"MY FERTILITY, MY CHOICE, MY RULES"

ICWEA
2016

TOOLKIT ON RESEARCH ON

SEXUAL REPRODUCTIVE HEALTH AND RIGHTS VIOLATIONS EXPERIENCED BY WOMEN LIVING WITH HIV WITHIN HIV AND REPRODUCTIVE HEALTH CLINICAL SETTINGS AND COMMUNITY SETTINGS

Researching and documenting experiences of women that were forced and coerced into sterilization may involve risk of their safety and that of their families, communities, and those who have tried to seek redress on their behalf (either informally or formally).

With support from:

STOP AIDS NOW!

LINKUP

TABLE OF CONTENTS

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ALN	AIDS Legal Network
CAT	Convention against Torture
CEDAW	Convention on the Elimination of Discrimination against Women
FGDs	Focus Group Discussions
GEM	African Gender and Media Initiative
HEARD	Health Economics AIDS Research Division
HIV	Human Immunodeficiency Virus
HRI	Her Rights Initiative
ICCPR	International Covenant on Civil and Political Rights
ICPD	International Conference on Population and Development
JAW	Justice and Women
KELIN	Kenya Legal and Ethical Issues Network
LAC	Legal Assistance Centre
NLAC	Namibian Legal Assistance Centre
OSIEA	Open Society Institute of Eastern Africa
SRHR	Sexual Reproductive Health and Rights
UNAIDS	United Nations Program for HIV&AIDS
WHO	World Health Organization

ACKNOWLEDGEMENTS

The International Community of Women living with HIV Eastern Africa (ICWEA) greatly applauds the indispensable technical and financial support from our partners who have supported us through the development of this Tool Kit.

The development of the Tool Kit was made possible by the support from 24 Research Assistants who participated in the study, “Violations of Sexual Reproductive Health and Rights of Women living with HIV in Clinical and Community settings in Uganda, as data collectors. They were able to recapitulate their experiences during the research processes and share the lessons learnt.

The Tool Kit development was also made possible by the technical support from Dorothy Acheing Odhiambo, founder and board member of Women Fighting AIDS in Kenya (WOFAK) who is currently a lecturer in Health Communication at the University of Nairobi, Kenya; Nienke Westerhorf, Advisor SRHR and Gender, STOP AIDS NOW (SAN); and all the Link Up Partners.

We acknowledge the support and hard work of ICWEA Board, ICWEA members and all Secretariat Staff that took lead in all the research processes and worked tirelessly to document the best practices, lessons learnt and highlight the different challenges. Finally, we appreciate the professional support of Levis Mugumya from the Department of Linguistics, English Language Studies & Communication Skills, at Makerere University.

1.0 INTRODUCTION TO THE TOOLKIT

1.1 Development of the Toolkit

This toolkit was developed by the International Community of Women living with HIV Eastern Africa (ICWEA), a registered regional advocacy network and membership-based organization founded in 2005 to provide visibility to women living with HIV. It is a result of a study conducted by ICWEA between 2014 and 2015, with support from STOP AIDS NOW, under the Link Up project. The study focused on sexual reproductive health and rights violations experienced by women living with HIV within HIV and Sexual Reproductive Health clinical setting in Uganda. Consequently, ICWEA documented cases and interviewed women living with HIV and interacted with experts at national, regional and global levels who are directly or indirectly involved in eliminating forced and coerced sterilization targeting women living with HIV to develop the toolkit. The toolkit also consists of responses of women living with HIV from selected African countries and information gleaned from the meeting of experts on Strengthened and Expanded Legal Services for People Living with HIV and Vulnerable Groups convened in Nairobi in August 2015.

1.2 Background to the toolkit and ICWEA's work

The first case of coerced sterilization of women living with HIV came to light in Namibia in 2007, during a training project with Young Positive Women when 3 out of the 30 participants revealed that they had been sterilized without their informed consent (ICW, 2009). Thus, the International Community of Women living with HIV (ICW) started documenting cases of forced and coerced sterilization in Namibia. Later on, similar studies were carried out in South Africa and Kenya.

While ICWEA was implementing the Sexual Reproductive Health and Rights Project in 2010 in Kenya, Tanzania and Uganda, coded, "Building a Political Voice for women living with HIV", the women in all the three respective countries, shared their experiences of being coerced into sterilization by health workers during birth due to their HIV positive status.

> ***ICWEA conducted the study in Uganda as a follow up to the revelations during the 2010 SRHR project implementation and as confirmed by the Uganda People living with HIV Stigma Index report.***

Later on, during the dialogue meeting with the key stakeholders in Kenya, the issue was picked on by Open Society Institute of Eastern Africa (OSIEA) that supported African Gender and Media Initiative (GEM), an organization that worked with the networks of women living with HIV to further document cases of forced and coerced sterilization in Kenya. With financial support from the Link Up Project under the STOP AIDS NOW, ICWEA conducted the study in Uganda as a follow up to the revelations during the 2010 SRHR project implementation and as confirmed by the Uganda People living with HIV Stigma Index report.

