Abstract

Women living with HIV are stigmatized and discriminated against. They often wish to have children, but they are subjected to the practice of forced (involuntary) sterilization in at least 27 countries under the guise of protecting maternal health and preventing the birth of infected infants. Some women are not asked to give consent, or a third party consents on their behalf. Others are given insufficient information or fed misinformation. The circumstances under which such women have been asked to sign consent forms for sterilization include fear, coercion, intimidation and undue influence. Courts have been clear that such practice is a breach of human rights. But, so far, it has not been formally declared in courts that such practice constitutes discrimination. More needs to be done in terms of education, sanctions against those who carry out this practice and help for victims.

Keywords

Coercion, consent, HIV, non-consensual, pregnancy, sterilization, women

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Introduction

Preventing and limiting the spread of HIV is a high-priority global public health initiative. Transmission of HIV from a pregnant woman to her fetus/infant is a disastrous event as it harms a new generation. The treatment, and hence the epidemiology, of HIV have changed beyond all recognition in the space of 35 years. Nearly 30 drugs have been developed belonging to six different classes of antiretroviral therapy (ART). This has led to more appropriate treatment of pregnant women living with HIV (WLWH).

HIV physicians, obstetricians and pediatricians all undertake a colossal amount of work caring for their patients living with HIV. The pregnant woman needs life-long guidance because of her HIV status and the fetus *in utero* must be protected. Infants born to WLWH require ART for several weeks and then follow-up for some months to determine whether or not they are infected.

There is no clear-cut medical indication that a pregnant WLWH should undergo an induced abortion for her own physical safety. The concern is mainly about mother-to-child (vertical) transmission (MTCT). At the time of delivery, or soon afterwards, the question is what other interventions can prevent the recent, and any potential subsequent, offspring from becoming infected. In addition to HIV management, contraceptive measures can be employed, or sterilization considered.

However, sterilization is an intervention whose effect must be considered permanent. It is rarely necessary on therapeutic grounds – such grounds include a life-threatening chronic medical condition which would deteriorate in pregnancy or a history of multiple cesarean sections and the subsequent risk of a ruptured uterus if a woman were to have another pregnancy.

This article examines non-consensual (involuntary) sterilization of WLWH. What is meant by this is that there is a lack of valid consent for the operation. One or more of the three fundamental principles of the doctrine of consent is not fulfilled:

- Has mental capacity
- Has been given sufficient information, with an opportunity for discussion
- Is willing and not being unduly influenced, pressured or coerced (voluntariness)

The authors conducted a literature search on all material freely available on the subject in English, French and Dutch. These sources included journals in various disciplines, books, theses, government publications, publications by non-governmental organisations, articles in the lay press and information from reliable internet sources.

A brief history of HIV

The clinical picture of AIDS was first described in gay men in 1982[1]. The first reports of AIDS in children came in 1983. In 1984 a blood test was created to screen for HIV; it became available commercially the following year. Later in 1985, the first recommendations for the prevention of MTCT were published in the USA[2]. In 1987, zidovudine was approved as

treatment for HIV infection; it was not until 1990 that it was approved for use in children. In 1999, the World Health Organization (WHO) announced that AIDS was the commonest cause of death in Africa; worldwide about 33 million people were living with HIV and 14 million people had died from AIDS since the onset of the epidemic. In 2000, WHO recommended the use of ART to prevent MTCT. In 2002, South Africa's Constitutional Court ordered the government to make nevirapine available to all pregnant WLWH and their babies. As of 2015, an estimated 13.4 million children worldwide had lost one or both parents to AIDS[1]. Many orphans have been brought up by their grandparents, by caretaker families or placed in residential care[3].

In the early years, undertaking a pregnancy for a WLWH was an unknown quantity. Before ART became mainstream and widely available, pregnancy was a high-risk state. Until the late 1990s, medical and public health concerns fed into policies that discouraged WLWH from even contemplating having children[4]. Early concerns that depressed immunity in pregnancy could have an adverse effect on the course of HIV infection have not been borne out. Yet, in WLWH, the incidence of miscarriage is increased and, in an established pregnancy, infectious complications are more likely.

