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POLICY FORUM

Forced Sterilizations of HIV-Positive Women: A Global Ethics and Policy Failure Stephanie Bi and Tobin Klusty

In an attempt to combat mother-to-child HIV transmission, there has been a preponderance of forced sterilizations of HIV-positive women in countries around the world, especially those with high HIV rates [1, 2]. "Forced sterilization" is a sterilization procedure, such as tubal ligation, performed without informed consent from the patient [3]. Forced sterilization violates the human right to autonomy and the principle of informed consent. Although the practice conflicts with their ethical duties, many physicians still forcibly sterilize HIV-positive women in an attempt to limit mother-to-child transmission of the virus [4-7]. This practice further marginalizes these women, who can already face discrimination due to the <u>stigmas</u> associated with womanhood and HIV [8]. South Africa, Namibia, and Chile all provide examples of the widespread use of and legal advocacy against this marginalizing practice [1, 2, 4, 9-17]. This is clearly a pressing ethical problem that reflects global discrimination against women with HIV. All nations must restrict forced sterilization by implementing and enforcing appropriate policy.

Forced Sterilization in South Africa, Namibia, and Chile

The country that has perhaps received the most attention for forced sterilization from the media and researchers is South Africa, due to the irony of its highly progressive laws concerning women's sexual and reproductive rights [9]. South Africa was the first country to grant the right to "health care, including reproductive health services" in its national constitution [10]. In addition, a 1998 South African law prohibited sterilization without informed consent [11]. Despite the promise of these progressive laws, enforcement is sorely lacking. For example, a South African study for the Her Rights Initiative interviewed 22 women who were sterilized and given no legal justice [4]. Eighteen of these women were coerced into signing consent waivers, which protected the medical staff from liability [4].

A neighboring country, Namibia, is facing the same problem [12], although, to some degree, Namibia has addressed the issue in its courts. In 2014, the Namibian Supreme Court upheld the High Court's ruling that medical personnel at public hospitals had sterilized three HIV-positive women without their consent [13]. The Court ruled that "individual autonomy and self-determination are the overriding principles towards which our jurisprudence should move in this area of the law" [13] and declared that "[t]hese

principles require that in deciding whether or not to undergo an elective procedure, the patient must have the final word" [14].

In Chile, forced sterilization of HIV-positive women is widespread, and legal advocacy has been less effective. A 2004 study showed that 12.9 percent of sterilized HIV-positive women had been sterilized without consent and 29 percent had consented under coercion [15]. In *F. S. v. Chile*, the advocacy groups Vivo Positivo and Center for Reproductive Rights sued on behalf of a 27-year-old HIV-positive woman who was sterilized during a cesarean section without her knowledge [15]. Following several years of unsuccessful litigation, the advocacy groups filed a complaint with the Inter-American Commission on Human Rights (IACHR) in 2009 [16]. Four years later, the commission announced it would hear the case—the first it has admitted related to HIV-positive women's sexual and reproductive rights [17]—which is still pending.

Forced Sterilization as a Violation of Medical Duty

Physicians performing forced sterilizations are violating not only internationallyrecognized human rights, but also their duties as medical professionals. Autonomy, as recognized by Amnesty International, is the right to make "choices free from outside pressure or violence, whether mental or physical" [18]. According to the American Medical Association's (AMA) *Code of Ethics*, a "patient should make his or her own determination about treatment" [19]. Such determination includes a woman's decision regarding what happens to her body [18]. Her ability to do so is diminished, and thus her right to autonomy is lost, if she is coerced into accepting a medical procedure.

The World Medical Association's (WMA) International Code of Medical Ethics lists several duties that physicians are expected to uphold regardless of the geographic locations of their practices: to "respect a competent patient's right to accept or refuse treatment," "not allow [clinical] judgment to be influenced by...unfair discrimination," "respect the rights and preferences of patients," "act in the patient's best interest when providing medical care" and "owe his/her patients complete loyalty and all the scientific resources available to him/her" [20].

