



ROBBED OF CHOICE

Forced and Coerced Sterilization Experiences of Women Living with HIV in Kenya

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A Publication by **African Gender and Media Initiative**

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Names of the women have been changed to protect their identity.

Acknowledgment

African Gender and Media Initiative (GEM) wishes to acknowledge the amazing and courageous women who shared their stories to break the silence on non-consensual sterilization of women living with HIV (WLHIV) in Kenya. This documentation goes a long way in contributing to the body of knowledge on reproductive health and sexual rights of women living with HIV. Further, it provides a basis for action by government and relevant stakeholders to end non-consensual sterilization of any vulnerable group of women in Kenya.

Special thanks to Njoki Otieno of Women Fighting Aids in Kenya, Maureen Murenga of Lean on Me and Inviolata Mmbwavi of Grassroots Empowerment Trust for their tireless effort in ensuring that forced and coerced sterilization becomes everybody's business. The three have helped shift the debate on non-consensual sterilization of WLHIV from the private arena in the confines of psychosocial support groups to the public domain in Kenya.

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Foreword

Family planning provides an important pillar in addressing population dynamics, safe motherhood, national and international development as well as environmental sustainability. The health-care giver in the continuum of sexual and reproductive health services is an important counselor, providing important health promotion messages and the service provider needs to be knowledgeable and skilled on the various family planning methods; be cognizant of clients with special needs; gender sensitive and strive to provide evidence based best practices acknowledging the individual's sexual and reproductive health and rights.

Amongst sexually active WLHIV, particular attention to reducing the risk of HIV transmission through use of antiretroviral; partner counseling, testing and treatment; preventing mother to child transmission through modified obstetric and infant feeding practices; with retention of the efficacy of the selected family planning method are important benchmarks. Strategies that include correct, consistent condom use or dual strategy are strongly advocated. HIV-positive women can have healthy babies. Any client considering permanent method of contraception either bilateral tubal ligation in women or vasectomy in men, there is need for ample time to counsel on the method and its implication, attend to clients, questions and feedback as cornerstones prior to her providing informed voluntary consent as a standard operating procedure. This is to ensure that her physical integrity and psycho-social well being are maintained.

Forced or coerced sterilization of WLHIV is an infringement of their reproductive rights and dignity as well as social injustice that must be abhorred. However, voluntary sterilization procedures are an important part of a full range of contraceptives options that should be available to all women including WLHIV. Properly performed surgical sterilization procedures should not lead to negative health consequences such as reported in some of the narratives in this report. As we read through these narratives, we need to take a deeper insight into the holistic approach needed when attending to clients seeking family planning and other reproductive health care services.

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Executive Summary

Forced and coerced contraceptive sterilization violates numerous rights guaranteed under the Kenyan constitution and multiple regional and international obligations that Kenya is signatory to. The Constitution of Kenya (CoK) 2010, states in Article 43. 1(a) that *“Every person has the right to the highest attainable standards of health, which include the right to health care services, including reproductive health care”*. Similarly, Article 29 (d) states *“Every person has a right...not to be subjected to torture in any manner, whether physical or psychological”*.

Similarly, the National Family Planning Guidelines for Service Providers in Kenya (2010) emphasizes informed and voluntary consent prior to female surgical sterilization. The guidelines note that *“special care must be taken to ensure that every client who chooses this method does so voluntarily and is fully informed about the permanence of the method and the availability of alternative, long-acting, highly effective methods”*.

The United Nations Human Rights Committee, which monitors compliance with the International Covenant on Civil and Political Rights (ICCPR), refers to sterilization of women without their consent as a violation of the right to be free from torture and other inhuman and degrading treatment. The Convention on Elimination on All Forms of Discrimination against Women (CEDAW) provides for the right of *“access to specific educational information....including information and advice on family planning.”* Article 10(h).

It is important to reiterate, therefore, that women living with HIV have a right to a family planning method of their choice and right to be sexually active and bear children.

This publication documents heart rendering experiences of 40 women living with HIV, who claimed that they were either forced or coerced to accept permanent sterilization procedures (bilateral tubal ligation) in healthcare facilities in Kenya. The study was conducted between October and November 2011 in Nairobi and Kakamega counties by the African Gender and Media Initiative in partnership with Women Fighting Aids in Kenya, Lean on Me and Grassroots Empowerment Trust.

According to the testimonies by the study’s participants, women living with HIV had undergone non-consensual tubal ligation when they visited health facilities to give birth through cesarean section. Others, who had normal delivery, were also later taken to the operating room for the procedure to be done. Reported circumstances under which the involuntary sterilization occurred include;

- a) Tubal ligation done without a woman's consent during an emergency cesarean section;
- b) Consent form signature obtained when the woman is in labor;
- c) Sterilization was required as a condition for receiving free or reduced-price medical treatment or receiving food and medical aid for their children, especially milk and anti-retroviral medications;
- d) Told by doctors who believed that WLHIV should not have more children to accept tubal ligation and that some of them already had too many children and, therefore, permanent and irreversible contraception was necessary;
- e) Spouse and/or parents gave consent for sterilization on behalf of the women;
- f) WLHIV agreed to sterilization on the basis of misinformation by healthcare providers about their family planning choices or the risks of future pregnancies to their health and that of their baby and
- h) Sterilization performed because of a woman's disability and HIV status.

In many cultures including the African, motherhood is at the core of femininity and status in society. The narratives documented here illustrate how WLHIV who have undergone non-consensual sterilization are no longer considered, women, in their respective communities as these sterilizations are permanent and irreversible in most cases. We hope that this publication will commit the government of Kenya to act by putting in place appropriate measures to prevent and respond to forced and coerced sterilization and ultimately stop torture of WLHIV in healthcare facilities.

Faith Kasiva
Director
African Gender and Media Initiative

Introduction

In January 2012, a Kenyan television news channel, Citizen, reported that Project Prevention, a United States-based organization, was paying women living with HIV (WLHIV) on the island of Mbita to have intrauterine birth control devices (IUDs) implanted (Kenya Citizen, 2012). This was in addition to previous media reports in May 2011 that had cited the presence of Project Prevention in Kenya. The news was met with outrage by the Kenyan government, and the Minister for Medical Services remarked that:

“We can’t say as a government we have been good at providing family planning needs of women or even men but we are putting measures in place. But it is important to stress that even HIV-positive women have the right to have children if and when they desire. HIV doesn’t take that right way, not at all.” (PlusNews, 2011).

However, around the same time as the Minister’s affirmation of WLHIV’s sexual and reproductive rights, leaders of multiple community-based, women-led organizations in Nairobi, Kisumu and Kakamega reported that numerous members of their WLHIV psycho-social support groups had recently told group facilitators that they had been forced or coerced to accept unwanted sterilization procedures. Despite the women’s consistent reporting of forced or coerced sterilization procedures to facilitators during community support group meetings for over two years, there had been no formal inquiry to attempt to determine the prevalence of forced and coerced sterilization of WLHIV in Kenya or to examine the circumstances under which it occurs.

In November 2011, the author interviewed forty (40) WLHIV who reported having undergone unwanted sterilization procedures in Kenyan health facilities. The analysis of data from those interviews presented here illustrates a preliminary snapshot of what may be a country-wide problem of non-consensual sterilization of WLHIV in Kenya. For the purposes of this study, coerced sterilization is defined as the use of financial or other incentives, misinformation or lack of information about the procedure and its consequences, or fear of bodily harm or denial of medical services deployed to influence an individual to undertake the procedure or permit the procedure to occur. Forced sterilization is defined as cases in which a person is sterilized without her knowledge or an opportunity to provide consent. As illustrated in this report, both practices are present in Kenya.

Medical and legal framework on informed and voluntary consent in Kenya

While there is no specific legislation in Kenya that addresses the issues of informed consent, medical ethics code of practice in Kenya underscores the importance of informed decision making and consent before medical procedures. Specifically, the National Family Planning Guidelines for Service Providers (2010) emphasizes informed and voluntary consent prior to female surgical sterilization. The guidelines note that *“special care must be taken to ensure that every client who chooses this method does so voluntarily and is fully informed about the permanence of this method and the availability of alternative, long-acting, highly effective methods”*. Further, the guidelines caution service providers against providing any incentive for one to accept any form of contraception or in recruiting potential clients to perform surgical operations. The right of a woman to change her mind even after she had initially consented is affirmed. The guidelines provide a sample consent form that a healthcare provider must administer to any client seeking voluntary sterilization. However, in highlighting that people living with HIV have equal rights to access family planning options, the guidelines do not explicitly state that HIV status should not be used as a criteria to force or coerce WLHIV to sterilization.

Similarly, the Kenya Medical Practitioners and Dental Board, the regulatory body of medical practice in Kenya in its mission, vision and core values statement eludes to quality of healthcare upholding ethics, professionalism and justice.

Forced and coerced sterilization of WLHIV in Kenya violates numerous rights guaranteed in the Kenyan constitution and international human rights laws that Kenya is party to. The Constitution of Kenya (Cok - 2010), states that *“Every person has the right to the highest attainable standard of health, which includes the right to health care services, including reproductive health care.”* Article 43. 1(a). Similarly, article 29 (d) states that, *“Every person has a right...not to be subjected to torture in any manner, whether physical or psychological”.*

The United Nations Human Rights Committee, which monitors compliance with the International Covenant on Civil and Political Rights (ICCPR) that Kenya is party to has referred to the sterilization of women without their consent as a violation of the right to be free from torture and other inhuman and degrading treatment.

The Convention on Elimination of All Forms of Discrimination Against Women (CEDAW) provides for the right of *“access to specific educational information...including information and advice on family planning”.* Article 10(h). WLHIV have a right to a family planning method of their choice and the right to be sexually active and bear children. The Special Rapporteur on Violence against Women: *“Forced sterilization is a method of medical control of a woman’s fertility without the consent of a woman. Essentially involving the battery of a woman-violating her physical integrity and security, forced sterilization constitutes violence against women.”* Rahhika Coomaraswamy (1999).

All women have the right to free and informed choice before consenting to sterilization including counselling on the possible consequences of choosing a permanent method of contraception. Healthcare providers should provide all their patients with full and accurate information to ensure that the individual’s decision to undergo sterilization is not subjected to misinformation, incentives and/or threats. The dignity, privacy and confidentiality of the patient must be respected at all times during the process to obtain informed consent. Healthcare providers have an obligation to respect the right to self-determination and to obtain informed consent for any medical procedure.