The recommendations for prevention of MTCT initially consisted of ways to minimize the physical transmission of HIV from mother to child: safer practices during labor, cesarean section (CS) when safe/feasible, minimization of the risk of postpartum hemorrhage and avoidance of breastfeeding if the woman's social circumstances were favorable.

Current situation in relation to HIV

Sub-Saharan Africa is the epicentre of the HIV epidemic. South Africa is the country with the largest population of HIV-positive people in the world: there were 7.1 million people living with HIV in South Africa in 2016, an adult prevalence of 19%[1]. The prevalence of HIV infection in women in South Africa is nearly twice as high as that in men. The explanation for this is thought to be poverty, low status and gender-based violence. More than half of all South African adults and children living with HIV are taking ART. ART has transformed the prospects of people living with HIV throughout the world from a disease with a high morbidity and mortality into a chronic condition which is monitored periodically with a near normal life expectancy[5].

Globally, approximately half of all people living with HIV are women of reproductive age[6]. MTCT from an HIV-positive woman to her fetus/baby may occur during pregnancy, labor, delivery or breastfeeding. African countries are the most at risk of MTCT. In the absence of any intervention, transmission rates range from 15 to 45%[7]. Since September 2015, WHO advises that all pregnant and breastfeeding WLWH should receive lifelong ART irrespective of clinical stage of disease or CD4 count (Option B+)[8]. Appropriate pharmacological treatment of women of child-bearing age living with HIV prevents MTCT in nearly all cases. In 2011, a Global Plan was launched to reduce the number of new cases of MTCT by 90% by 2015[1]. Many countries have already reduced MTCT to such low levels that it no longer constitutes a public health problem[9]. Elective CS should no longer generally be promoted for WLWH taking ART[10].

Reproductive intentions of WLWH

As life expectancy has improved, more WLWH have expressed a desire to have children[11-13]. Some of these women even feel this wish to have a family is stronger than before their diagnosis[4]. In addition to the personal motivation to have children, there is societal pressure and pressure from male partners. However, community attitudes to such child-bearing are often negative: a substantial proportion of the population in certain African and Asian countries think that those living with HIV should not have children[14]. These attitudes appear to spill over in exchanges with healthcare professionals (HCPs) who can be disapproving and unsupportive about reproductive choices[4 15].

Extent of non-consensual sterilization of WLWH

Non-consensual sterilization of WLWH has been reported from low-resource countries with high HIV prevalence in four continents. The authors found reports of this practice in 11 African countries, seven Asian, one Australasian and eight Latin American countries. Almost certainly, the practice is hidden away elsewhere.

The examples of non-consensual sterilization of WLWH on record are not merely isolated reports, but part of an ongoing systemic problem. There is evidence of this practice taking place from reports over the time-period 2009 to 2015. In a nationwide survey of 10,473 South African people living with HIV, 498/6,719 (7%) of WLWH reported that they had been forcibly sterilized because of their infection[16]. In Uganda, a survey of 1,107 people living with HIV revealed that, of the 89 women who had been sterilized, 12 (13%) stated that they

had been coerced[17]. In Kenya, forced sterilization has been documented in more than 40 testimonies from WLWH[18].

A study carried out in four Latin American countries (El Salvador, Honduras, Mexico and Nicaragua) showed that one-quarter of a sample of 285 WLWH had experienced pressure to be sterilized[19]. In a study conducted in six Asian countries (Bangladesh, Cambodia, India, Indonesia, Nepal and Vietnam), 86/228 (38%) of WLWH felt coerced into sterilization[20]. Pregnant WLWH with diagnosed HIV positivity were almost six times more likely to experience coercion than their counterparts not known to harbor the virus. Twelve out of 16 Chilean WLWH who had undergone sterilization had done so under pressure or by force[21]. In a Namibian survey, 40 out of 230 (17%) WLWH had been coerced into sterilization[22].

Maura Elaripe had a forced sterilization in Papua New Guinea in 1999 at the age of 23 years[23]. She reported this experience at the 17th International AIDS Conference in Mexico City in 2008. She had trained as a nurse and subsequently became an HIV activist. At the 20th International AIDS Conference in Melbourne in 2014, she reported that forced sterilization was 'option number 1' for pregnant WLWH in Papua New Guinea.