Forcing sterilization upon women diagnosed with HIV conflicts with all of these duties. Firstly, it is a violation of their right to autonomy and the doctrine of informed consent. Many HIV-positive women in South Africa, Namibia, and Chile are sterilized without their knowledge or are compelled to accept the procedure to receive food or necessary medical treatment [1, 2, 4]. Lindsey McLaughlin reports that women in South Africa were threatened with halting of life-sustaining antiretroviral medication if they did not sign a consent form for sterilization [21]. HIV-positive women often succumb to sterilization due to this kind of duress and coercion, as well as to fear of disappointing or inconveniencing health care professionals or lack of knowledge of their right to autonomy [4]. One South African survey participant explained, "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" [22].

Furthermore, this procedure violates the medical ethics principle of beneficence, that treatments must benefit the patient. The main medical rationale for these sterilizations, that HIV-positive-women should be sterilized to reduce mother-to-child HIV transmission [5], is flawed. Sterilization is not necessary for this purpose; consistent antiretroviral treatment has been shown to reduce risk of mother-to-child HIV transmission to less than 2 percent in nonbreastfeeding populations [7]. These medications, developed in the 1990s, are available inexpensively even in countries without fully developed health care systems [23]. And if the justification for sterilization is not medical benefit but the public good, as can be the case [7], the duty of loyalty to the patient is violated.

Forced Sterilization and Intersectional Discrimination

Intersectional discrimination is defined as "the phenomenon of multiple and compounded forms of discrimination" [24]. According to Ronli Sifris, separate marginalized qualities may overlap and eventually compound the degree of discrimination a person faces [8].

In South Africa, for example, "being part of a group of people who are [already] structurally and systematically discriminated against increases one's chances of contracting HIV" [25]. Consequently, the prevalence of HIV is disproportionately high among already marginalized groups, such as women, members of sexual and racial minorities, those in poverty, and drug users, due to the lack of access to essential health care and social resources among these groups [25]. Specifically, the subordinate social status of South African women hinders their ability to "negotiate safer sex" or participate in the workforce, factors that may make a woman feel compelled to remain in a relationship with an HIV-positive partner and that heighten vulnerability to HIV [25]. After an HIV diagnosis, women are further stigmatized by the cultural assumption that they have engaged in deviant behavior [26]. As a result, South African women with HIV are viewed as irresponsible and promiscuous, leading to social isolation [27] and, in some cases, sterilization. In South African medical culture, an imbalanced physicianpatient power dynamic disproportionately affects women [6]. Exemplifying this power imbalance, physicians judge women with HIV to be irresponsible and thus "unworthy" of having children, and sterilize them to prevent public harm [28].

Sterilization leads to even more cultural stigma due to the great emphasis in South African culture on marriage and motherhood for women [29]. Because a husband must pay a "lobola" (bride price), married women are expected to be fertile and experience pressure from their husbands to have children for financial reasons [30]. After sterilization, women sometimes become social outcasts who are banned from family activities, weddings, and funerals [29]. To evade this extreme stigma, many sterilized women avoid telling their families and partners about their sterilization [31]. In this sense, HIV-positive status can be likened to having a history of mental illness or sexual assault: it constitutes a "concealable stigmatized identity," the strain of which can manifest as depression, anxiety, and/or self-reported illness symptoms [31]. Sterilization thus harms already marginalized HIV-positive women.

The use of forced sterilization is a widespread violation of internationally recognized human rights. As Lindsay McLaughlin has recommended, laws must be created or amended to prohibit sterilization without informed consent, and the punishments for violating these laws should be made more stringent [32]. She recommends that, in addition to fines and incarceration, the medical license of health care workers be suspended or revoked if they perform sterilization without informed consent [32]. The laws should be strictly enforced to provide a sufficient deterrent through such means as reducing barriers to women's accessing adequate legal representation, using a special court to address these cases in order to reduce the formality and intimidation of a traditional courtroom, requiring all-female adjudicators, and allowing anonymous testimony [33]. In addition, medical staff should be educated on the issue and trained to provide adequate information for the patient to give informed consent [32]. Lastly, she argues, women who have been forcefully sterilized should be granted reparations to mitigate social and psychological damage, perhaps in the form of not only monetary compensation, but also free trauma counseling and mental health care [34].

Conclusion

Forced sterilization of HIV-positive women is a global problem of great ethical importance. Sterilization without informed consent is a violation of women's right to autonomy, and sterilization to prevent transmission to children is medically unnecessary. To help achieve reproductive justice, there needs to be a global call to end forced sterilizations through well-implemented and enforced policy.

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