The International Federation of Gynecology and Obstetrics (FIGO) guidelines on Female Contraceptive Sterilization define the conditions under which consent for a sterilization procedure can be sought, and also note conditions under which consent cannot be sought in any case. Of particular importance to the Kenyan context, are the provisions that *a) Prevention of future pregnancy cannot ethically be justified as a medical emergency, and thus cannot be used as a reason for a doctor to sterilize a woman without her full, free and informed consent; b) no minimum or maximum number of children may be used as criteria to sterilize a woman without her full, free and informed consent, c) Only women themselves can give ethically valid consent to their own sterilization; d) Women’s consent to sterilization should not be made a condition of access to medical care, such as HIV/AIDS treatment or of any benefit such as release from an institution; e) Consent to sterilization should not be requested when women may be vulnerable, such as when requesting termination of pregnancy, going into labour or in the aftermath of delivery; f) As for all non-emergency medical procedures, women should be adequately informed of the risks and benefits of any proposed procedure and of its alternatives and g) The right of all persons with disabilities who are of marriageable age to marry and to found a family is recognized.*

Methodology

The purpose of this study was to document experiences of selected WLHIV who reported having undergone forced or coerced sterilization. Safety, security and psycho-social support for the study's participants were of utmost concern, and study organizers consulted the World Health Organization guidelines on researching violence against women (WHO, 2004) as part of the protocol development process. A qualitative research inquiry was used. The relevant research permit and ethical approval were obtained from the Ministry of Education and Kenya Medical Research Institute respectively.

All research participants were members of the WLHIV support groups: Women Fighting Aids in Kenya (National), Lean on Me (Nairobi and Kisumu) and Grassroots Empowerment Trust (Kakamega). Prior to participants' recruitment, the research staff carried out community education forums on forced and coerced sterilization with all potential research participants identified in the three support groups to help distinguish potential participants who had voluntarily consented and those who had been forced or coerced. Participant selection criteria included a) A woman living with HIV, b) Aged 18 years and above at the time of the interview and at time of sterilization, c) Having reported experiencing forced or coerced sterilization in Kenya, d) Desire to voluntarily participate in the research.

No monetary incentive was provided for participation. Organizers allowed seven days after the education forum before approaching potential participants about participating in the study. The waiting period was intended to help potential participants process the implications of their possible involvement in the study and to ensure they did not feel pressured to participate. The interview questionnaire was pre-tested by administering it to four potential participants and improvements made to ensure validity.

Forty participants from Nairobi and Kakamega counties who met the participation criteria were selected using snowballing sampling, starting with members of the three support groups. Scheduling of interviews was guided by the utmost protection of the privacy and confidentiality of participants. The choice of venue for interview was determined by the participant. An audio recorder was used to record the conversation with consent from the respondent. The recordings are in the custody of the author and will be destroyed after three years. The interview questionnaires had five sections: Demographics, Sterilization experience, Rights and choices, Disclosure of sterilization status and Impact of the sterilization experience. Data collected were transcribed and the transcripts were used to write a short narrative for each participant's sterilization experience.

Testimonies

Selina

According to Selina, she was admitted at the Kenyatta National Hospital in 2000 with tuberculosis and pre-term labor pains. At the time, Selina says that she was seven months pregnant and at delivery underwent a cesarean section. In the process, Selina claims that she was sterilized but only got to know about it seven months later when her husband decided to marry another wife.

Selina's husband had signed the consent forms but did not inform her. She thought her husband only signed forms to allow the hospital operate on her as she delivered.

A young woman of twenty three (23) years, Selina says she was never given a chance to choose the family planning method of her choice. Her husband has since married another wife because he *"could not live with a woman who cannot give birth"*.

"Your illness cannot allow you to carry a pregnancy to term, so I have no option but to marry another woman," Selina recalls her husband's words. A mother of two, her husband sent her away from their matrimonial home and took away their children. *"The sterilization ruined my life,"* she says bitterly.



Alice

Alice got to know of her HIV status in 2001 when she visited an ante-natal clinic. Alice says that, she remained in denial after she was given the results until 2008 when she had an opportunistic infection. At the time, Alice says that she was pregnant and attended ante-natal clinic where she was advised that she should not breastfeed her baby because of her HIV status.

Following a referral by healthcare providers at the East Deanery Health Centre in Komarock, Nairobi, 28-year-old Alice went to deliver her baby at Pumwani Maternity Hospital. According to Alice, she was coerced into signing consent forms for sterilization by a doctor at Pumwani Maternity Hospital. She was promised milk for her baby in exchange for her consent.

“While I was groaning in pain, the doctor looked at my file and said to me, ‘Woman you are still giving birth and you are HIV positive,?’” she recalls. Alice says that she was asked by the doctor to sign consent forms authorizing a tubal ligation. Her ability to give informed consent was impaired as she was in labor.

“When they insisted on tubal ligation, I signed the documents so that they could attend to me and relieve me of the pain I was going through. I was not able to reach my husband as he had no phone”.

Alice is yet to disclose the sterilization to her husband. She is worried that if she tells him, he will abandon her and marry another woman. She is also worried that she is no longer be able to satisfy him sexually as her sexual desire has reduced tremendously. She suffers heavy menstrual periods that last for more than seven days. Alice has since sought assistance in many clinics, but the problem persists. Being a vegetable hawker, she cannot



walk long distances or undertake heavy duties. *“Imagine I can no longer wash clothes. I have to constantly beg my friends and my children to wash for me,”* she says.

At the time of sterilization, Alice says she did not know of her reproductive health rights or the existence of other family planning methods. This information was not provided to her before being coerced to give consent for tubal ligation. She recommends that women living with HIV should be provided with information on available options for family planning and be given the right to choose what works best for them.

Lucy

In 1996, at the age of 23, Lucy was pregnant and HIV positive. Confronted with hostility and discrimination at the Chogoria Hospital, she says that she had no alternative but do what the doctors wanted. According to Lucy, the doctors at Chogoria Hospital asked for consent for tubal ligation. Out of fear and lack of knowledge about her reproductive health rights and choices, she consented to the sterilization. Lucy claims the doctor told her that she had a dreadful disease and, should not have any children.

“He said since I am about to die, I cannot give birth to a healthy child and took me to a ward that had children with extreme Aids-related infections so that I could decide if I still had the desire to have a child,” she remembers.

This was the beginning of her problems. Upon disclosure of her HIV and sterilization status to her

husband, She says he left their matrimonial home. A mother of two, Lucy has been unable to find another partner because when she tells men of her condition, they refer to her as ‘ukebe’ (an empty can). Stigma has followed her even within family where they refer to her as the “aunty who fears to give birth”.

“This is really painful because I have seen women who are HIV positive get healthy children while I am not able to,” she says.

After sensitization on reproductive health rights of women living with HIV and group psychosocial support, Lucy now knows her rights. She recommends education and legal action against doctors who take advantage of illiterate women’s ignorance to sterilize them without informed consent.

Purity

Purity claims that she was sterilized at Kenyatta National Hospital when she sought medical assistance for an ectopic pregnancy in 2004. According to Purity, her husband was persuaded by the doctors to sign the consent forms arguing that with a history of still births and ectopic pregnancies, it was better if she did not get pregnant again.

According to Purity, her husband claims to have consented to her sterilization to reduce her suffering. Purity says she is confronted with constant verbal

abuse and their relationship is strained. *“I cannot discipline my children, when I try to, he tells me I have a rotten stomach,”* she says.

For a long time, Purity was bitter with her husband for consenting to the procedure. However, she has come to accept her situation after joining a psychosocial support group for therapy. She recommends that clear laws be put in place to stop men from making reproductive health decisions on behalf of their wives.

Nancy

At 29 years old, Nancy says that she faces triple discrimination. She is living with disability, HIV and was sterilized against her will. Nancy tested positive in 2002 and was in denial until 2006 when she suffered streptococcal meningitis and eventually lost her eye sight. At the time she had one child.

In 2007, Nancy decided to have a second child for her old age security. *"I hoped that once the child grows up, he/she would be able to support me."* However, this dream was cut short. Nancy says that she was sterilized at Makindu District Hospital at the age of 25.

Through a network of friends, Nancy had learnt that HIV positive women can have children who are HIV negative. She decided to get pregnant and took the necessary precaution to ensure that the baby would not be infected. Eight months into the pregnancy, Nancy says that she developed severe labor pains and was admitted at Makindu Hospital in critical condition. When she regained consciousness, Nancy had lost the child and had been sterilized. *"The doctor told me 'you are not only positive but also blind'. You cannot continue to have children,'" she says.*

Sick and visually challenged, Nancy suffered as her husband could not live with her any longer. He abandoned her. This was the point at which Nancy decided to accept her status and join a psycho-social support group through which she attended various sensitization programs that have enabled her to live positively. She has since become a counsellor and has been able to transform the lives of many women living with HIV.

Nancy notes that the doctor assumed that since she is blind, she could either have been raped or manipulated into pregnancy. *"He ignored the fact that I was married*



at the time and had one other child and so I could take care of children despite my condition."

Nancy constantly experiences abdominal pains and is unable to undertake heavy tasks. She gave up on finding a partner because all the men she meets want children of their own. Her troubles are exacerbated by societal stigma since she is HIV positive, blind and a single parent.

Halima



In 2007, Halima, a HIV positive woman living with disability was taken by her mother to Kenyatta National Hospital to deliver a baby. According to Halima, the doctor persuaded her mother to sign the consent forms for sterilization because *“she is not only HIV positive but also disabled”*. Halima says that her mother agreed and gave consent for her sterilization. Halima only came to know about this when she overheard doctors discussing that they had performed a tubal ligation on her. She later confirmed with a nurse that her mother gave consent for her sterilization.

Halima was 25 years old, of sound mind and capable of giving informed consent. Feeling betrayed by her mother, she turned to her sister for solace. She disclosed her forced sterilization experience to her elder

sister and her fears about how the experience may negatively affect her relationship with the fiancé. Unfortunately, he got wind of the sterilization from her sister and cancelled the engagement.

Prior to being forcibly sterilized, Halima says that she had given birth to two daughters, from her first husband who had died.

In spite of the psychological trauma of sterilization, challenges of single parenthood and physical pain associated with the procedure, Halima is hopeful that she will succeed in bringing up her two daughters as a single mother. She has started a hairdressing business in Kibera, an informal settlement.

Winnie

When Winnie’s husband said they were going to Makunga Hospital, she did not know what lay in store for her. It was in 2004 when he took her to the hospital and informed her that he had arranged for a family planning surgery. He then signed some papers that Winnie came to learn later were consent forms for her sterilization.

At the time, Winnie says that she did not understand why she was being taken to hospital for surgery and did not dare ask her husband out of fear that he would beat her. Just before being wheeled into the operating room. *“The doctor told me that after having had a conversation with my husband, they will proceed to conclude their work,”* she says.