ICWEA's work focuses on addressing the Sexual Reproductive Health & Rights of women living with HIV, addressing and overcoming the stigma and discrimination they are subjected to through influencing policy and programmes to ensure they take into consideration women's needs and realities within the human rights framework. ICWEA's advocacy is based on evidence of daily lived experiences of women living with HIV and it employs participatory processes to address the priorities of women living with HIV from all walks of life. Therefore, this toolkit captures the lessons learnt and best practices from ICWEA's research work in order to support others who would like to do similar work.

1.3 What is the purpose of this toolkit?

This toolkit is intended for organizations that may be interested in addressing Sexual Reproductive Health & Rights violations of women in all their diversity with a particular focus on forced and coerced sterilization. It is designed as a reference tool for researchers, NGOs, CSOs and networks of women living with HIV who wish to document reported cases of forced and coerced sterilization, carry out research to facilitate the litigation processes, and conduct related advocacy programming activities. The toolkit shares lessons learnt and best practices in researching Sexual Reproductive Health & Rights violations and coerced and forced sterilization of women living with HIV and evidence-informed advocacy.

BOX 1: Importance of documenting cases of forced/coerced Sterilization of Women living with HIV in Africa

I. **Seeking redress and remedies**
The main reason is to obtain redress for the victims or seek justice through legal action. Monitoring and documenting these violations ultimately ensures that violations of women living with HIV do not go unnoticed and women are supported and educated on issues of coerced and forced sterilization

II. **Changing policies and Research on Sexual Reproductive Health and Rights violations of women living with HIV**
The research aims to change laws and practices of the affected countries to ensure that these are consistent with International standards and compel governments to comply with their treaty obligations.

III. **Changing behavior and attitudes of the establishments**
Human Rights Activists also aim to influence or change the behavior, attitudes and thinking of policy-makers, judges, local chiefs, health workers and police officials about human rights of women living with HIV.

IV. **Raising public awareness**
Publication of human rights violations including those of Women living with HIV is meant to raise awareness among the public to mount protests against these forms of violation, prevent further violation as well as attracting International attention with the aim of stopping violations.

1.4 How to Use This Toolkit

The toolkit can be used as an independent reference tool or as a resource for conducting research on Sexual Reproductive Health and Rights violations experienced by Women living with HIV. It can be used independently or in conjunction with other tools, depending on the local needs and context. The toolkit is made up of four sections. The next section provides an understanding of the terms ‘coerced sterilization’ and ‘forced sterilization’. It also demonstrates how involuntary sterilization violates the rights of Women living with HIV in the context of national and international human rights conventions. It further provides the linkages between HIV and forced and coerced sterilization. The third section highlights the research processes carried out to document cases of coerced and forced sterilization in Africa. It also underscores ICWEA’s experiences on documenting cases of coerced and forced sterilization in Uganda. The last part provides the lessons learnt and best practices derived from documenting cases of coerced and forced sterilization in Uganda, including the initial steps of research, gathering information, reporting and disseminating information and issues of advocacy.

2.0 FORCED AND COERCED STERILIZATION

2.1 What is Coerced and Forced Sterilization?

In many parts of the world, women rely on a range of methods to control their fertility, including voluntary sterilization. Sterilization is defined as "a process or act that renders an individual incapable of sexual reproduction." Forced sterilization occurs when a person is sterilized after expressly refusing the procedure, "without her knowledge or is not given an opportunity to provide consent" (Open Society Foundations, 2011, p. 2). On the other hand, coerced sterilization occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. Women living with HIV are particularly vulnerable to forced and/or coerced sterilization performed under the pretext of legitimate medical care or the consent of others in their name.

The involuntary sterilization of women living with HIV is a global issue. Cases have been documented in various countries, including Kenya, Namibia, South Africa, Uganda and Zimbabwe. This reality sits in sharp contrast with the fact that involuntary sterilization amounts to a violation of numerous international human rights norms including the right to be free from discrimination.

Forced sterilization occurs when a person is sterilized after expressly refusing the procedure, "without her knowledge or is not given an opportunity to provide consent".

Sterilization without full, free and informed consent has been variously described by international, regional and national human rights bodies as an involuntary, coercive and/or forced practice, and as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to found a family and the right to be free from discrimination,[1] the right to be free from torture and other cruel, inhuman or degrading treatment or punishment. International human rights bodies and professional organizations have explicitly condemned coercive population policies and programs as well as forced and coerced sterilization. They have urged governments to protect persons from such treatment including where such practices are committed by private individuals, such as health-care professionals.[2]

All countries where forced and coerced sterilization of women living with HIV have been documented (Namibia, Kenya, Zimbabwe, South Africa and Uganda) assented to the International Covenant on Civil and Political Rights (ICCPR); the Convention on the Elimination of Discrimination Against Women (CEDAW); and the Convention Against Torture (CAT). These international treaties are legally binding and obligate signatory governments to comply with these rights: right to information, health, bodily integrity, non-discrimination, equality, and to live free from inhuman and degrading treatment, non-interference in one's privacy, right to health, and reproductive self-determination.[3]

