emotional abuse, especially from her in-laws, and culturally, marriage is synonymous to having children and having many children is important. Therefore, we find that although all the research participants had biological children when they were sterilised, some report that they were still rejected and/or abandoned by their spouses, who expected more children. One participant even mentioned that her family regarded sterilisation as worse than being HIV positive. This highlights the importance of children. For Participants 2, 3 and 5, who have never been married and still hope to get married, marriage now seems impossible because they are unable to

have children whereas Participant 3 reported having lost three intimate partners after revealing that she was sterilised.

Decision-making

All participants indicated that in Namibian culture, women are not supposed to make major decisions (of which sterilisation would be one) without informing their spouses or partners and in some cases even families and elders. Participant 1, for example, reports that, as the sterilisation occurred without her husband’s knowledge, it resulted in the loss of her marriage. Both her mother and husband blamed her saying, *“if you are married you cannot be sterilised without letting your husband know”*. In this patriarchal system, forced sterilisation has led to conflicts in intimate and other interpersonal relationships as it seems to violate cultural principles and values around the gendered norms of decision-making. Forced sterilisation resulted in two participants losing their marriages, one participant not disclosing to her family, one participant being ostracised by her family and all seven being blamed for apparently making such a huge decision without consulting partners and families. Although this decision was something the women were forced and coerced into, they continue to suffer the consequences.

Negative social effects

Effects on interpersonal relationships

In addition to conflicts around confused roles in making the decision to be sterilised, conflicts

with intimate partners also arose due to inability of participants to have children and physical symptoms that affected the women's ability to have sex. These conflicts contributed to loss of the relationship within a marriage; one participant reports her husband saying, "I can even go and look for someone that can be able to give me children" (Participant 1). Unmarried participants reported conflict-filled intimate relationships characterised by constant rejection from potential spouses upon sterilisation disclosure. Participant 3 explained that

"This feeling (stress) does not end, it is always in my mind. There are things that make sterilisation even more difficult to live with, such as revealing it to someone who wants to marry you. In my life so far, I have been left by three men who wanted to marry me, but just because I can't have children they left."

Forced and coerced sterilisation also negatively affected the participants' interpersonal relationships including relationships with in-laws and family members. Participant 5's sterilisation led to interpersonal difficulties with her family that resulted in her being estranged and ostracised, so that she had no support in dealing with the physical and emotional effects of the sterilisation.

Abuse and violence in intimate relationships because of forced sterilisation were also mentioned. While none of the participants reported physical violence, they perceived it as something that some women who were sterilised experience. The participants reported that they have faced verbal and emotional abuse from their intimate partners, families and communities, which subsequently led to emotional distress or stress.

Discrimination and victimisation

Discrimination is an action or practice that excludes, disadvantages or differentiates between individuals or groups of individuals on the basis of ascribed or perceived characteristics.²² Victimisation happens when individuals are treated badly because they have complained about discrimination or when they help someone who has been discriminated against.²³ All participants reported instances of discrimination or victimisation. They indicated that they had received poor healthcare services: for example, if the healthcare providers discovered that they were sterilised, they were not examined and treated properly. As Participant 2 expressed,

"If you are not feeling well you just tell them that you have a backache then they will give you the back-pain medicines, you don't have to mention about the issue of being sterilised because you won't be helped well ... If you mention anything to the nurse that you are sterilised they will inform others that, that person should not be treated because is one of those that wants to sue the government."

Participant 5 mentioned that, "once they look at my health passport they tell me that nothing can be done, and I should just go home and accept my situation". Most participants reported that because of the Stop Forced Sterilisation campaign in which the government was sued and the Ministry of Health and Social Services implicated, healthcare professionals mistreat, victimise and insult the women who were sterilised when they seek assistance. As Participant 2 states:

"When you go there in the consulting rooms, the nurses will say those are the people that have been marching against us in the streets saying that they want their wombs back, therefore you won't be treated as you were supposed to anymore."

Effects on occupational functioning

The negative health and psychological effects of forced and coerced sterilisation have affected occupational functioning for all participants, including those who are not employed and do casual jobs such as selling in the market and cleaning. For the three employed participants, health effects have meant that they spend more time in hospital which negatively affects their income. For the four unemployed participants, negative health effects also affected occupational functioning. For example, Participant 1 indicated that due to her health problems, which include heavy bleeding and severe back and leg pain, she is sometimes unable to do the casual jobs that give her income to take care of her children, and it is stressful when she is unable to work.