Lack of valid consent to sterilization

Reports demonstrate that all three essential constituents of consent have been disregarded; in the examples below, one or more of these were not met. Performing a sterilization without valid consent is unethical, infringes professional codes of conduct and breaches

human rights law[24]. A Chilean study showed that 42% of a sample of WLWH who had been sterilized had not given valid consent[25].

No consent obtained

It is reported that some women were not asked to sign consent forms at all[26]. The high-profile case of Francisca was taken to the Inter-American Commission on Human Rights in 2009 by the Center for Reproductive Rights and Vivo Positivo[27]; her case, *FS v Chile*, is still pending at the time of writing. Francisca was 20 years old when she was sterilized with a complete absence of consent (oral or written – Chilean law requires written) during a CS in Curicó in 2002. In 2007, she filed a complaint against the surgeon, but despite a police investigation confirming that she had not given consent, the Public Prosecutor dismissed the case. She then exhausted all her domestic remedies in the Chilean court system; an appeal to a higher court was unsuccessful[25].

A number of WLWH have had 'consent' given on their behalf – by husbands, partners or family members[18, 20].

Lack of capacity

Lack of mental capacity can be permanent as in the case of intellectual disability[28] or temporary as in the case of women who are anesthetized. In a case in Mexico, a thumbprint was taken on the consent form while a WLWH was unconscious during a CS[19].

Insufficient information provided

Provision of insufficient information may be a deliberate or negligent act on the part of HCPs. All 22 WLWH in a South African qualitative study believed that the information they were given before their sterilization operation was inadequate [26]. A common expression used for sterilization in South Africa is 'getting your womb closed'. It may be vernacular but, when used by HCPs, it is a euphemism that is imprecise and misleading. Latin American women have also reported that they were inadequately informed[19]. Some women were not told the purpose of the operation[22] or they signed without being given any explanation[26]. A few WLWH did not find out that they had been sterilized until sometime later[26].

Misinformation

Misinformation ranges from more subtle forms of influence to 'scare tactics' which could be seen as fraudulent. Latin American women have been misinformed about the hazards of MTCT, the risks being deliberately exaggerated[19]. In South Africa and the Dominican Republic, HCPs misinformed women that they were likely to transmit HIV to their fetus in the future and so should not have any more children[29]. In Namibia, WLWH have been told that future children will die during birth, due to HIV[22]. In Kenya, HCPs informed WLWH that it was 'illegal' for HIV-positive women to have children[18]. Many WLWH were told that the procedure could be easily reversed[26].

Coercion and intimidation

When HCPs act in a paternalistic fashion, there is a power imbalance between provider and patient, disproportionately affecting illiterate women[30]. Women are susceptible to exploitation and can be forced into submission. HCPs have put pressure on WLWH with only one child to be sterilized, and made this a condition for receiving medical services[19]. In India,

some women were given free choice to make the decision but were then incentivized with free formula milk, a major consideration for those living in poverty[20].

Some doctors in South Africa have refused to prescribe ART to WLWH unless they agree to be sterilized[31]. Also in South Africa, postpartum WLWH have been detained in hospital until they agreed to be sterilized, a violation of their right to liberty[26].

In 1997, Sethembiso Promise Mthembu, a WLWH, was sterilized at the age of 22 years in South Africa, during an admission for gynecological treatment. She was coerced into the operation: the hospital refused to treat her without first performing a sterilization. She has stated "the pain of coerced sterilisation never ends ... at every point in your life you interact with it. If you start a new relationship, if a new child is born into the family, or if you start a new job and people ask you about your life"[32]. She went on to establish a charitable women's group called Her Rights Initiative in 2009. Subsequently she undertook a Master's degree at the University of KwaZulu-Natal, submitting a dissertation on an HIV-related subject. Ms Mthembu is a co-author of two of the articles cited as references in this paper. She can be seen making a presentation on forced sterilization on YouTube (https://www.youtube.com/watch?v=SW0cw3rSpYI).