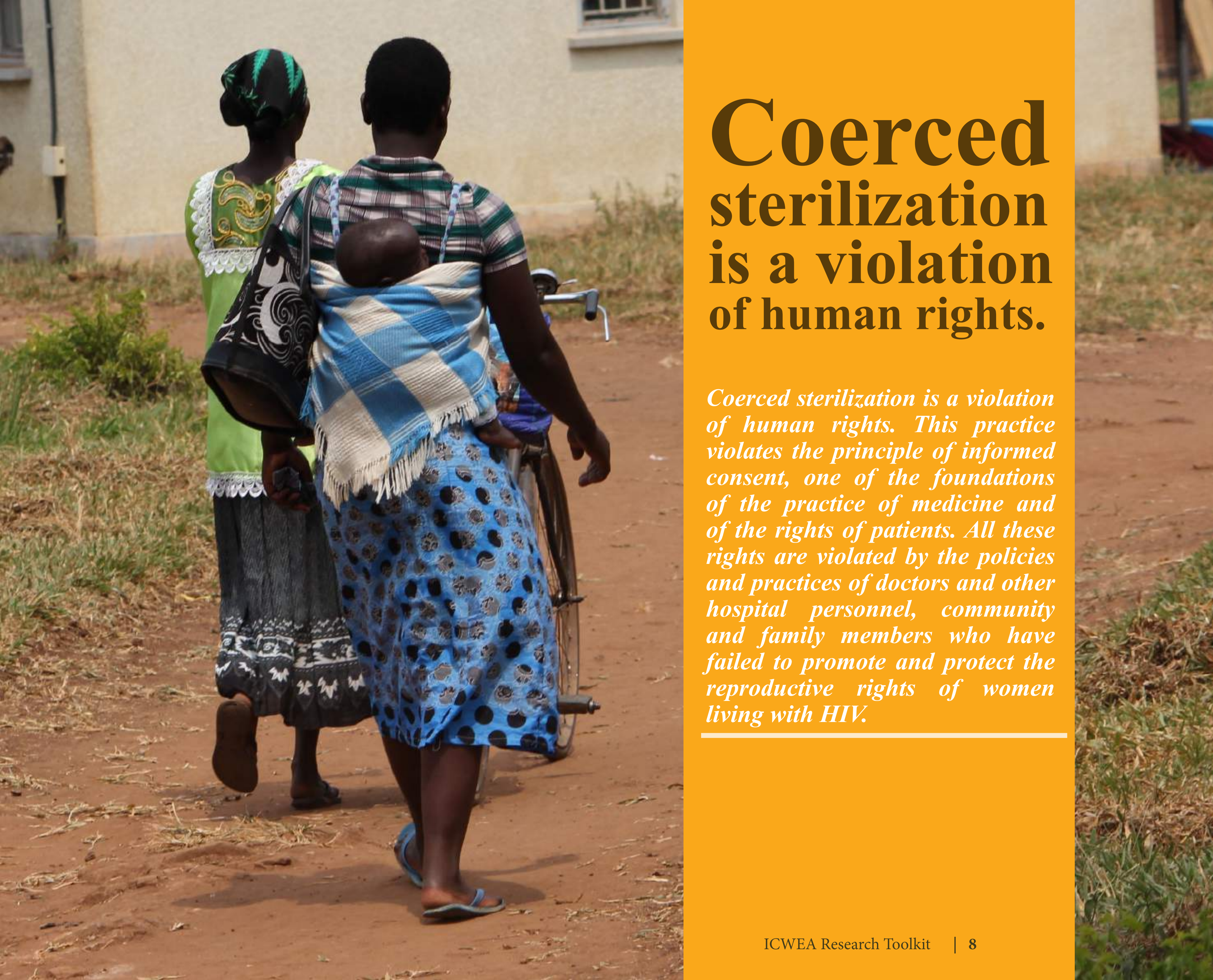
Despite the presence of international standards and protocols and the general medical practice of acquiring informed consent, forced and coerced sterilization remains a common practice in nations with high HIV infection rates, particularly among the African countries (South Africa, Namibia, Kenya and Zimbabwe) (Sethembiso et al., 2011). For example, South Africa's Constitution and Sterilization Act of 2008

---

[1] Universal declaration of Human Rights

[2] http://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf

[3] The Forced and Coerced Sterilization of HIV Positive Women in Namibia, ICW MARCH 2009



Coerced sterilization is a violation of human rights.

Coerced sterilization is a violation of human rights. This practice violates the principle of informed consent, one of the foundations of the practice of medicine and of the rights of patients. All these rights are violated by the policies and practices of doctors and other hospital personnel, community and family members who have failed to promote and protect the reproductive rights of women living with HIV.

promotes autonomous decision making and protects patients by requiring voluntary, informed and written consent before sterilization. Contrary to this, coerced sterilization is still practiced in South Africa. Therefore, the need to guarantee the human rights of women is still a pressing concern.

Coerced sterilization is a violation of human rights. This practice violates the principle of informed consent, one of the foundations of the practice of medicine and of the rights of patients. All these rights are violated by the policies and practices of doctors and other hospital personnel, community and family members who have failed to promote and protect the reproductive rights of women living with HIV. Given the varying nature of the health services sought, discrimination at health care settings has a gendered aspect.