Support and coping with sterilisation

When stressful and traumatic events occur, individuals' ability to cope effectively is partly determined by the nature and amount of support they receive in their social circles. All participants indicated that they received most of their support from NWHN and the Legal Assistance Centre (LAC) when they found out they were sterilised. The support

indicated by participants included litigation support, emotional support through counselling, material support in the form of sanitary pads or taxi money and practical support by accompanying some of the women to the hospital. According to participants, the counselling obtained from NWHN assisted them by lessening the impact of the emotional problems (such as stress, sadness, fear and anger and feelings of helplessness) during difficult times. Support groups are also said to have played a major role in supporting the women within their communities as they served as a space in which women who were sterilised strengthened and encouraged each other. For example, Participant 5 reported being ostracised by her family and that the support group members were her only support system. Additionally, all participants reflected that faith in God played a critical role in helping them cope. Consistent in all the participants' accounts was the fact that little or no support, acceptance or understanding was obtained from spouses, intimate partners, family members and community members.

Discussion

The recognition of forced and coerced sterilisation as one of the worst forms of human rights violations,²⁴ which is also traumatic,⁴ has resulted in increased recognition of the need for augmented research and interventions, specifically targeting the psychological and social well-being of those affected.¹⁷ We found that the WLHIV in our sample experienced negative psychological and socio-cultural effects as a result of forced and coerced sterilisation and that they continue to need psychological and other support.

Forced sterilisation and mental health

The WLHIV in this study reported psychological symptoms and that these symptoms commenced after sterilisation. Anxiety and stress-related symptoms were seen in all seven cases. Forced and coerced sterilisation was judged as threatening, negative or harmful as a stimulus, and sparked the stress process for participants. The event was perceived and experienced as harmful and threatening to their health, relationships, dignity and personal goals. Further, reactions included feelings of sadness, worry, distress, anger, frustration and fear; symptoms for anxiety, stress and depression. Research in South Africa on the forced sterilisation of WLHIV found ongoing and significant emotional

distress, a few cases of clinical depression, and feelings of trauma, isolation, helplessness and stress.¹⁰ Likewise, Leppert, Legro et al found symptoms of depression, anxiety, anger, and confusion, which persisted for two years.²⁵ Apart from anxiety and stress-related symptoms, participants also reported feelings of helplessness, worthlessness, hopelessness, self-blame, anger, shame, fear, sleep disturbance, loss of weight, loss of interest and isolation. These symptoms were also reported in other documented cases of forced and coerced sterilisation of Roma women.¹² Our study adds to these findings by showing that psychological symptoms may persist even longer, as the average timeframe since sterilisation was eleven years. The persistence of symptoms may be linked to the ongoing consequences reported including the adverse negative health effects, discrimination, mistreatment and victimisation from healthcare professionals, repeated rejection by intimate partners/potential spouses because of the sterilisation, loss of family and dignity in society. While the current study did not explore diagnoses of specific psychological disorders such as depression and anxiety that may be related to forced and coerced sterilisation, it nevertheless reveals enduring negative psychological effects as was indicated in other studies on sterilisation and mental health.^{7,12,25,26}

According to Robertson, "What doesn't kill you makes you mentally stronger ... What doesn't kill you gives you one crucial lesson ... so long as adversity is not too severe, adversity teaches us that bad things will come to an end eventually"^{27, p.189–190} While our study tapped both the negative and positive consequences of forced sterilisation, with questions such as "have there been any positive or good changes in your life ever since you found out that you were sterilised?" none of the women reported any positive meanings or post-traumatic growth from the experience. This study highlighted that the negative medical effects and socio-cultural effects were still present over 10 years after the sterilisation. As Robertson indicated, resilience is possible only if the adversity is not too severe and when there is an expectation that bad things will come to an end.²⁷ While the women may have experienced some hope from the Stop Forced Sterilisation campaign, in which they were assisted by civil society to seek justice for the violations, the campaign itself lasted for over a decade before a final decision was made. Additionally, the negative health effects reported by the participants are severe, yet there are

significant barriers to access to health. While the literature reports instances of mental resilience after adversity,²⁷ for cases in which the effects are too severe and if occurring over a prolonged period, post-traumatic recovery may be limited.