Winnie says that she learnt about her sterilization from the nurse three days after the surgery during a medical check up. *“The nurse told me that it was a wise decision to close my tubes since giving birth to more babies would*

lower my immunity.” Since then her life has never been the same. Her husband became hostile and remarried. He justified his action with the assertion that he had to protect his family. *“Had I known, I would have refused because now he is busy looking for a child from other women,”* says Winnie.

Winnie has since learnt that she had the right to refuse to be sterilized after attending a sensitization meeting organized by Grassroots Empowerment Trust (GET). She cautions women living with HIV against signing consent forms for sterilization without being properly informed as it has grave consequences.

“I would not want any woman to be misled and or sterilized out of ignorance,” advises Winnie. She eventually shared her sterilization experience with her mother-in-law, after the relationship with her husband became unbearably strained.

Maureen

“The nurse came and picked my card and said ‘I can see in your file that you are HIV positive. You must have tubal ligation since HIV positive women are not supposed to give birth.’”

This is the story of Maureen who at the age of 22 in 2005 says she was sterilized at Kakamega General Hospital. According to Maureen, she was coerced into consenting to the process by a nurse, while in labor and not given any other option.

Maureen says she was verbally insulted and humiliated by nurses at the hospital because of her HIV status. The doctors delayed in attending to her and when the surgery was finally done, the baby survived for only a few hours.

“I was in pain and crying. I begged them to wait for my husband to come but they refused. They brought the paper and I signed before they wheeled me into the theatre,” she says.

Having discovered her HIV status during a visit to the ante-natal clinic, Maureen says she had taken all the necessary precautions including taking Nevirapine while in labor to ensure that her baby was not infected.



However, she laments that her efforts were in vain because the baby died a few hours after birth. The situation did not get any better when she disclosed to her husband that she had been sterilized. Maureen’s husband and family abandoned her at the hospital. *“They even refused to bury the baby.”*

Maureen knew of her right to decide on the family planning option of her choice but was coerced to sign the consent forms. *“I knew my uterus was being tied completely and that I would never give birth again. I tried so hard, but I didn’t have anyone to help me,”* she says.

Jobless and vulnerable, Maureen suffers serious depression. She is currently receiving counseling support at Grassroots Empowerment Trust in Kakamega town.

Since the surgery, Maureen says that she has gone back to the hospital numerous times to look for the nurse who coerced her into sterilization. She has also tried to find out if she can give birth again but it has all been in vain. She can hardly speak about her situation without breaking into tears. Her husband now has another wife and has refused to take care of her and their only child.

Doris

“I don’t feel like a woman anymore,” says Doris who believes she has lost her social status by not having a child.

In 1993, at only 21 years old, Doris says she was sterilized without her consent at Muthara Hospital, the current Tigania District Hospital, after an ectopic pregnancy. Her husband signed the consent forms after being advised by the doctors that Doris *“needed a surgery to clean her womb”*. After the operation, Doris says she was advised to attend a number of follow up clinics. She only came to know that she had been sterilized three years later when she could not conceive.

Doris blames her husband for taking such a drastic and life changing decision without consulting her. She says that her husband consented to her sterilization because she was HIV positive and did not want to have children with her. Since undergoing the forced sterilization, Doris says that her marital relationship deteriorated. Her husband has since married four other wives and has 18 children.

Due to pressure and stigma, Doris separated from her husband in 2003 for some time. *“My husband and his family ostracized me. They said I was a liability,”* she says.

Doris moved to Nairobi and later reconciled with her husband, but says they live a difficult life. *“I am so angry and bitter, I can never trust him. My family also has problems with him because of his decision to intentionally get me sterilized,”* she says.



She became stressed and lonely as she cannot explain to people why she does not have a child. She was forced to foster her late brother’s child. She would like civil society organizations to conduct public awareness on the issue of forced and coerced sterilization to empower women and medical practitioners to bring the practice to a stop.

Lillian

In 1997, Lillian says that she had a still birth. She conceived again in 1999. According to Lillian, she had never taken an HIV test during pregnancy, but after giving birth, the baby became constantly ill prompting the doctors to recommend a HIV test for herself and the child. They both tested positive.

In 2000, Lillian, a mother of two, says that she was coerced into signing 'strange' documents by the doctor and her husband at a VCT clinic in Makunga Health Centre. At the VCT clinic, they both tested positive for HIV, confirming her results from the post-natal clinic. Numerous counseling visits led to discussion between her husband and a doctor about her sterilization. Lillian says that she did not understand their conversation since they mostly spoke in English. Lillian alleges that the conversation between her husband and the doctor led to the tubal ligation procedure, which neither the doctor nor her husband discussed with her. She thought the surgery was normal treatment for someone living with HIV.

"I think my husband was advised by the doctor that since we were both HIV positive, we are not supposed to have children," she says. When she inquired about the procedure, Lillian was told the doctors wanted to help her so that she could live longer.

Four years after the surgery, Lillian says that she did not get pregnant. So she went back to Makunga Hospital to find out what had happened to her and was informed that she had actually been sterilized. Even though her husband was involved in consenting to her sterilization, he has since abandoned her and the children. He moved to Nairobi and she has never seen him since 2007. *"If I knew it was tubal ligation, I would not have accepted,"* she says.



Lillian recommends that women should be sensitized on the different options for family planning. *"Some women go for tubal ligation thinking that it is a pill or tablet and end up getting involved with something they do not understand,"* she says.

She urges women who have been forcefully sterilized to take the initiative to sensitize other women about it. Lillian feels empty and robbed of her womanhood and that she has lost her social status in the community. Lillian worries that she cannot take legal action against the hospital because she has no documentation to prove her husband consented to the surgery.

Olive

Olive says that she came to know of her HIV status in 2004 during a visit to the Lions ante-natal clinic in Mathare North. In looking for a second opinion, she went to Pumwani Maternity Hospital to re-confirm her status and later delivered normally in 2005. Olive says that the nurse at Pumwani Maternity Hospital who provided her with milk for the baby after delivery told her that since she already had three children, she should stop getting more because her CD4 count was declining.

Olive claims that she asked about other contraceptive methods that were available and the nurse said *“if I took family planning pills they would interfere with the ARVs and make them lose strength. Also, the other family planning methods would affect my health”*.

“Then I was tested and my CD4 count was 90 so I was told first I was to go for tubal ligation because if I was

to get pregnant again I would leave my newly born child so small and I will not be there to bring him or her up. Then I decided it was better to go for the tubal ligation because I did not have a choice.”

Even though the delivery was normal, Olive says that she was sterilized after giving birth. Olive says that she was operated by Marie Stopes doctors at the Lions clinic. *“We were in a group of those who had been coerced to sign the consent forms since our CD4 count was extremely low.”*

Olive says after the procedure, one of the nurses said to her, *“you see we have treated you, if you add more children you will be sick again”*.

She disclosed to her husband about the sterilization because he kept on insisting that he wanted another child and they disagreed on this. This degenerated to constant conflicts and in 2006 he eventually left her and remarried.

Peris

Peris says she knew that she was HIV positive after her husband died in 2002. She tested positive at MSF clinic at Kwa Wangwa in Kibera. Two months into the pregnancy she was having severe stomach pains for almost a week and was rushed to hospital in Mukumu, in Western Kenya. *“I found a white doctor doing the rounds. If he had not been fast in responding to me. I could have died. They operated on me and removed some fluid on the outside of the uterus and closed it permanently.”*

Peris says that the doctor told her that she had an ectopic pregnancy and could have died if she had not sought immediate medical attention. *“I was unconscious when they did the operation.”*

The next morning, when the doctors were doing their morning rounds, Peris says she overheard one of them briefing the other that they had performed surgical sterilization on her.

Peris says she asked the doctors to explain to her about the operation. *“The doctor said if the pregnancy continued to grow, I would have died and given that I was HIV positive, with no husband and other children, at my age they decided to do tubal ligation”*.

At the time, Peris says she was vulnerable and could not question the doctor’s decision. *“In the rural area health facilities, doctors know best and poor women like me have no right even on their own bodies.”*

Sara

It was not easy for 50 year old Sara when in 1999 her husband insisted on having their last baby delivered at Makunga Hospital. Sara says that she tested positive for HIV when attending ante-natal clinic and during delivery, she was tricked into signing consent forms for surgery. According to Sara, she did not know what was going on and thought she was signing payment forms.

“They gave me the consent forms for my signature while I was in labor, no one explained to me. I thought they were payment forms.”

Sara says that nobody explained to her why she had to sign the forms although earlier she had rejected the idea of sterilization when it was suggested to her. After signing the documents, Sara notes that the hospital insisted on performing the surgery claiming that they had instructions from her husband.

“You people with the virus just disturb people. You will give birth to children and the way you have the virus, where will you take the children?” Sara recalls the doctor telling her.

Sara claims that she was never informed about other family planning options. After she left hospital, Sara’s husband confirmed that he had consented to the sterilization. Sara says her husband used her sterilization experience as an excuse to marry a second wife. *“My co-wife is given preferential treatment because she does not have the virus,”* she says. Sara would have liked to have a baby girl since all her other children are boys. She has since lost her husband and struggles to bring up her children on the small piece of land left in her name.

A mother of six, Sara says women must not be coerced into sterilization regardless of the number of children they have. *“The decision to have a child is an individual’s, it should not be up for debate,”* she says.

Sara would like the media to highlight violations of the rights of women living with HIV. The tubal ligation has affected her life. *“I am no longer respected, my in laws call me the woman who was afraid of giving birth,”* she says.



Jane

In 2004, Jane says she went to Kakamega General Hospital for treatment of malaria. This was six weeks after the delivery of her fourth baby. Jane notes that her husband was not happy that she was only giving birth to girls, he wanted to have boys. Subsequently, he decided that she must have a tubal ligation.

“My husband said he was punishing me for giving birth to girls,” she says. Jane’s says that her husband had prior discussions with doctors at the hospital to have her sterilized. All Jane remembers is that she was sedated and when she woke up, she had a huge scar on her lower abdomen.

Jane suspects that her husband had her sterilized without her knowledge out of bitterness. She says that she had tested HIV positive during the ante-natal care but out of fear of violence did not disclose her status to him. Her husband only came to learn about her HIV status later from a friend of his who is a doctor at the Kakamega Hospital. Jane’s husband has since married another wife and though he also tested positive for HIV, he blames her for infecting him.

Abandoned in a small farm in her husband’s home, uneducated and unemployed, Jane struggles to bring up her four children single handedly. She is bitter that her co-wife has been able to bear sons. *“He would probably treat me with respect and support my children if I was able to have a son,”* she says.