“HIV positive women and men have the right to healthy sexual and reproductive lives. Health services that provide non-coercive, non-judgmental support and services for HIV positive women and men can help them to make informed decisions about sex and reproduction. With political and communitywide commitment to the human rights of HIV+, as well as positive people’s meaningful involvement in policy and program design, truly transformative change can take place” (Bell, Mthembu, O’Sullivan & Moody, 2007).

2.2 Linkage between HIV and Forced and Coerced Sterilization

To date, the HIV epidemic has had its most profound impact in sub-Saharan Africa and women make up the majority of People living with HIV (PLHIV) (Henry J. Kaiser Family Foundation, 2006). WHO and UNAIDS (2014) estimates indicate that women in sub-Saharan Africa constitute 60 per cent of people living with HIV. Women are especially vulnerable to HIV because of less decision power, lower education, gender inequality and their employment status which is dependent on labor intensive activities, lower incomes, least access to formal social security and least entitlements to or ownership of assets and savings (Mutangadura, 2001; De Bruyn, 1992).

Women living with HIV are particularly vulnerable to rights violations due to persisting stigma and discrimination. Because of their vulnerability, there are increasingly reported instances of forced sterilizations of Women living with HIV in Africa. HIV-related discrimination experienced by Women living with HIV when they are seeking reproductive health services and negative attitudes towards their right to procreate reported by healthcare providers in many countries suggest that HIV status may be a critical driver of coerced and forced sterilization. For example, in response to the rising HIV infection rates among women (in their reproductive age) and its link to poverty, many government health facilities have resorted to forcibly sterilizing Women living with HIV in order to prevent the transmission of HIV during childbirth. Therefore, the apparent main reason for coerced and forced sterilization is to prevent Women living with HIV, especially those from poor backgrounds from further child bearing as well as preventing Mother to Child Transmission (MTCT). However, research has shown that, if managed correctly, the risk of Mother to Child Transmission (MTCT)/vertical transmission of HIV can be reduced to less than 2 per cent among the non-breastfeeding populations.

Women living with HIV are particularly vulnerable to rights violations, due to persisting stigma and discrimination. Because of their vulnerability, there are increasingly reported instances of forced sterilizations of Women living with HIV in Africa.

Since 2007, there have been increasing reports of forced and coerced sterilization of Women living with HIV in Kenya, Namibia, South Africa, Uganda, Zimbabwe and in some countries in Asia Pacific and South America. Since the first three cases were documented in Namibia by ICW, many other cases have been documented in other countries.

3.0 RESEARCHING FORCED AND COERCED STERILIZATION: ICWEA'S EXPERIENCES

3.1 Overview of studies in Africa

Studies on forced and coerced sterilization of Women living with HIV in Africa and elsewhere have generally employed qualitative research designs. Questionnaires were used to collect data while focus group interviews facilitated by research assistants were useful in eliciting information from the research participants.

The target populations largely entailed Women living with HIV, within the reproductive age (18 and 49 years) and were using at least family planning or had undergone sterilization as a form of Family Planning. However, in most countries in Southern Africa, young women living with HIV were targeted.

The process of protocol development was very participatory involving inputs from principal investigators, staff from researching organizations, research consultants and women and girls living with HIV.

The relevant research permits and ethical approvals were obtained from various establishments mandated to oversee research processes in each of the countries studied. Informed consent is the cornerstone of ethical research on human subjects. Like all studies targeting Women living with HIV, the country-specific studies were approached with great sensitivity to respect the respondents' intimate private, sexual and emotional life. The purposes of the research, preserving confidentiality, structure of data collection tools and the risks and benefits of those involved were explained in order to elicit consent. Informed consent from the potential study targets and beneficiaries (all interviewees and fieldwork participants) was obtained before fieldwork started.

Below (Table 3.1), we provide highlights of various studies conducted in Namibia, South Africa, Zimbabwe, and Kenya.

Table 3.1: Summary of Research Process on Coerced or Forced sterilization in Africa

Study Location	Study Population	Ethical Consideration	Approach Used	Data Collection	Provision of Safe Space	Use of Incentives	Cases of forced and coerced sterilization
Kenya – Nairobi and Kakamega counties	40	The Ministry of Education and Kenya Medical Research Institute endorsed the study, informed Consent	Qualitative design involving support group members and selected using snowball sampling	Questionnaire research Assistants from partner organizations	All countries provided safe space for conducting the interview	N/A	Women living with HIV underwent non-consensual tubal ligation during an emergency (during C-section delivery). Consent obtained when woman is in labor or provided by spouse/relative
Namibia	230	Informed Consent	Qualitative design using support groups	Focus Group Discussion, Interviews by staff and volunteers of ICW and LAC		N/A	Doctors and nurses sterilized Women living with HIV without providing truthful information and obtaining voluntary, informed consent. Consent given at the last minute when the woman is on delivery table in pain
South Africa – Gauteng and KwaZulu-Natal provinces	27	Informed Consent	Snowball sampling, screening to distinguish Women living with HIV voluntarily sterilized and those involuntarily sterilized, questionnaire administered to Women living with HIV	Semi Structured Interviews, Trained Research Assistants from partner organizations to collect data		Women were paid US$ 4 for completing the screening questionnaire and US$10 for participating in the study to compensate them for their time, inconvenience and expenses	22 of women living with HIV (unemployed and unmarried) coerced into sterilization in a public facility
Zimbabwe -	59, mostly members of local HIV support groups	Informed Consent	Qualitative design involving support groups	Community workshops, in-depth interviews, Women living with HIV trained to collect data		N/A	HIV diagnosis impacts every aspect of women’s lives