Socio-cultural effects of forced sterilisation

When pertinent issues challenging the cultural or contextual status quo arise, resistance ensues because cultural equilibrium is threatened. The system reacts in a way that tries to revert the situation or to protect engrained beliefs. In a bid to do so, individuals or ideas that are found at the opposing side of cultural values and principles may be rejected or shunned. Accounts given by participants revealed that Namibian cultural principles and values place great importance on child-bearing, thus sterilisation is disdained. Literature also corroborates this; for example, Gockel-Frank found that, regarding reproductive decisions in Namibia, 50% of women stated that the most important task in a woman's life was to have children and to take care of them.²⁸ For women, their worth and dignity is weighed against their ability to have many children.⁸

The socio-cultural effects reported in this study include broken marriages, limited marriage prospects, fear of losing marriages, discrimination, victimisation and gender-based violence, all ensuing from the inability to bear children. In countries with culturally deep-seated patriarchal systems, female sterilisations go against the decision-making structural norms and often lead to gender-based violence.^{8,28,29} Participants intimated that gender roles in decision making are critical. In Namibia, Gockel-Frank also reported that even though women knew their rights, it was still the man as head of the household who decided on important things.²⁸ The communalistic and patriarchal aspect of most African societies, including Namibia, is such that major decisions are not considered by the individual alone but rather through consultations with spouses, extended family and even in-laws.

Issues of culture, gender inequality and HIV have previously been noted in Namibia, with gender inequality recognised as a crucial element to understanding the HIV epidemic, and more especially issues affecting WLHIV.³⁰ It has been noted that women's relative and unequal position in society not only increases their vulnerability to HIV, but also limits their power to make decisions regarding their sexual and reproductive health.³⁰

We show that these same socio-cultural issues extend to women who were forcibly sterilised. While Namibia is making good progress in developing policies targeting gender inequality and the rights of People Living with HIV, significant barriers in implementation remain.³⁰

Recommendations

The recommendations that follow are informed by the findings of the current study as well recommendations directly shared by research participants. The input of the target group is important as they have a role in determining their needs and priorities.³¹

All research participants emphasised the need for psychological, medical, social, legal and financial forms of intervention. Psychological interventions may include professional psychological assessment and treatment for possible mental health problems. Increased and ongoing social support, through group counselling and support groups, will assist in dealing with isolation, discrimination and victimisation. The important contribution of civil society organisations in assisting women with the litigation should be recognised as a key element for the prevention of future human rights abuses. Civil society organisations should continue with their support for the women, with a focus on how women can be assisted with information on mental health and access to free state mental health services and other professional mental health institutions where possible. We nevertheless recognise there are challenges in public service provision in Namibia, including the limited number of practitioners available to provide mental health services, and many trained from Western perspectives that may not readily align with beliefs about mental illness contextualised in Namibian culture.³²

Additionally, interventions targeting the physical well-being of the women are essential. The negative health effects of forced sterilisation were a prominent theme in the data and all participants expressed a need for medical examinations and treatment. Civil society organisations may intervene by facilitating the provision of comprehensive medical care for the women.

Furthermore, at a broader systemic level, financial compensation for all survivors of forced and coerced sterilisation in Namibia is crucial, whether the cases are proscribed or not. Civil society organisations may continue with advocacy efforts for litigation in this regard. Additionally, there is a need

for continued awareness-raising initiatives in the country to ensure that vulnerable populations, especially WLHIV, are cognisant of their sexual and reproductive health rights, and that forced and coerced sterilisation is eliminated in the country.

Limitations

This study cannot be generalised to women who were sterilised involuntarily in other countries or to other vulnerable populations that have experienced involuntary sterilisation because of different cultural and socio-economic contexts. Nonetheless, the study can be used as a reference point to give guidance or it can be replicated in other areas if need be.

Due to the qualitative design of this study and its objectives, these findings cannot prove the causal relationship of forced and coerced sterilisation and possible negative psychosocial effects because of possible extraneous variables. However, the study did not set out to establish causality but rather to describe women's experiences with forced and coerced sterilisation and some consequences of those experiences, in order to inform interventions.