Aware of her rights after sensitization and group therapy for women living with HIV, Jane is seeking legal representation that will enable her get child support and equal division of the matrimonial property.



Having been unaware of her rights at the time of sterilization, Jane now emphasizes the importance of informed consent to all the medical examinations and procedures. She appeals to doctors not to take advantage of women who are not informed of their rights. Jane would like the government to retrain doctors to respect patients’ right to information and non-discrimination. Jane was forced to disclose her situation to her mother-in-law when the relationship with her husband deteriorated.

Amani

Having tested HIV positive during an ante-natal clinic check-up, Amani says she was advised to deliver in hospital so as not to infect the baby. While in labor before a cesarean section, Amani recalls overhearing nurses recommending that she be sterilized because of her HIV status. That was in 2003 at the Mukumu Hospital.

“I discovered that the tubal ligation had been done when I took my baby for clinic after delivery. The nurse requested me to allow her to examine my wound, and in the process, a colleague passed by and asked how the tubal ligation scar was healing. I did not know about it and only thought they had cut me because I was having a baby,” she says.

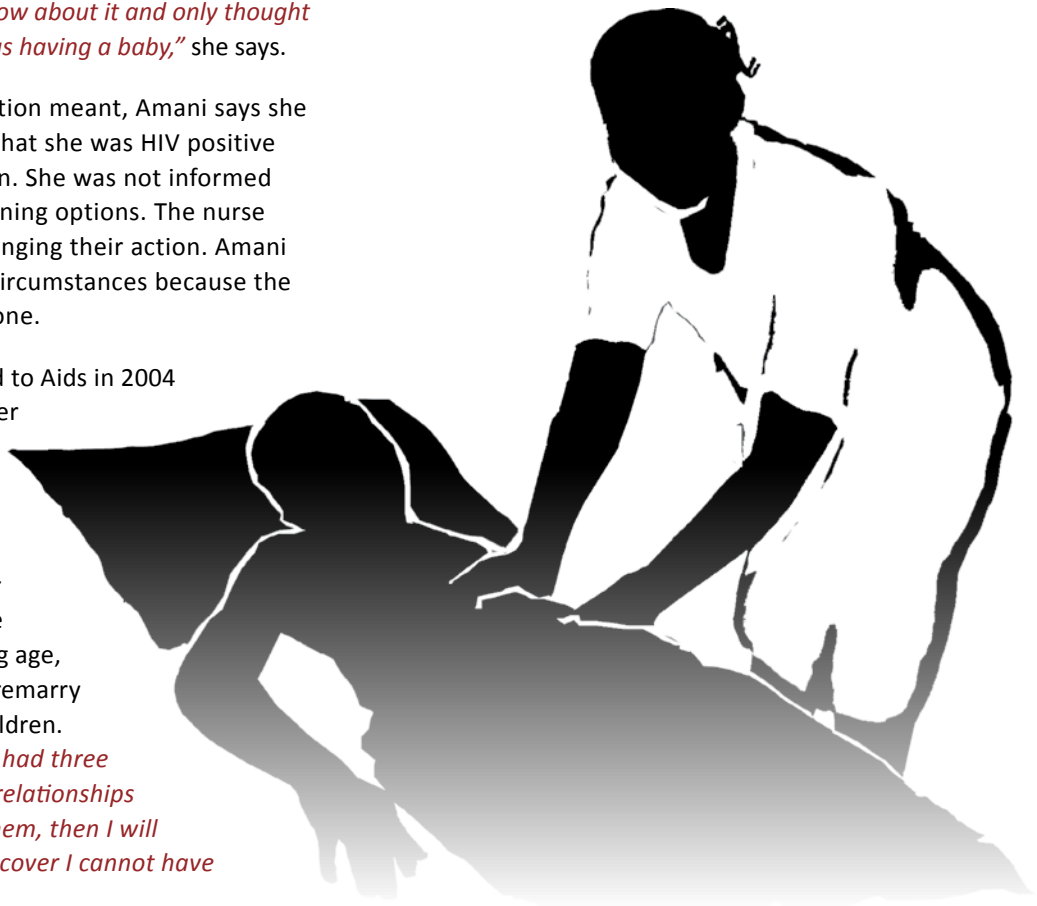
On inquiring what tubal ligation meant, Amani says she was informed by the nurse that she was HIV positive and should not have children. She was not informed of other existing family planning options. The nurse cautioned her against challenging their action. Amani says she had to accept her circumstances because the surgery had already been done.

Amani’s husband succumbed to Aids in 2004 and she was chased out of her matrimonial home by the in-laws since she had only given birth to a girl. Unemployed and dejected, she took her daughter to her parents’ home. Although she was widowed at a very young age, Amani says that she cannot remarry because she cannot have children.

“In the last few years, I have had three suitors but I had to stop the relationships because if I get married to them, then I will be abandoned when they discover I cannot have children,” she says.

She hopes a scientific discovery can be made that will be able to reverse tubal ligation so that sterilized women can have children again.

Amani also hopes to find a job at the hospital so that she can learn about reproductive health rights and assist other women in similar circumstances. She appeals to civil society organizations to prioritize sensitization of women’s reproductive health rights. Even as she shares these thoughts, Amani cannot carry out heavy chores and constantly experiences back and abdominal pains.



Rita

Rita tested HIV positive in 1998 but was never informed of her results. She says that she only got to know of this later when she read what had been written on her medical card. In 2005, she was admitted to Kenyatta National Hospital with pregnancy complications.

Rita claims that she does not know exactly what happened to her, but all she remembers is that she underwent a surgery. She recalls signing something but does not know what it was for. According to Rita,

she only discovered that she had been sterilized five years later when she could not get pregnant. *“I was not able to tell that I had been sterilized because I had had a cesarean procedure,”* she says.

Over the years, she has suffered heavy bleeding and was hospitalized for about a month at the Kenyatta National Hospital following the surgery in 2005. She would like to have more children but lacks resources for proper medical examination.



Esther

Esther was 32 years old when she got to know of her HIV status in 2007. According to Esther, her husband had known about his status much earlier in 2002 but hid it from her. He also kept his drugs and medical documents at his parents' home since they lived in the same compound with them. He never informed Esther about his status until she stumbled upon the information accidentally through a relative of his. When she confronted him, he became very hostile and accused her of having infected him with HIV. Esther says that at the time she was pregnant though she lost the baby at delivery due to prolonged labor. Later that year, Esther says she got pregnant again and gave birth at the Kakamega District Hospital in 2009. According to Esther, she was sterilized during delivery but only got to know about it two months later when she started

experiencing acute abdominal pains and heavy bleeding. It was then that the nurses disclosed that her husband had asked the doctors to sterilize her without her consent. When she confronted the husband with the

information, he confirmed that he indeed gave consent for her sterilization. He argued that since they were both HIV positive, he did not see the point of having more children.

Since the surgery, Esther says their relationship has been strained and her husband has become abusive and unfaithful. His parents and the other in-laws are also hostile to her. Esther faces stigmatization from family and friends. She would like the government to put in place policies to stop discrimination against women living with HIV.

Tina

In 2000, Tina had been sickly and decided to seek treatment for suspected typhoid at the Kaimosi Friends Mission Hospital. She says that as part of the provider-initiated testing for pregnant mothers in Kenya, the doctor decided to test her for HIV. Tina says that she tested positive for HIV and was advised by the doctors to choose between dying and accepting sterilization.

“They just told me that if I continue to give birth then I will just die,” she says. Tina says that she sought further information on alternative options of family planning but was advised against any method other than sterilization.

Frustrated and ailing, she accepted the sterilization, but never disclosed this to her husband until four years later. He reacted to the news by sending her away.

“When I told him about the sterilization, he picked a machete and threatened to cut me into pieces,” she says. *“Had it not been for the children, he would have killed me.”*

Her husband’s family also became hostile and supported his action. Tina says that she was also rejected by her in-laws after she was sent away by her husband. She moved from the village to the city where she attended sensitization on including HIV treatment literacy and reproductive health rights.

“I now know that I have the right to be treated without discrimination, right to live and right to have children,” she says.

Tina has told her parents and children about her sterilization because of her ill health. She appeals to the government to allocate sufficient resources for empowerment of women living with HIV on their rights to informed consent on testing and sterilization.

Tina regrets disclosing to her husband that she had been sterilized. She has been forced to bring up her children by herself. Tina says that as a result of sterilization she has lost the security of marriage and financial support.



Mary

Pregnant and HIV positive, Mary says she went to Gendia Mission Hospital in Rachuonyo District, Nyanza Province for delivery. According to Mary, she was informed that during delivery she would be put on family planning. She says that she was never told that this meant being sterilized and never getting pregnant again. Mary says she learnt about the tubal ligation from her sister a week after the procedure had been performed.

A mother of one, Mary lost her husband in 2009 and remarried, but has not been able to have children. Out of pressure from her new husband, she has been to a number of hospitals to ask if the procedure could be reversed, but they have all said it is not possible.

Before her pregnancy, Mary says that she had been on Depo Provera (or “the needle” as it is called in the village). She was never given a chance to choose whether to continue with the needle or to get sterilized.

Although Mary told her family about the sterilization for emotional support, she says that she has not disclosed the fact that she was sterilized to her second husband and is afraid that he will abandon her. *“I only encourage him to marry another woman, but I can’t tell him why I am insisting on that,”* she says.

Mary is desperate to have her tubal ligation reversed. In spite of a number of counseling sessions, she is still convinced that one day she will find a solution and have a child.

Anita

“I wanted to ask, Is this tubal ligation permanent? Is there any way that it can be reversed?” says Anita, 27, at a group therapy meeting convened by a local organization.

A mother of three, Anita says she was forcefully sterilized at Kakamega District Hospital in 2009 when she was 25 years old.

“They decided that since I gave birth through cesarean and had also tested HIV positive, it was better that I have tubal ligation done,” Anita recalls.

All she remembers is being told that women who are HIV positive should not have children, and on that basis she signed the consent forms. Anita says that she was never informed of other family planning options. She did not know that sterilization was a permanent birth

control method. In labor and under duress, she signed the consent papers without much information on the consequences.

Since the surgery, Anita’s health has deteriorated. She experiences lower abdominal pains and cannot do heavy work. *“I think the surgery was not done well because my stomach is constantly swollen and people always think I am pregnant,”* she says.

Anita appeals to doctors to respect patients’ rights to informed consent. Considering low education levels in the rural areas in Kenya, she urges doctors to give women accurate information. Anita shared information about her sterilization with her family members and is concerned that no man will want to marry her because she cannot bear children.

Rebecca

According to Rebecca, when she tested HIV positive in 2002, the results were never disclosed to her. She only confirmed her status in 2005 during an ante-natal clinic checkup after three years of rumors from her colleagues. Due to ill health and regular visits to the PMTCT clinics, Rebecca lost her job as a cleaner with the armed forces.