3.2 Documentation of Forced and Coerced Sterilization of women living with HIV in Uganda

In 2010, while implementing the Sexual Reproductive Health & Rights Project in Kenya, Tanzania and Uganda, ICWEA discovered that the women shared their experiences that demonstrated violations of their sexual reproductive health and rights within the clinical and community settings. What was striking was the trend of these events and the similarity in their narratives[4]. In addition, there was no documentation of what was happening to these women. The women had not known that their rights were violated; they thought that they were being assisted. The women's responses and experiences prompted ICWEA to further engage in an inquiry into the nature of these violations.

Time of study

The study was conducted between 2014 and 2015.

Approach Used

The participants were identified through existing networks of ICWEA and other likeminded organizations, existing support groups, and from health care facilities. Research assistants, who were also women living with HIV of reproductive age helped in identifying some respondents. Largely purposive sampling was used and data was collected using in-depth questionnaires, key informant interviews and FGDs led by young women living with HIV. Other sources of data included family members, government officials and spouses of the women. In addition, the study carried out desk reviews of key documents that deal with forced and coerced sterilization.

Target Population

A total of 770 participants from 9 districts were involved. Women living with HIV within reproductive age (18 – 49 years) were targeted.

Protocol development

The research protocol was developed by ICWEA with technical support from the consultants. It was then reviewed by the members of the Global Technical Working Group, members of the National Steering Committee, and The AIDS Support Organization (TASO) IRB research committee. Finally, approval was granted by the Uganda National Counsel of Science and Technology.

Ethical Considerations – Informed Consent

TASO Institutional Review Board (IRB) and Uganda National Council of Science and Technology (UNCST) provided review and approval respectively.

All the respondents provided their informed consent before the questionnaires were administered. Written consent forms were explained in the various languages and given to the study participants to sign before the interview. All research assistants were trained to ensure that they protect the confidentiality of research subjects and ensure their safety. At the beginning of each interview participants were assured of confidentiality, and the manner of noting responses explained to them. Where responses needed to be recorded, consent was sought from the participants. Where participants were uncomfortable with recording; the responses were written down instead. Participants had the liberty not to answer questions they were uncomfortable with. Confidentiality was maintained throughout the data collection, analysis and report writing processes. Pseudo names were used to voice the responses of Women living with HIV and other respondents. The participants were informed about the aim of the study, probable benefits and assured that participation in the research would not culminate into any harm, denial of services or access to resources in the organizations where they work or are affiliated.

---

[4] The sterilization happened when women had gone to deliver in government facilities. The medical personnel did not inform the person concerned, explain the procedure or seek their consent.

Cases of forced and coerced sterilization identified

A total of 23 study participants revealed that they had experienced Sexual Reproductive Health and Rights violations. Out of these 20 had been coerced or forced into sterilization. Most cases of forced and coerced sterilization had taken place in government health facilities, where the women had to undergo a caesarean section during childbirth. Consent for the procedure had not been sought prior or the procedure was carried out without the knowledge of the individual or family members.

From these studies, it was evident that Women living with HIV were denied information while seeking medical care. In some cases, participants reported that test results were handed over to them in language unknown to them. In many facilities, medical personnel and caregivers were often described as unable or unwilling to explain procedures and processes to women living with HIV. However, doctors and medical personnel dismissed concerns being raised by the women.

The right to seek, receive and impart information forms part of the interdependent and interrelated corpus of human rights. Information is a key component of the right to health as well. Accurate information must be available and accessible, both in terms of content and language.

The International Guidelines on HIV&AIDS and Human Rights have made it clear that ending stigma and discrimination against people living with HIV is critical to stemming the progression of the epidemic. Unfortunately, the practice of coerced and forced sterilization of Women living with HIV has the opposite effect of further entrenching pre-existing stigma by removing the power from them to exercise control over their bodies and health. By targeting women living with HIV, medical personnel are sending a message that these women do not have the right to procreate, specifically due to their HIV status. By failing to stop the practice and hold perpetrators to account, the governments are reinforcing the stigma and discrimination against women living with HIV.

Therefore, the need to eliminate stigma and discrimination in the health care sector is particularly important in the context of HIV, where women repeatedly need to interact with medical personnel in managing HIV. A number of the women indicated their heightened unwillingness to go to public hospitals due to this experience and have expressed their alienation from the public health care system. Ending the practice of coerced sterilization will not be enough to remove the stigma and discrimination Women living with HIV have experienced. Governments and the medical community must categorically reject the values underlying the practice of coerced and forced sterilization, hold perpetrators to account, and ensure that mechanisms are in place to avoid the continuation of the practice. By doing that, the government will make clear that such violation of women's fundamental right to sexual reproductive health and rights will not be tolerated. It is the national governments' role to prevent coerced and forced sterilization, prohibit such practices, respond to the consequences of these practices, hold the perpetrators responsible, and provide redress and compensation in cases of abuse.