Conclusion

The forced and coerced sterilisation of WLHIV results in long-lasting negative psychological and socio-cultural effects. Given that psychological symptoms of stress, anxiety, sadness, isolation, shame, fear, self-blame, anger, feelings of helplessness, feelings of worthlessness, feelings of hopelessness, loss of interest, sleep disturbance and weight changes may be present due to forced sterilisation, findings pointed to the importance of

professional psychological interventions to facilitate healthy coping strategies. Professional psychological interventions are equally imperative to assist with the negative socio-cultural effects of loss of marriages, loss of family, loss of respect, loss of health, loss of dignity, loss of self-worth, verbal and emotional abuse, discrimination, victimisation, and gender-based violence. In light of the negative health, psychological and socio-cultural effects of forced sterilisation, this research recommends as interventions: professional psychological counselling, quality or professional medical attention to deal with negative health effects, compensation by the Government of Namibia for ALL WLHIV who were forced or coerced into sterilisation, continued support from NGOs, and awareness-raising initiatives to stop forced sterilisation. The findings show that when human rights violations occur, there are immense and long-lasting psychological effects, hence psychological interventions to expedite positive coping should be prioritised.

Acknowledgements

The authors wish to thank the study participants, research assistants and Namibia Women's Health Network (NWHN) who made this research possible, in partnership with the University of Namibia's Faculty of Humanities and Social Sciences.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Résumé

La stérilisation contrainte et forcée des femmes vivant avec le VIH est un phénomène signalé dans plusieurs pays. En Namibie, les poursuites judiciaires entreprises pour des cas de stérilisation forcée ont été couronnées de succès, pourtant le

Resumen

La esterilización forzada y coaccionada de mujeres que viven con VIH (MVVIH) es un fenómeno reportado en varios países. En Namibia, los esfuerzos de litigio por casos de esterilización forzada y coaccionada han sido exitosos; sin embargo, aún no se ha

bien-être psychologique et socio-culturel des personnes touchées n'a pas fait l'objet d'investigations et de mesures suffisantes. Pour déterminer les conséquences psychologiques et socio-culturelles de la stérilisation involontaire des femmes vivant avec le VIH en Namibie, des données qualitatives sur sept de ces femmes ont été recueillies au cours d'entretiens en face à face. Notre analyse a montré, premièrement, qu'il y a des effets psychologiques négatifs qui se manifestent sous la forme de symptômes psychologiques associés avec l'anxiété et la dépression. Deuxièmement, on observe des répercussions socio-culturelles, notamment la discrimination, la victimisation et les violences sexistes. Les valeurs culturelles patriarcales concernant la procréation, le mariage et la prise de décision contribuent aux conséquences psychologiques et socio-culturelles négatives. Enfin, les effets psychologiques et socio-culturels négatifs de la stérilisation involontaire sont durables. Les participantes ont toujours du mal à faire face, même une décennie après la stérilisation. Compte tenu des conséquences psychologiques et socio-culturelles négatives à long terme, les interventions psychologiques pour aider les femmes à s'en sortir plus vite et favoriser leur bien-être doivent être prioritaires.

investigado y abordado el bienestar psicológico y sociocultural de las personas afectadas. Para determinar los efectos psicológicos y socioculturales de la esterilización involuntaria en MVVIH en Namibia, se recolectaron datos cualitativos de siete MVVIH por medio de entrevistas en persona. Nuestro análisis mostró que, en primer lugar, hay efectos psicológicos negativos que se manifiestan en síntomas psicológicos asociados con ansiedad y depresión. En segundo lugar, hay efectos socioculturales negativos tales como discriminación, victimización y violencia de género. Los valores culturales patriarcales con relación a la reproducción, el matrimonio y la toma de decisiones contribuyen a efectos psicológicos y socioculturales negativos. Por último, los efectos psicológicos y socioculturales negativos de la esterilización involuntaria son duraderos. Para las participantes, continúa siendo difícil afrontar este problema, incluso más de una década después de la esterilización. En vista a los considerables efectos psicológicos y socioculturales negativos duraderos, se debe dar prioridad a intervenciones psicológicas para acelerar el afrontamiento positivo y el bienestar.