“They tested me without my consent and the doctor told the nurses that he was going to perform the tubal ligation as they were delivering my last child. This was at the Defence Forces Memorial Hospital. He said there was no need for me to continue having children since I was HIV positive. I did not understand what he meant by tubal ligation. I just thought it was an easy way of helping me with the delivery,” Rebecca laments. She says she came to learn that the surgery included sterilization two days after the procedure was performed when a nurse informed her.

Rebecca has three children, two of whom are HIV positive. She says that, though she never consented to sterilization, she has come to accept her situation. Having attended a number of treatment literacy workshops, Rebecca has learnt that she has the right to informed consent before both HIV testing and sterilization procedures.

In order to live positively, she has trained as a community health worker and earned a certificate in psychology. She conducts door-to-door sensitization on the importance of HIV testing, care and support for people living with HIV and Aids. She cautions women against forced or coerced sterilization.

As a way to prepare her children to overcome stigma and discrimination, Rebecca disclosed her HIV status and the fact that she was sterilized to them. She also wanted them to understand why their younger siblings are constantly on medication. *“I have discovered that*

disclosure has helped me one way or the other. My eldest son will never let me carry heavy objects if he is around because he understands my status.”

Rebecca would like to conduct awareness campaigns on forced sterilization. She calls on the government to address contraception needs of women who are HIV positive.



Deby

Deby says she was admitted at the AIC Githumo Hospital in Kandara with pneumonia in 1997. As part of routine examination at that time, her blood sample was tested for HIV. *“The doctor told me that I was HIV positive and that I must go to the theater. I had a certain swelling on my leg and I thought that was why I was going for an operation.”*

Deby says she was skeptical about the operation because the doctors had not sent her for an X-ray. However, Deby says that she still went ahead and signed “another paper” and was wheeled into the operation room.

When she regained consciousness after the operation, Deby says that she realized there was a bandage on her lower abdomen. She asked the nurse who told her that her tubes had been cut because she was HIV positive with

high viral load. *“The nurse said to me, ‘I can see from your file you have another child, your viral load is very high and we fear if you get pregnant again you will die. The doctors cut your tubes.’”*

Deby says that she feels betrayed because she has met other HIV positive women who have had children after they were diagnosed with virus. *“They should not have done tubal ligation without my consent; they withheld my rights and it hurts me.”*

Deby regrets that her non-consensual sterilization affected her marriage. *“My husband was unhappy, he started drinking alcohol excessively and coming home late, sleeping on the chair then leaving early in the morning without saying a word, he left me and got another wife.”*

Aisha

Aisha was 17 years old and being raised by a poor single parent when she gave birth to her first child in 1988. In 1989, upon suspicion that she had contracted Syphilis, she sought treatment at the City Council Clinic in Huruma, an informal settlement in Nairobi, at which time she was also tested for HIV in 2001.

Aisha had been in two failed marriages that resulted in three children within six years. In financial despair, Aisha married a third husband who was abusive and also demanded for a child. Since she depended on him for financial support, Aisha says that she agreed to bear him a child and got pregnant. This was in 2004 the man died soon after.

Through a network of friends, Aisha notes that she was referred to MSF Blue House in Mathare where she received counseling and attended the Prevention of Mother to Child Transmission Clinic. When she was due

to give birth, Aisha says that she was sent to Pumwani Maternity Hospital where she gave birth to twins in October 2004 and Blue House paid her maternity bill. According to Aisha, she continued to receive assistance from Blue House including milk for her twins. It was during her post-natal clinic at the Blue House that Aisha claims a nurse recommended tubal ligation for her without offering other contraceptive options. *“The first time when I was told I had to go for the procedure for tubal ligation, I refused and I went back home to think. I wanted the injection (Depo Provera). However, I felt obliged to consent since Blue House was supporting me and had said that it was a must for me to have the TL done so the children could receive milk.”*

Aisha says that she returned to Blue House and signed the forms. On the material day, Aisha notes that she was sent to Lions Huruma Clinic accompanied by two community health workers for her tubal ligation on June 8, 2005.

Flo

When Flo got pregnant with her first child in 2006, she says that she was informed that due to her HIV status and high viral load she was not supposed to be giving birth. Flo claims that she continued to attend ante-natal clinic at Marie Stopes Eastleigh in 2009 when she conceived again. A counselor was the first to propose that she required tubal ligation, and the doctor confirmed. *“Although, they discussed other contraceptive options like the injection and pills, the counselor said for me the only option was the tubal ligation.”*

Flo notes that her CD4 count was 140. The nurse further told her that she would not be able to have breast milk because of her CD4, which was considered very risky. Flo says that she also attended clinic at MSF in Mathare in 2009 as they monitored her CD4 count.

Seven months into her pregnancy, Flo says she was told she had to deliver and under go tubal ligation. According

to Flo, she agreed to sterilization as a condition for receiving milk for her baby. *“This was because they said that if it does not happen they will not give me milk for the baby and if I breast feed then the child will become positive. I thought it was true since at that time my CD4 was low and it was risky. I agreed to have the TL done since I could not afford to buy milk for the child. After giving birth in March 2010, I underwent the TL and I was able to get milk from the clinic.”*

Flo says she has not been able to tell her family about the tubal ligation. However, she told a friend who came to visit her at the hospital. She thinks that people living with HIV should not be discriminated, and their condition should be viewed the same as that of people with diseases such as diabetes or cancer who are on medication throughout.

Sem

Sem lives in the sprawling slum of Kibera and has given birth nine times. She says in 2005 she became pregnant with her tenth child. While visiting the village in Western Kenya she fainted and was rushed to Sabanah Government Hospital in Kakamega. *“I found myself at the hospital and they helped me deliver the child but he came out dead. During the delivery they operated on me and also tied my tubes”.*

“I don’t know what happened that made them do the tubal ligation. I was not told immediately, so I went home, and I asked my husband what happened. He told me that he felt I needed to have a tubal ligation done as he did not want me to continue giving birth.”

Sem notes that her husband told her that after she was admitted, the doctors approached him and said that they strongly recommended that She gets a permanent family planning method. According to Sem, her husband

was convinced and he signed the consent forms authorizing her sterilization.

Sem is angry and feels that before a procedure as permanent and irreversible as tubal ligation is carried out, it requires consultation and consent from the woman. *“I felt he [husband] did me no good. It is against the law...until we agree on something and then we do it. He wronged me because I can meet someone who will tell me he wants a child and I am unable to give birth...I can miss a place to stay because I can’t give birth”.*

“My husband died after the sterilization surgery. However, I have now met a man and he says he wants to live with me...how will I live with him when I cannot give him children?” Sem laments. She believes that the choice to undergo a tubal ligation is a woman’s because it is done on her body. *“Nobody, not even doctors or husbands, should be allowed to make choices for women.”*

Nereah

With a history of complicated deliveries, coupled with her positive HIV status, Nereah says her doctors advised that she should not continue giving birth. A mother of two, Nereah has been living with HIV since 2001. She notes that she would like legal action taken against doctors and nurses who force or coerce women into sterilization. She observes that forced sterilization is common among women with low education and low income in the rural areas as well as informal settlements within urban areas.

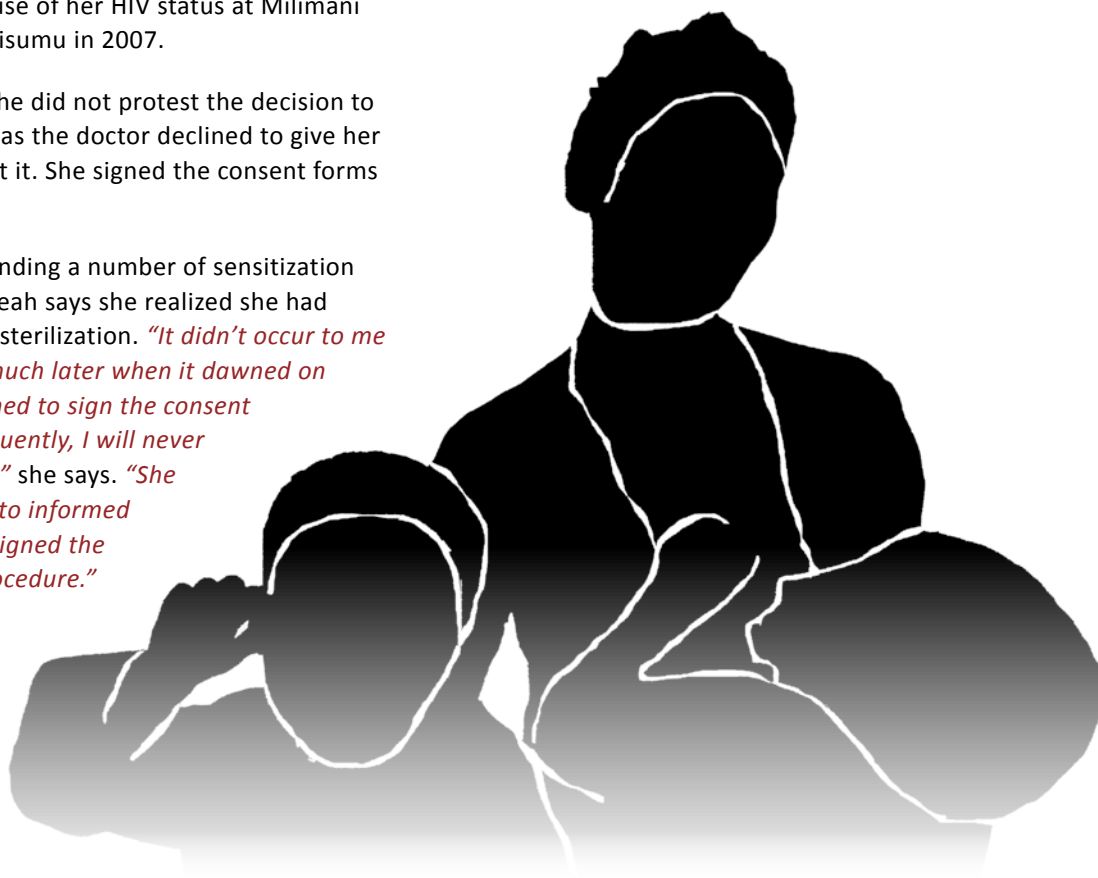
A community health worker and counsellor, Nereah says she was pressured into sterilization by her gynecologist because of her HIV status at Milimani Nursing Home in Kisumu in 2007.

Nereah says that she did not protest the decision to be sterilized, even as the doctor declined to give her time to think about it. She signed the consent forms after the surgery.