23 participants had **experienced** **Sexual Reproductive Health & Rights Violations**

20 participants had **been coerced or forced into Sterilization**

4.0 LESSONS LEARNT AND BEST PRACTICES

Lessons learnt for the research approach/design

- A country study on coerced and/or forced sterilization using qualitative approaches to document Women living with HIV's experiences of coerced or forced sterilization is suitable because it provides the women who underwent coerced or forced sterilization an opportunity to give comprehensive information on their experience of coerced and/or forced sterilization.

- The research project should predominantly engage Women living with HIV who are selected from existing support groups and trained to act as research assistants.

- Using snowball sampling method where interviewees are asked to identify potential participants or identification through a screening questionnaire is a good sampling technique for the recruitment of study participants and ensures voluntary participation.

- A model of partnership that includes researchers, Women living with HIV and those who are negative or untested, community leaders and health care workers is recommended for an effective study on forced and coerced sterilization.

- Young Women living with HIV are engaged in all aspects of research program planning, development, implementation, and evaluation. They should be trained in Sexual Reproductive Health and Rights and in research methodologies to guarantee confidentiality for research respondents and obtain informed consent. This process is empowering to young women but also builds confidence in the respondents who could identify with fellow Women living with HIV.

- Carrying out community education forums on forced and coerced sterilization with all potential research participants identified from the support groups by the research staff prior to participants' recruitment, (refer to the Kenyan and South African studies) helps to distinguish potential participants who have voluntarily consented and those who have been forced or coerced.

- A waiting period of seven days helps potential participants process the implications of their possible involvement in the study and ensures they do not feel pressured to participate (refer to Kenyan study).

- The criteria for selecting study participants should include the following: women living with HIV, age bracket (18 years and above at the time of interview and sterilization), having reported experiencing forced or coerced sterilization, and desire to voluntarily participate in the research (Kasiva, 2012).

- *Managing Expectations of Research Participants*
  Involvement of target populations and beneficiaries in the field work generates enthusiasm and anticipation about future development interventions. While this is positive, it could lead to challenges if expectations are too high or implementation does not occur.

  To manage such expectations, one should be honest and clear from the beginning of the study and throughout the process about whether or not resources from outside development organizations will be available and in what capacity.

  Provide realistic estimates of what participants should expect and when resources would be implemented.

If resources will not be available or the level of support is unknown at the time of the study, this information should be communicated to participants in a diplomatic way and explain the importance of participation within the context of the study and future programming.

Lessons learnt for protocol development

- An all-inclusive and systematic process provides an opportunity for protocol review and input by various individuals.
- The process for developing the protocol should be very participatory and provide for building in mechanisms for input including co-investigator, the staff from the researching organizations, the consultants who lead and guide the study, the community of women and girls living with HIV, technical support from consultants, members of technical and national steering committees, and relevant research boards. The process should ensure clear and transparent communication about the types of input that the various stakeholders can or cannot incorporate into the protocol based on the nature of the study.

Lessons learnt for ethical issues

- All participants should provide signed informed consent before participating in the research.
- Ensuring confidentiality and anonymity of the respondents as well as explaining manner of noting responses at the beginning of each interview participant leads to openness and instills confidence among research participants. It also gives assurances about the confidentiality of the information gained from the interview (for example, asking permission for any quotes or names to be used in the report). In this regard, training all research assistants to ensure that they protect the confidentiality of research subjects and ensure their safety is beneficial owing to the sensitive information being sought.
- Privacy of the information obtained from Women living with HIV should also be ensured.
- The relevant research permits and ethical approvals should be obtained from the relevant government and international agencies.

Lessons learnt for gathering information

- Scheduling of interviews should be guided by the utmost protection of the privacy and confidentiality of participants and the choice of venue for interviews should be determined by the participants.
- It is important to structure interview questionnaires on the basis of information one wishes to obtain from participants including aspects of sterilization experience, rights and choices, disclosure of sterilization status, impact of the sterilization experience, etc.
- Focus group discussions are rewarding because they are essentially an open and flexible tool, and work by building and communicating consensus around a particular topic while the one-to-one interviews are equally informative because they allow a deeper exploration by the researcher.
- Although all members of the data collection team ought to be carefully selected and receive relevant and sufficient specialized training, they ought to be provided with ongoing support to foster continued zeal and handle challenges they encounter along the way.

- To help researchers to adhere to these recommendations, each major process of research from inception, identification of objectives, formulating research problem, sampling, data collection, analysis and reporting should address safety and ethical considerations ensuring confidentiality and that participation in fieldwork should never lead to harm.

Safety and Security of Sensitive Data

- Research that involves gathering sensitive information, such as the personal details of forced and coerced sterilization of Women living with HIV requires specific efforts to ensure that soft copies of records are stored in a secured, password-protected, or locked location.