Preying on vulnerability

The vulnerability of being in labor and going through childbirth make this time inappropriate for decisions about permanent fertility control. WLWH have been sterilized in association with CS and normal delivery, sometimes as a condition for receiving treatment[19 22]. Some women have been asked to sign consent forms while in labor[18, 22, 26].

Consequences of non-consensual sterilization

Psychological sequelae

Most of those who have a forced sterilization develop emotional distress. Feelings of traumatization, isolation, helplessness, stress and humiliation are long-lasting. One woman said "I feel like half a woman all the time"[26]. There is impact too on relationships, a negative effect on women's relationship with their partner being common. Male partners may react to a sterilization by withholding money, domestic violence or abandonment. Sterilization may be considered a ground for divorce too.

Stigma

Some of the vulnerability of marginalized groups targeted for sterilization derives from stigma[33]. WLWH are vulnerable to social exclusion and discrimination in healthcare settings[34]. Once sterilized, women are deprived of the possibility of motherhood, which is in itself stigmatizing[35]. In Africa, the stigma associated with the inability to have children is greater than that associated with HIV[29, 30].

HIV infection in Sub-Saharan Africa is highly stigmatized and associated with deviance and disease, including notions of indiscriminate promiscuity and irresponsible behavior[36]. Some HCPs have verbally abused, humiliated and embarrassed their female HIV-positive patients[26]. WLWH have been bullied, humiliated, neglected and treated with a lack of compassion. Treatment by HCPs can be aggressive or violent, perhaps as 'punishment' for

women's behavior. This unprofessional conduct can continue after sterilization; one South African WLWH described being called 'inyumba', which means a worthless woman who cannot bear children[26].

Following sterilization, women often demonstrate the characteristic internalization of stigma[36, 37]. Most tell no one about the procedure, often not even their partners. There are reports that, when disclosure is made, it is considered a more difficult undertaking than disclosure of their HIV status.

Discrimination

It is not just HIV status that is discriminated against. The discrimination is highly gendered; the authors did not find any reports of men living with HIV being targeted for sterilization. WLWH have the compounded effects of discrimination on the basis of both HIV status and gender[38]. This is part of the long history of the subordination of women, the medical profession being no exception in having played its part. Doctor-patient power disparity is greater when women are being treated[39, 40].

Medical malpractice

In 2000, the International Federation of Gynecology and Obstetrics (FIGO) stated that "no incentives should be given or coercion applied to promote or discourage any particular decision regarding sterilization". In Goa in March 2011, FIGO agreed on new ethical guidance for the performance of female sterilization emphasizing that patients must be informed that tubal occlusion is irreversible, that it cannot be justified as a medical

emergency and that consent must never be obtained as a condition for provision of other medical care[41].

Physicians who take part in the malpractice of non-consensual sterilization are not honoring their professional and ethical duties[42, 43]. The mistreatment of WLWH in this way cannot be excused by lack of availability of ART in low-resource countries, as ART is now widely available throughout the world[44].

Legal aspects

Human rights

In 1999, the Committee on the Elimination of Discrimination against Women encouraged all countries to make more effort with respect to article 12 of its 1979 Convention on women and health[45]. Non-consensual sterilization is a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination[46]. Human rights bodies have also recognized that non-consensual sterilization is a violation of the right to be free from torture and other cruel, inhuman or degrading treatment. Human rights standards require that family planning services for WLWH should not restrict reproductive freedom and should be non-coercive.

Forced sterilization is outlawed by Article 7 (Section 1g) of the Rome Statute of the International Criminal Court[47]. The African Commission specifically condemns involuntary sterilization of WLWH in its Resolution 260[48].

South Africa was the first nation to include the right to reproductive health services in its Constitution and has a specific statute that prohibits sterilization without valid consent[30]. It is disappointing that this country lacks the ability to enforce its progressive laws.

Court cases in Africa

The findings of the 2008 International Community of Women living with HIV/AIDS (ICW) study in Namibia resulted in a government investigation; this found no wrong-doing[25]. Not content with this outcome, ICW and the Legal Assistance Centre filed a total of 16 lawsuits against the Ministry of Health and Social Services as well as the three hospitals in question.