It is only after attending a number of sensitization programs that Nereah says she realized she had been coerced into sterilization. *“It didn’t occur to me as an issue, until much later when it dawned on me that I was pushed to sign the consent papers and consequently, I will never have a child again,”* she says. *“She violated my rights to informed consent as I even signed the forms after the procedure.”*

Nereah appeals to the Ministry of Health to put in place policy guidelines to prohibit forced or coerced sterilization of women living with HIV. She also recommends that medical practitioners be re-trained on women’s reproductive health rights to reduce discrimination of people living with HIV.

Nereah has shared her experience in public forums to create awareness on the existence of the problem in Kenya and called for action to be taken against medical practitioners who sterilize women without their consent. She has also shared the experience with her husband who has been supportive.



Gina

When Gina got pregnant in 2010, she says she attended ante-natal clinic at Blue House. Gina says she liked the fact that they were taught how to protect their children from HIV infection.

When Gina was due for delivery, she says she was referred to Pumwani Maternity Hospital where she was scheduled to deliver through cesarean section. *“At Pumwani, I met a sister [nurse] who talked to me about the family planning; I told her that I had not been on any method before my pregnancy.”*

According to Gina, the nurse then told her that since she was 36 years old, HIV positive and with enough children she should undergo sterilization at delivery. Gina was in the hospital to deliver her third child. Gina notes that she was given consent forms to sign before she was wheeled into the operation room.

During the first post-natal clinic at the Blue House, Gina says that nurses wanted to confirm if indeed she had undergone tubal ligation before they could attend to her. She says that she recounted her conversation with the nurse at Pumwani about the sterilization, but the nurses at Blue House sent her back to Pumwani to bring documented evidence. *“When I got back to Pumwani they went through my records and confirmed that indeed a tubal ligation had been done. This was endorsed on my Blue House clinic card.”*

According to Gina, the endorsement secured her medical attention at the clinic. However, she has never told anyone about the sterilization, not even her husband because she is afraid of how he will react since she doesn't know if he would want more children. She says women who are poor and living with HIV are disadvantaged because they are manipulated into accepting sterilization.

Laura

Laura and her husband had lived with HIV for a number of years. Though they were on anti-retroviral drugs, they believed they would die soon. According to Laura, they began to worry about their children when Laura got pregnant with the third child. Laura's husband approached a friend, a medical officer, and discussed their situation.

Laura says the medical officer recommended that after giving birth, she should have a tubal ligation. This was in addition to a recommendation by a nurse that it was time she stopped giving birth.

Laura says that in 2000 she delivered twins at Kenyatta National Hospital through cesarean section and had

the tubal ligation done. *“My husband was furious (that Laura had twins); he said ‘now see what you are doing, next time you will even give birth to four children at a go. Whom will we leave these children with?’”* Laura continues: *“I did not want to consent but I was under pressure from my husband and the medical officer. I knew of other-long term methods of family planning because I had heard women discussing them at the clinic.”*

Two months after delivery, one of the twins, a girl, died due to lack of milk. Laura wishes the nurse and the medical officer spoke to her about other methods of family planning.

Betty

When Betty discovered in 1993 that she was HIV positive after a visit to the ante-natal clinic in her second trimester, she says that her husband was not amused. He accused her of *“bringing the disease to their marriage”*. Arguments and fights were the consequences of her disclosure, which led to their separation. Betty says she was forced to go back to her parents’ home from the city.

At her parents’ home there were no open arms waiting to welcome her. Betty’s parents were dead, and her brothers questioned her ability to bring up her soon-to-be-born fourth baby without an income and a husband.

According to Betty, three weeks after she gave birth, community health workers visited the home and asked her to accompany them to the market center the following day to meet doctors from Marie Stopes who had visited to offer healthcare services to women living with HIV.

“One community health worker told me, they want to take me to the place because I needed help for my baby because of my HIV status.”

The community health workers had been referred to Betty by her brother. Though she was hesitant to go, as an incentive, the community health workers offered to pay her fare just for her to meet the visiting doctors.

“I thought I would get financial assistance from the Marie Stopes doctors to support myself and the children since my brothers were not supportive.”

When she arrived at the hotel where the doctors had pitched a mobile clinic, Betty says that she was given forms to sign but did not understand the content. *“No one told me what I was signing for. I thought it was part of the registration.”* After signing, Betty notes that a nurse led her to another room. *“The nurse told me to get on the bed to be cut.”*

After the operation, Betty says that she sought information on the reason for the procedure and was told that the community health workers had identified her as a woman who needed tubal ligation because she was HIV positive, separated from her husband with no income and had many children.

Looking back, Betty says that her rights were violated and wishes the doctors explained what the procedure was all about as well as giving her an opportunity to make an informed decision.



Kate

Kate says she was rushed to the Kenyatta National Hospital by her daughter because she had an ectopic pregnancy. Since in an ectopic pregnancy the baby cannot survive, the doctor wheeled her into an operation room, removed the fetus and sterilized her without her consent. Kate says the doctors gave her sixteen year old daughter some forms to sign, and she (Kate) did not know what was going on. According to Kate, her daughter was only told to sign a form on behalf of her mother.

Kate notes that this incident happened 15 years ago, and she has not been able to get pregnant since. *“I*

got to know that I had undergone a tubal ligation when I started having a lot of pain after I regained consciousness. My daughter was by my bedside, and she told me she had heard the doctor say they did tubal ligation on me.”

While Kate says that even if she warranted a tubal ligation, she is hurt because the choice was made for her by the doctors. *“They just said it was an emergency and they wanted to save my life and thought it was a good measure to also cut my tubes.”*

Aida

A mother of three children who include a set of twins, Aida says she relied on the MSF-Blue House for medication and anti-retroviral therapy. After giving birth to her last child, she visited the clinic for post-natal care. *“I visited Blue House and was told I had to think about tubal ligation because I was a mother who was HIV positive and had many children. I said I did not want to the sterilization because there were many methods of family planning, but I was told if I did not undergo tubal ligation I would not receive the drugs again and should think of what to do after that as I would not be given the milk again.”*

According to Aida, she had anti-retroviral drugs from the Blue House clinic that would last her a week, and she returned home to think over her options. After agonizing for a week about her choices, Aida says she returned to Blue House because she did not know about other clinics where she could get her supply of medicine and milk for the children. *“I decided to consent for tubal ligation so that I could receive help for medicine and milk.”* Aida says

that she signed the forms and was referred to Mathare North City Council Clinic.

Aida believes that her surgical procedure was botched. *“When I got to the clinic, I was called to a room and told to remove my clothes and lie down. The doctors injected me [anesthesia] but I did not become numb or go to sleep and could feel everything that was being done to my body.”* She says she was stitched and slept on the hospital bed for about one hour. *“The whole process took two hours and I walked home about two kilometers away. I arrived home with so much pain, I slept for three days and was unable to do nothing including eating or cooking.”*

Aida says that she had no prior knowledge of tubal ligation and did not know what to expect. She believes doctors need to explain the procedure to their patients. For Aida the only way to stop forced and coerced sterilization of women living with HIV is through public awareness education.

Caro

When Caro suspected that she could be pregnant in 2006, she says she decided to visit a public hospital in Nairobi. She was tested for pregnancy and subsequently when attending ante-natal clinic she was also tested for HIV. Caro says her results turned positive and she was immediately enrolled for the Prevention of Mother to Child Transmission Clinic (PMCTC).

Caro received counseling including recommendation for tubal ligation. *“The nurse told me that since I was very young, the only way to live well for many years is not to get pregnant again because if I gave birth my immunity will reduce leading to death and my children will be left orphans.”*

Further, Caro notes that she shared with her husband the advice she had received from the nurse who in turn encouraged her to go for the tubal ligation. When she was due to give birth, Caro says she could not afford to raise KSh10,000 that was required as a down payment to book her into a maternity ward in either Pumwani Maternity Hospital or Kenyatta National Hospital. Caro says she shared with the nurse about financial difficulties. The nurse offered to help.

“She asked me to raise KSh300 and she will send me to a community health worker who will give me a voucher card charging KSh200 for delivery and KSh100 for tubal ligation at Marura Nursing Home, in Mathare North.”

Caro says she obliged since she was in dire financial need. She gave birth through cesarean section and a tubal ligation was done. According to Caro, the doctor who operated on her was from Kenyatta National Hospital. *“The doctor asked if I knew I was going to have a tubal ligation and I said I did because TL was a pre-condition for accessing low cost maternity attention. The doctors did not tell me how tubal ligation will affect my health; he assumed someone else had told me.”*

Caro says she returned home four days after the operation. Four months later, thugs attacked and killed her husband when he was on his way from work. Two years later, she met another man who wanted children despite the fact that Caro had told him that she can no longer give birth. They soon parted ways.

Caro would want nurses and doctors to allow mothers to decide for themselves after elaborately explaining the consequences of the procedure including the side effects. The consent forms should be printed in an easy to understand language and possibly written in Kiswahili.



Emma

Immediately Emma tested HIV positive in 2001 during a visit to the Prevention Mother to Child Transmission clinic, she claims that her husband abandoned her while she was two months pregnant with their third born child. During a group therapy, Emma says she met a man who was living with HIV and they got married. Soon after, she began attending ante-natal clinic at the MSF-Blue House in Mathare. *“At the clinic, the nurse recommended that since I will give birth through cesarean, I should undergo tubal ligation because of my HIV positive status.”*

At first, Emma says she refused to sign the form as instructed but she had no choice since Blue House was catering for her maternity bill at Pumwani. *“The nurse told me if I did not agree to tubal ligation then Blue House will not take care of my maternity expenses. I got to Pumwani and I was given a form, the nurses insisted I had to sign. They called me ‘a useless woman with HIV’. I took the form and signed it because I was kept waiting in the labor ward until I signed.”*

According to Emma, she was wheeled to the theater on May 20, 2010. Emma says that she delivered

through cesarean section and was sterilized. *“I gained consciousness hours later and was in a lot of pain. I asked the doctor why I was in so much pain and he told me that I had undergone an operation twice, for delivering the baby and the other for tubal ligation. He also said that there is a tail that is normally cut so that HIV positive women cannot give birth.”*

Emma says that she was in Pumwani Hospital for three days before she was discharged. It took her two months to recuperate. When she disclosed to her husband about her non-consensual sterilization experience, he was not amused. *“The news made him very unhappy and it affected our relationship because he felt that my other children were not biologically his and he had hoped I would give him a child someday.”*

Emma says that before the sterilizations she was a casual laborer who did manual jobs like washing clothes in up market residential estates in Nairobi. *“Since my double operation, I cannot do heavy work so I have no income. Tubal ligation took away my relationship with my husband and my job.”*

Atieno

During the post-election violence of 2007 that took place in Kenya, Atieno says that she was taken ill at the St. Mary’s Hospital with severe stomach pain in what looked like heavy menstrual periods that lasted for two weeks. At the hospital, Atieno notes that she was examined and diagnosed with a growth in the stomach. She was immediately taken to the theater for a surgical procedure to remove the growth. *“They removed the growth but also cut my tubes.”*

At the time of discharge, Atieno says that she did not know that she had been sterilized. She only got to know about it when she went back for follow up. *“I*

went back to the hospital after two weeks from the time of operation and found a nurse, who told me that they closed my tubes since I had suffered a serious miscarriages, was HIV positive and also lost a lot of blood”.