- Hard copies of sensitive information such as photos, medical records and personal records on the situation of forced and coerced sterilization should be stored in locked safe boxes and/or filing cabinets housed within a secured facility. All storage of information and data should follow safety and ethical guidelines (WHO, 2007).

Lessons learnt for meaningful participation

- The teamwork process provides participants with skills and self-confidence, consequently making them strong advocates of representing the issues of Women living with HIV in many fora and making presentations at high-profile, nationally and internationally.

- Gathering of data by young women living with HIV, Women living with HIV or support group members (who are trained as research assistants) is an empowering process in itself of the data collection process because women living with HIV learn together what they know about themselves. In addition, the process builds confidence and trust among the research participants - “peer confidence”.

Lessons learnt for dissemination of findings

- Inviting a cross section of stakeholders including women living with HIV, CSO representatives and advocates, para-church organizations, SRHR/HIV service providers, Human Rights bodies, local community leaders, relevant government agencies, United Nations officials, healthcare providing institutions (public and private), National AIDS Commission officials, District Health Officers, research assistants and the media who understand SRHR violations helps to enhance the fight against coerced and forced sterilization and advocate the implementation of the recommendations of the study.

- Disseminating research findings at different levels – community, national, regional and international (International AIDS Conferences like ICASA) is crucial for highlighting and sharing challenges encountered at local levels, harnessing support from various partners and launching a campaign to end SRHR violations.

- Dissemination also helps in enforcing the existing laws and policies on forced sterilization by the state. Dissemination informs the roles played by different stakeholders and ensures that governments remain accountable to their mandate of protecting the rights of Women living with HIV seeking reproductive healthcare services and provide redress and remedies for violations of these rights. This is critical in stimulating dialogues between people who might normally not discuss these issues together. It is also critical in stimulating dialogues between people who might normally not discuss these issues together.

In many regions those who have disclosed that they were forcefully sterilized often face other forms of violence from the health service providers, partners and sometimes from the medical community who feel that their atrocious actions have been exposed.

Photo by: KELIN

Lessons learnt for advocacy

Expanding capacity and expertise in human rights documentation

- Investing in community led documentation and related advocacy is critical in building a new cadre of human rights advocates and to enable positive women to engage directly as fact-finders and evidence gatherers.

Community Mobilization

- Sustainable coerced and forced sterilization prevention initiatives should be anchored in a community where leaders and citizens are fully engaged in mobilizing the community, educating stakeholders, implementing evidence-based research interventions, and increasing access to Women living with HIV –friendly sexual, reproductive health and rights services in response to their needs.
- Community mobilization intended to reach out to different sectors of a community and create partnerships is essential for focusing on and ultimately addressing a pressing issue such as forced sterilization.
- Community mobilization is also useful during the initial stages of developing the research protocol on coerced and forced sterilization to ensure that most women of reproductive age and their communities are sensitized on the research and willingness to share the research findings for evidence based programming.

Women living with HIV led processes and meaningful community involvement at every level

- The leadership of Women living with HIV is fundamental to the success of the advocacy on coerced and forced sterilization of Women living with HIV and the process of seeking accountability, which in itself is empowering and transformative.

Seeking Legal Redress

- Although litigation can be a powerful tool, it is resource-intensive, and the judgments of human rights tribunals are only implemented where the political will is present to do so.

- Women living with HIV who have been coerced or forcefully sterilized should be allowed to make informed decision on how to seek redress or compensation, but must never be coerced into legal processes before they are ready to face it.

- Women living with HIV may find themselves in situations where they have little or no evidence to take health workers or their people who might have violated their rights to courts of law. For example, most of the women who underwent forced or coerced sterilization did not have sufficient evidence to take on litigation.

- Besides litigation, it is important to explore other options of redress with women including advocacy, documentation, and institutional and human capacity building. The women should be supported to weigh the advantages and disadvantages in order to make informed decisions on what action they want to take.

- Through advocacy, Women living with HIV may be able to tell their stories and mobilize themselves to ensure health facilities that practice forced sterilization are exposed and curtailed.

Training of women living with HIV in sexual reproductive health and rights

- Regular training is critical in advancing women's empowerment and agency through expanding their knowledge of their bodies and of their rights.

Building a national movement and engaging in grassroots activism

- Building alliances between Women living with HIV and other gender, sexual reproductive health and rights, and human rights advocates will help foster new platforms for affected women to have a voice.

Investment in Women living with HIV organizations and initiatives

- The leadership of Women living with HIV is not possible without funding for the institutional platforms and the organizational capacity to support and enable leadership.

Advocating change in Medical and legal framework

- Following the successful documentation of coerced and forced sterilization in the respective countries, especially public hospitals, there is the need to revise the codes of conduct of Medical Practitioners.

- Medical Practitioners need to be continuously trained on rights of informed consent and the rights of Women living with HIV (Anand et al, 2009).