In 2012, three of the 16 WLWH each sued the Namibian government in the High Court. All three had been sterilized in public hospitals in the mid-2000s at the time of a CS. The women alleged violations of a range of constitutional rights, lack of valid consent and discrimination based on their HIV-positive status. The Namibian High Court ruled that there was evidence that the women had been sterilized without valid consent but found insufficient evidence that they had been discriminated against because of their HIV status[49].

The government appealed to the Supreme Court, which upheld the High Court ruling in 2014. The Supreme Court judgment, *Government of the Republic of Namibia v LM and*

others[50], was a landmark decision. Although the women had signed consent forms for cesarean section and BTL (abbreviation for bilateral tubal ligation), it was ruled that consent could not have been valid when (i) the women were in labor, (ii) the procedures had not been properly explained to them (use of abbreviations and lack of Oshiwambo interpreters contributed to this) and (iii) there was no opportunity to weigh options. The Supreme Court did not find discrimination based on HIV status but deplored medical paternalism as specifically harmful to the three women in this case and more generally. Legal scholars have suggested that, not only did the Court miss an opportunity to consider the human rights implications of forced sterilization, but that a case for gender-based violence should have been mounted by the lawyers acting for the women[51].

A similar case (*SWK & 5 others v Médecins Sans Frontières-France & 10 others*) concerning four women is still pending in the High Court of Kenya at the time of writing. It is hoped that this Court will take a more progressive approach to the human rights issues raised by involuntary sterilization than the Namibian courts did.

In 2014, a South African WLWH who had been forcibly sterilized won her case against the Durban Health Department and was awarded almost ZAR500,000 (about US$37,000) in an out-of-court settlement[52]. The woman had been sterilized without her express consent during a CS in 2009. She had signed consent forms for the operation but did not appreciate that the forms included sterilization.

Preventive and ameliorative measures

Possible ways of reducing non-consensual sterilization abuses have been mooted[30]. Medical training in sexual health can be improved. National obstetric and gynecological associations could make it a priority to develop continuing professional development programs that focus on taking consent for sterilization. Professional regulators could suspend or revoke medical registration if sterilization is performed without valid consent. Legislation can be adopted by parliaments making it illegal to attempt to obtain consent for sterilization during labor, immediately preceding any surgical procedure or induced abortion, or after administration of sedatives, psychotropic drugs or premedication for anesthesia.

The lives of those women who have already been subjected to the intervention can be improved by governments promoting access to justice and by the granting of reparations (including an apology and a cash payment).

Discussion

Findings and interpretation

Non-consensual sterilization of WLWH is being practised in 27 countries. The fact that their Intentions to have children are similar to those of seronegative women is not taken into account. Some HCPs are unaware that the wishes of the patient in front of them should come before any public health considerations. Professionals are treating WLWH in ways that do not fully respect the women's autonomy; they are misusing their power.

HCPs are riding roughshod over guidance on the consent process. Forced sterilization takes away women's fertility and their choices for family building in the future. Such an intervention is discriminatory on the basis of both gender and HIV status, even though the courts have so far been hesitant to find as much. In the countries in which these sterilizations are taking place, loss of fertility is extremely stigmatizing and affects considerably the lives of WLWH. Ostracism in society for such women is more due to the sterilization than to HIV, the latter being so commonplace in certain countries.

Relevance of the findings – implications for clinicians and policymakers

HCPs need educating on the scientific aspects of HIV, the ethics of consent and on their own attitudes. Not only are they causing physical and psychological harm to WLWH but they run the risk of falling foul of their professional regulators and the courts. Consideration should be given by the medical profession and governments to introducing further measures to increase awareness of this continuing violation of human rights, imposing sanctions on those who perpetrate this type of malpractice and providing justice for the victims.

Unanswered questions and future research

Reports of non-consensual sterilization of WLWH have only come to light because they are actively sought or because women choose to speak out. In the majority of countries in the world, there is no published evidence. The prevalence of the practice needs to be determined by more systematic investigations. Health ministries of all countries should conduct surveys of WLWH who have been sterilized to ascertain the validity of their consent.

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The authors declare that there is no conflict of interest.

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