Atieno asked the nurse why they did not seek her consent before they sterilized her and *“the nurse said it was an emergency, they had to do the procedure.”*

Unfortunately, Atieno’s husband was also killed during the post-election skirmishes. *“Post-election violence took away my husband and my womanhood, I feel lost.”*

Nekesa

In 2008, Nekesa says she got pregnant and was chased out of home by her parents. With nowhere to go, she notes that she moved from her rural village to Kakamega town where she started attending ante-natal clinic. Nekesa says that she also tested positive for HIV and was on medication to prevent transmission of the virus to her unborn child. However, at delivery, Nekesa says she was stunned by health care providers at the Kakamega General Hospital.

According to Nekesa, the doctor warned her that *“It is an offence for women who are HIV positive to have children.”* The doctor told her that they will only allow her to have the baby she was due to deliver if she allowed them to perform a surgical operation to permanently stop her from having more children.

Nekesa says that she protested against the sterilization arguing that she may meet a partner who wants children. Her attempts to convince the nurse that she was open to other family planning methods apart from tubal ligation were futile.

“I asked the nurse why they were discriminating against me because of my HIV status, and she said ‘it is illegal for HIV positive women to have children,’” Nekesa recalls. Though she was in labor, she says that she put up a spirited fight but lost as she was sterilized without signing the consent forms.

Nekesa later got married but was abandoned by her husband for not being able to bear children. *“I wish I never revealed to him that I had been*

sterilized. My husband was ready to support me but when I disclosed to him that I had been sterilized, he left,” she says.

She recommends that doctors and nurses be sensitized against abuse of the rights of women living with HIV. She urges that the women also be empowered to make informed choices on family planning methods.



Liz

Liz says that she tested positive with HIV in November 2001 while attending ante-natal clinic at Upendo Hospital in Eastleigh.

When labor set in, Liz claims that she could not raise fees to pay for maternity bills so she gave birth at home. After child birth, Liz notes that she became very sick and was taken to Kenyatta National Hospital. The baby was taken by nurses from MSF-Blue House to Dagoretti Centre where it stayed for three years. When she recovered, Liz took back her child and they began living together.

In 2004, Liz says that she conceived again and continued to attend her clinic at MSF-Blue House where she was given anti-retroviral drugs and milk. She was also advised on how to manage her health. According to Liz, at the time there were a number of women at the Blue House who were HIV positive and were being discouraged from getting pregnant.

“We were told that if we continue to give birth then we will die so we have to stop permanently. The doctors at Blue House told us that doctors from Kenyatta Hospital were visiting the Lions clinics and carrying out tubal ligation. Blue House doctors said that if we did not go for the tubal ligation, some of us will continue to give birth and our immune system will go down.”

Given that she did not have a job, her husband was jobless as well and they had other children to take care of, Liz says she decided to go to Lions to have sterilization done to protect her immunity. *“I do not have a job. I am just there and we have children. I thought there is no need to refuse, so I decided to have the tubal ligation done. My TL was done in 2005 at Lions which is a City Council clinic next to Redeemed Gospel Church.”*

The doctors at Lions Clinic explained to her that she needed to have the sterilization performed but did not tell her about the other available options for family



planning. *“I had to do tubal ligation since I thought truly; we have been told that there is no medicine. Yet this disease kills and if we continue to give birth then our immunity will go down, we are putting our lives in danger and we can die.”*

“I decided if that is what will cause me to leave my children, then it is better to agree and take care of them. I would rather accept to have the sterilization done and then I take care of these other children.”

Liz has had adverse health effects as a result of the operation. *“After the tubal ligation, there are times I feel pain down here. The wound feels painful and the pain moves to my back. At times when I tell my husband I am in pain, he quarrels and says that is something I brought on myself that is why it is causing me problems. So these days even though I feel pain I do not tell him.”*

Mary

From 2008, Mary says she had a persistent cough and decided to go to Eastern Deanery Hospital in the Kariobangi area of Nairobi that is run by the Catholic Church to be tested for Tuberculosis (TB). While at the hospital, Mary was also tested for HIV and the results turned positive. *“I was told that since I was HIV positive, they will give me drugs for TB and they will also help me by counseling.”*

Mary was told that TB is curable but HIV was not. The nurses at Eastern Deanery Hospital referred her to the Kariobangi City Council clinic. *“They told me that there are doctors who visit there every three months to carry out tubal ligation for women.”*

Since Mary had only one child, she says that she did not like the idea of tubal ligation and therefore, did not go back to the clinic. Mary says she decided she will lie to the nurses at Eastern Deanery because she needed medical services from them.

“I told them I didn’t get a chance to go and they told me they will stop giving me medicine because it seemed I did not want to be helped and improve my life.” Afraid of losing out on the services she was getting from Eastern Deanery, Mary says she visited Kariobangi City Council clinic and signed the forms to give consent for sterilization. According to Mary, the procedure was conducted by doctors from Marie Stopes.

“The tubal ligation was done on 13th June 2010 by a male doctor and two years later I started having problems of controlling urine.” While the nurses at Eastern Deanery told Mary that there many different types of family planning, they insisted the best one for her is the sterilization.

Because of her inability to control urine, Mary has suffered adverse social stigma. She is not able to travel upcountry because it requires her to sit for long hours in

a bus and yet she needs to use the bathroom frequently. Mary feels pained by what happened to her and would like to seek legal redress. *“The government should make sure that medical practitioners do not deceive women and action should be taken against those who are involved in such malpractices.”*

Note: Authors of this report were not able to establish if Mary’s condition post tubal ligation was as a result of the operation of progression of her illness.



Nelly

Nelly says she knew of her HIV status when she visited a Voluntary Counseling and Testing (VCT) center in 2009. At the time she was pregnant with her youngest child and was attending ante-natal clinic in Kariobangi. She says that she continued visiting the clinic until she delivered later in the year. After giving birth, Nelly notes that she was told that if she breastfeeds she could infect her child and her immunity would come down. She was put on ARVs.

“At the Kariobangi South City Clinic, the nurse recommended that since I had five children I had to do the tubal ligation. They told me this was because my immunity was low and I had to undergo the tubal ligation. They also said I should not breastfeed and that they will give my baby milk as I was on septrin. The nurse was very clear and told me that if sterilization is done then the baby would get milk from the clinic. No tubal ligation, no milk.”

Nelly says that she was against the tubal ligation because she wanted more children and made that known to the nurse. She held on to her resolve not to have the sterilization for two months during which she gave birth normally. Two months after giving birth, Nelly says she gave in and agreed to the tubal ligation being done by doctors from Marie Stopes.

However, after the surgery Nelly became very sick, could not stand or bend and her immunity went down. Her periods became very heavy and would last for as long as two weeks. This affected her jua kali (informal) business, which involved travelling to the beach and lakeside to collect dried fish for selling.

Her husband’s attitude towards her also changed when she disclosed to him that she had undergone tubal ligation. *“He sees that my life is over, I can’t get another child. He does not even eat at home.”* Two of her children have disability; the second born is deaf and

dumb and the fourth born is knock-kneed and requires an operation to rectify the problem.

“Let people be told the truth and be left to decide what is best for them not blackmailed and given conditions for them to be assisted because they can see you are in a difficult situation. Let them tell you advantages and disadvantages of tubal ligation.”

Note: Authors of this report were not able to establish if Nelly’s condition post tubal ligation was as a result of the operation or progression of her illness.



Tess

Tess has three children from a previous marriage and one from her current husband. She says in 2000 she fell sick and was taken to Kenyatta National Hospital. At the hospital, the doctors told Tess that she had to be operated on because she had a growth in her stomach. *“They asked me, can you read, and I said yes I could read. He asked if I could sign? I replied in the affirmative. I was given a form which I signed before my husband came back.”*

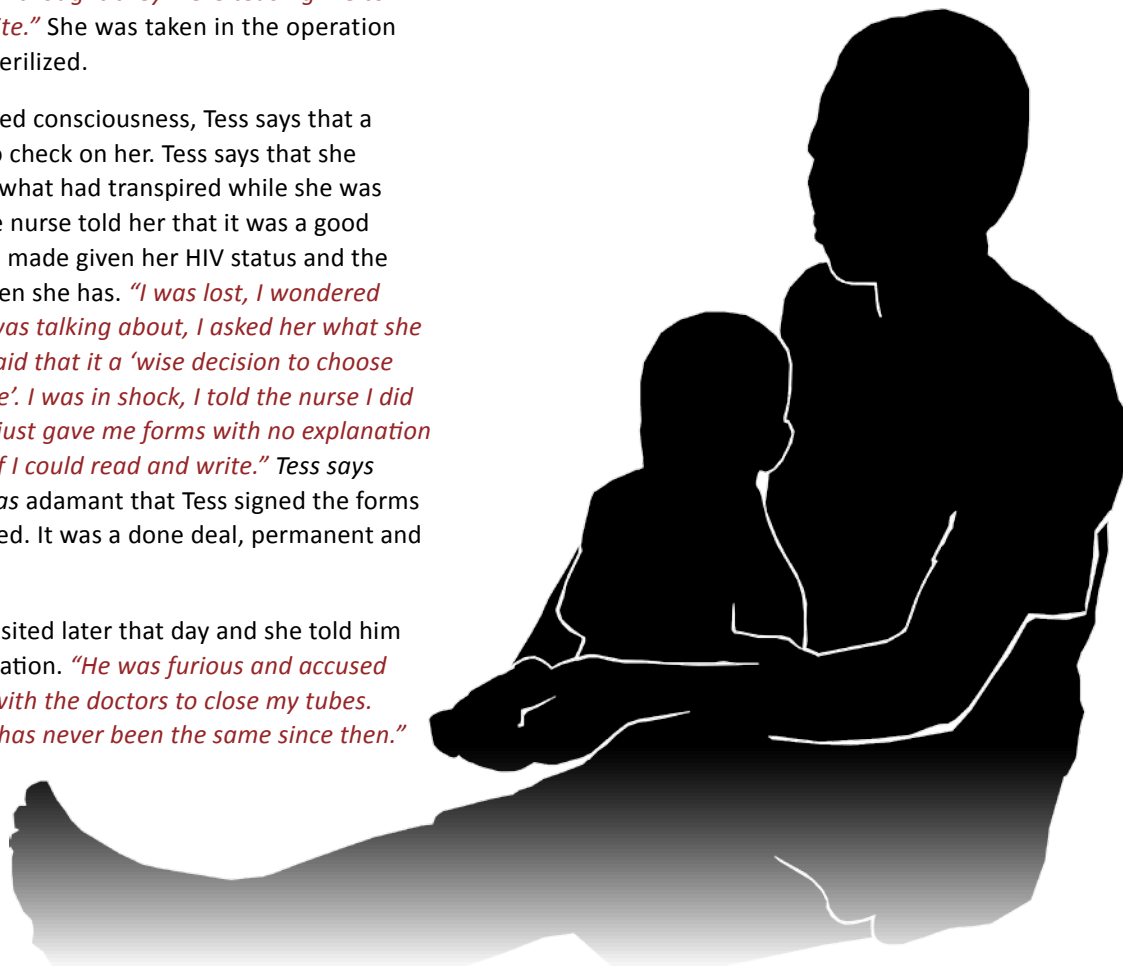
For Tess, the problem is they did not tell her what she was signing for. *“I thought they were teasing me to test if I could write.”* She was taken in the operation room and was sterilized.