- Meaningful participation of key HIV-affected women and girls must be ensured in order for policy makers to understand and respond to the nature of their experiences in health care settings.
- Consultations ensuring participation of all stakeholders should be planned and should focus on joint development of laws, policies and programs to mitigate health facility and clinical setting related rights violations.
- There is great need for extensive counselling before undergoing sterilization because of the long-term psychological effects of the procedure such as restricted marriage prospects, physical intrusion upon bodily autonomy, stigmatization, and isolation among others.
- Linkage of women who were coerced and forced into sterilization to support groups like Networks of Women living with HIV is important.
- Researching on women who were forced or coerced into sterilization should conform to the World Health Organization Guidelines (WHO, 2007). Researching and documenting their experiences may involve risk of their safety their families, their communities, and those who have tried to seek redress on their behalf (either informally or formally). In many regions those who have disclosed that they were forcefully sterilized often face other forms of violence from the health service providers, partners and sometimes from the medical community who feel that their atrocious actions have been exposed. Families or even community members may feel that they have been humiliated by the disclosure. Monitoring prevalence and impact of forced and coerced sterilization may also increase the risks of violence among certain individuals or groups of Women living with HIV who have not previously experienced Gender Based Violence, by highlighting their vulnerabilities to potential perpetrators of such inhuman actions. When planning and implementing forced and coerced sterilization research and mitigation interventions, the safety and security of affected Women living with HIV must be the first priority from the beginning to the end of the research and litigation processes.

REFERENCES

Anand et al. 2009. *Bridging the gap: Developing a human rights Framework to address coerced sterilisation and abortion*. International Reproductive and Sexual Health Law Programme, Faculty of Law, University of Toronto.

Bell, E, Mthembu, P, O'Sullivan, S, Moody, K., (2007). *Sexual and Reproductive Health Services and HIV Testing: Perspectives and Experiences of Women and Men Living With HIV and AIDS*. Reproductive Health Matters, Vol. 15, No. 29, pp. 113-135

Gatsi-Mallet, J (2008). *Denying us the right to reproduce: Forced and coerced sterilization of HIV positive women*. Paper presented at the HIV Criminalization National Roundtable Discussion, 27-28 November, Cape Town, South Africa

Henry Kaiser Foundation, (2006). *The HIV/AIDS epidemic in sub-Saharan Africa. HIV/AIDS Policy Fact Sheet*. Washington DC

International Community of Women Living with HIV/AIDS (ICW), (2009) *The Forced and Coerced Sterilization of HIV Positive Women in Namibia*. International Community of Women Living with HIV/AIDS: London

Kalambi, V., (2008). *A Case Study: Forced Sterilizations of Women living with HIV in Namibia*. Paper presented at the ARASA Sexual Reproductive Health Rights Advocacy Workshop. 21 to 22 October 2008, Johannesburg, South Africa

Kasiva F. (2012). *Robbed of choice, Forced and Coerced Sterilization Experiences of Women Living with HI V in Kenya*. African Gender and Media Initiative: Nairobi.

Knauth D. R, Barbosa R. M and Hopkins, K., (2003). *Between Personal Wishes and Medical "Prescription": Mode of Delivery and Post-Partum Sterilization among Women with HIV in Brazil*. Reproductive Health Matters 11 (22).

Mutangadura, Gladys Bindura (2001). *Women and AIDS in southern Africa: the case of Zimbabwe and its policy implications*. Jenda: A Journal of Culture and African Women Studies: 1, 2.

Office of the High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, (2006). Hereinafter Guidelines on HIV/AIDS and Human Rights. Available at: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf. []

Open Society Foundations, (2011). *Against Her Will: Forced and Coerced Sterilization of Women Worldwide*. Available at: https://www.opensocietyfoundations.org/sites/default/files/against-her-will-20111003.pdf

OAU (2003). *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa*.

Feldman, R, Jo Manchester, J and Maposhere, C., (2002). *Positive Women: Voices and Choices project report*.

Rome Statute of the International Criminal Court art. 7, July 17, 1998, 2187 U.N.T.S. 90, 37 I.L.M. 1002.

Sethembiso, M, Zaynab, E and Strode, A., (2011). *I Feel Like Half a Woman All the Time': A qualitative report of HIV-positive women's experiences of coerced and forced sterilizations in South Africa*. International Community of Women Living with HIV/AIDS

The International Community of Women Living with HIV/AIDS (ICW) (2009). The Forced and Coerced Sterilization of HIV Positive Women in Namibia. The International Community of Women Living with HIV/AIDS: London

United Nations Human Rights Committee, General Comment No. 28: Equality of Rights between Men and Women (Art. 3), U.N. Doc. CCPR/C/21/Rev.1/Add.10 (2000).

WHO and UNAIDS (2014). Report on persons living with HIV. UNAIDS: Geneva.

WHO, (2007). *WHO Ethical and safety recommendations for researching, documenting and monitoring sexual violence in emergencies*. Gender, Women and Health Family and Community Health, World Health Organization (WHO): Geneva

My Fertility Choice Rules

End forced and coerced sterilization of women living with HIV

ICWEA

STOP AIDS NOW!

LINKUP

International Community of Women Living with HIV Eastern Africa (ICWEA)

Physical Address: Plot 1106 Ssenge Road - Wakiso District
Postal Address: P.O.Box 32252 Kampala, Uganda
Tel: +256 414 531 913
Fax: +256 414 533 341
admin@icwea.org
www.icwea.org
@ICWEastAfrica
ICW Eastern Africa