When she regained consciousness, Tess says that a nurse came by to check on her. Tess says that she wanted to know what had transpired while she was unconscious. The nurse told her that it was a good decision that she made given her HIV status and the number of children she has. *“I was lost, I wondered what the nurse was talking about, I asked her what she meant and she said that it a ‘wise decision to choose to close your tube’. I was in shock, I told the nurse I did not decide, they just gave me forms with no explanation after asking me if I could read and write.”* Tess says that the nurse was adamant that Tess signed the forms and had consented. It was a done deal, permanent and irreversible.

Tess’s husband visited later that day and she told him about the sterilization. *“He was furious and accused me of colluding with the doctors to close my tubes. Our relationship has never been the same since then.”*

Tess says the arguments with her husband about the sterilization culminated into a separation and he married two more wives arguing that Tess was of no value to him.

Tess feels betrayed by the doctors and her husband. She wants justice to take its course. *“Why should doctors trick women to sign forms that they do not understand. Tubal ligation is a life changing operation, it is not like you are removing a tooth,”* Tess laments.



Conclusion

While the country-wide prevalence rates of non-consensual sterilization of HIV-positive women in Kenya are unknown, this study confirms that the violation is happening, and appears to be systemic in public health facilities. As the study was coming to a close, word had spread across the country through the various support groups of women living with HIV about the interviews, and numerous additional WLHIV contacted us eager to share their experiences of non-consensual sterilization, motivated by their resolve to break the silence of what they termed as ‘the hidden violation’ of women living with HIV.

The study has shown that healthcare providers, both doctors and nurses in some health facilities are violating the reproductive rights of WLHIV by coercing or forcing them to accept unwanted surgical sterilization procedures. Family members, especially spouses and parents, have also participated in coercing or forcing WLHIV to be sterilized, often based on misinformation provided by trusted medical professionals about the need for sterilization. Further, consent was routinely sought when the patient was in a vulnerable position, especially while in labor pains just about to go for a caesarian section. In some instances, incentives such as food were offered. The study illuminates how the intersection of low socio-economic status, HIV and gender exacerbates vulnerability of WLHIV to non-consensual contraceptive sterilization.

It is unethical and a violation of human rights for healthcare providers to intentionally misinform them or collude with their spouses or parents to coerce WLHIV to consent to sterilization. The use of abusive language by healthcare providers on vulnerable women who visit public health facilities is a systemic problem in Kenya (Failure to Deliver, 2007). The lack of or minimum intervention by the government to address patient abuse by public health care providers may embolden them to continue with unethical medical practices including coercing and forcing women living with HIV to undergo contraceptive sterilization.

The impact of non-consensual sterilization on the women’s physical, emotional and personal lives and their socio-economic status was evident. WLHIV reporting forced and coerced sterilizations endure immense physical, psychological and social trauma due to the permanent loss of the ability to give birth. Reported health complication post-tubal ligation including severe abdominal and back pains has negatively affected the active lives of these women who are mainly casual workers who rely on their physical fitness to earn a living. However, it was beyond the scope of the study to establish if the reported post-tubal ligation complications were as a result of the procedure or progression of the illness or both.

Recommendations

The study's findings warrant urgent action by the Government of Kenya. The Government has an obligation to prevent and redress non-consensual sterilization. The study recommends a couple of issues for the Kenyan government including;

1. National survey to better understand the scope of the problem of forced sterilization among women living with HIV and other vulnerable categories.
2. Review of the national family planning guidelines to align to international standards including the FIGO guidelines. The review should update provisions of the national family planning guidelines relating to women living with HIV that are ambiguous to explicit state that women living with HIV should be presented with the full range of contraceptive options, the risks and benefits of each, and that their consent is a must.
3. Clear-cut training on procedures around sterilization for all women with emphasis on the counseling and consent obtaining procedures. Specifically, by strengthening the informed consent requirements in overall and training healthcare providers on these. To safeguard against violations, the report recommends a waiting period between the explanation of the sterilization procedures and the time consent is sought and/or having informed consent be transmitted both verbally and in writing in a language that the client understands.
4. Accessibility to medical records, all patients should have access to their medical records.
5. Public education on reproductive health rights and choices for women living with HIV targeted to both women and men.
6. Establishment of accessible and effective complaint mechanisms. Women who have experienced non-consensual sterilizations must have access to justice including options to adopt a child. Redress should include the possibility of surgery to reverse the TL if the woman wants it though this may not work in all cases but women should be given the option.

Response from some of the healthcare facilities mentioned in the report

Female sterilisation in Kenya Response from Marie Stopes

We sought responses from a number of healthcare facilities mentioned in this report. Kenyatta National Hospital did not give a formal written response but verbally denied that such cases happened in their facilities and reiterated that it is against the hospital's policy to forcibly sterilize any patient.

The Medicine San Frontiers "Blue house" committed to investigate the highlighted cases but declined to give a written response.

Marie Stopes Kenya gave the following response;

The issues raised in this report are of great concern to Marie Stopes International. The principles of voluntarism, informed choice, and informed consent are fundamental to our values, policies, and practices in all of the 42 countries we work in around the world. We undertake rigorous ongoing training and monitoring to ensure that the highest standards on these issues are adhered to at all times, and we are a leader in the sector in our respect for and protection of client rights.

We are grateful to GEM for raising awareness of these very important issues, and the harrowing stories these women have been brave enough to share. We thank GEM for the opportunity to include this statement in their report.

We would be deeply concerned about any possibility that any woman had the kind of experience outlined in the report while under our care, and emphasise that our policies ensure that all women considering a tubal ligation are counselled by a Marie Stopes Kenya team member both in a group and individually, before choosing freely if they wish to go ahead with the procedure and formally giving consent.

All of our clients are first given information about the full range of family planning options in an appropriate language and / or medium, to ensure that they alone



can make an informed choice about the family planning method right for them.

Individual counselling and signing of the consent form with a Marie Stopes Kenya team member takes place regardless of whether the client has been counselled and / or given consent at a referring clinic previously.

Marie Stopes International is committed to ensuring that HIV positive clients have equal, non-discriminatory access to high quality, voluntary family planning services. We recognise the value of integrated HIV and family planning services across the world: for example we are currently working to establish a gold standard in family planning care for both HIV prevention and people living with HIV throughout the Marie Stopes International partnership, to ensure they can access these services without bias or barriers.

We provide hundreds of thousands of women in some of the most remote regions of Kenya with access to the full range of family planning methods. It is important to remember that the testimonials in this report represent a very small and, we believe, unrepresentative, sample and do not reflect the very positive experience of these hundreds of thousands of women, including HIV positive women.

In the last five years alone, Marie Stopes Kenya has provided over one million family planning services to women and men across the country. Service quality and client satisfaction is regularly monitored through client exit interviews, mystery client surveys, and clinical quality audits, which consistently show good and improving quality of care.

Specific client statements

Betty (Page 21)

The process described by Betty is absolutely contrary to Marie Stopes International's values, policy and practice on informed consent, outlined in detail on page 21. We take any potential non-compliance on this issue extremely seriously. Unfortunately with the level of available information on this case, it is not possible for us to verify or investigate the information provided by Betty. This is further complicated by the fact that the procedure in question took place almost twenty years ago.

Flo (Page 18)

The process described by Flo is absolutely contrary to Marie Stopes International's values, policy and practice on informed consent and working with HIV positive clients, outlined in detail on page 18. We take any potential non-compliance on this issue extremely seriously.

For the last seven years, Marie Stopes Kenya has run dedicated training for team members in issues relating to HIV and family planning. The guidance allegedly given to this client around needing a tubal ligation, and the allegation of a tubal ligation being given without consent during an emergency caesarean, would be a direct contravention of Marie Stopes Kenya policy, training and practice, which is regularly and rigorously monitored.

Mary (Page 27)

Marie Stopes Kenya is mentioned in this case as the service provider: it does not suggest or allege that Marie Stopes Kenya was involved with coercive

practices. The principles of voluntarism, informed choice, and informed consent are fundamental to Marie Stopes Kenya's values, policies, and practices (outlined in detail on page 27). What this does highlight is that we can work with organisations who refer clients to Marie Stopes Kenya to strengthen their policies and practices around informed consent, and this is something that we will seek to do immediately.

Nelly (Page 28)

Marie Stopes Kenya is mentioned in this case as the service provider: it does not suggest or allege that Marie Stopes Kenya was involved with coercive practices. The principles of voluntarism, informed choice, and informed consent are fundamental to Marie Stopes Kenya's values, policies, and practices (outlined in detail on page 28). What this does highlight is that we can work with organisations who refer clients to Marie Stopes Kenya to strengthen their policies and practices around informed consent, and this is something that we will seek to do immediately.

Olive (Page 9)

Marie Stopes Kenya is mentioned in this case as the service provider: it does not suggest or allege that Marie Stopes Kenya was involved with coercive practices. The principles of voluntarism, informed choice, and informed consent are fundamental to Marie Stopes Kenya's values, policies, and practices (outlined in detail on page 9). What this does highlight is that we can work with organisations who refer clients to Marie Stopes Kenya to strengthen their policies and practices around informed consent, and this is something that we will seek to do immediately.

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