

Violation of Sexual and Reproductive Health Rights of Women Living With HIV in Clinical and Community Settings in Uganda



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

ICWEA
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LINKUP

About STOP AIDS NOW

STOP AIDS NOW! is the collaborative initiative between Aids Fonds, Cordaid, Hivos, ICCO and Oxfam Novib concentrating on poverty and AIDS. The organization works in Sub-Saharan Africa in countries with large generalised epidemics. It focuses on funding and implementing programmes in collaboration with local and international partners. Main program areas are youth and prevention, women and children, and HIV and STIs in combination with sexual and reproductive health.

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About LINKUP Programme

Link Up aims to improve the Sexual and Reproductive Health and Rights (SRHR) of one million young people affected by HIV across five countries in Africa and Asia. It is funded by the Government of the Netherlands' Ministry of Foreign Affairs through its Sexual and Reproductive Health and Rights (SRHR) Fund.

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The project draws on the strengths of a consortium of organizations including International HIV/AIDS Alliance, Gyca, Marie Stopes STOP AIDS NOW (SAN), ATHENA Network and International Population Council.

ICWEA with support from SAN carried out this research - "Violations of Sexual and Reproductive Health and Rights of Women Living with HIV in clinical and community settings in Uganda". ICW EA is documenting the methods, tools and good practices from this and the previous research projects to allow women living with HIV elsewhere to conduct similar research in their own countries. ICWEA also builds the capacity of young women living with HIV to develop their own advocacy agenda to improve their access to sexual and reproductive health information and services.

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Acknowledgement and Dedication

This report is dedicated to all women living with HIV in our diversities including young women and adolescent girls, who have experienced Sexual Reproductive Health and Rights violations.

We are convinced beyond doubt that this body of evidence will lead to increased awareness of the Sexual Reproductive Health Rights. We hope that it will also lead to better policies and programmes, positive change of attitude and practice. Our ultimate aim is elimination of Sexual Reproductive Health Rights violations particularly, forced and/or coerced sterilization in the world.

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List of Abbreviations

ACHPR	African Commission on Human and People's Rights
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ARASA	AIDS Rights Alliance of Southern Africa
ART	Antiretroviral Therapy
CEDAW	Convention on Elimination of all Forms of Discrimination Against Women
EMTCT	Elimination of Mother-to-Child Transmission
EU	European Union
FGDs	Focus Group Discussions
FIGO	International Federation of Obstetrics and Gynaecology
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immune Virus
HSSP	Health Sector Strategic Plan
ICPD	International Conference on Population and Development
ICW	International Community of Women living with HIV
IDPs	Internally Displaced Persons
IPPF	International Planned Parenthood Foundation
IUD	Intra Uterine Device
IVF	In Vitro Fertilization
KII	Key Informant Interview
LAC	Legal Assistance Centre
MDGs	Millennium Development Goals
MMR	Maternal Mortality Rate
MoH	Ministry of Health
NACWOLA	National Community of Women living with HIV /AIDS
NAFOPHANU	National Forum of People Living with HIV/AIDS in Uganda
NGOs	Non Governmental Organizations
NSP	National Strategic Plan
OVCs	Orphans and Vulnerable Children
PMTCT	Prevention of Mother-to-Child Transmission of HIV
PNC	Post Natal Care
SEROCO	French Cohort study of HIV Infected Adults
SRHR	Sexual and Reproductive Health Rights
SSA	Sub-Saharan Africa
STD	Sexually Transmitted Diseases
STIs	Sexually Transmitted Infections
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
US	United States
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

Definition of key terms

Sterilization: a procedure done to stop the egg from meeting the sperm. Female sterilization, which is commonly known as tubal occlusion, is done by cutting, sealing or blocking the fallopian tubes (which carry an egg from the ovary to the uterus – womb). Male sterilization is carried out by cutting and sealing or tying the vas deferens (the tube that carries sperm from the testicles to the penis) – commonly known as vasectomy. Sterilization is a permanent method of contraception, suitable for people who are sure they do not want or will never want more children (Family Planning Association [FPA], 2014).

Coerced sterilization: use of financial or other incentives, misinformation, or in-

timidation tactics to compel an individual to undergo sterilization. In addition, sterilization may be required as a condition of health services or employment (Open Society Foundations, 2011, p. 2)

Forced sterilization: a person is sterilized without her knowledge or is not given an opportunity to provide consent (Open Society Foundations, 2011, p. 2).

Sexual and reproductive health: a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity in all matters relating to the reproductive system and to its functions and systems. Reproductive health therefore implies that people choose and are able to have a satisfy-

ing and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the rights of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant" (United Nations, 1994: paragraph 7.2).

Executive Summary

This report presents the findings of a study that examined violations of the rights of women of reproductive age living with HIV as they sought Sexual Reproductive Health (SRH) services in clinical and health care settings in Uganda. It focused on forced and/or coerced sterilization. The study adopted a cross-sectional research design with a mixed method approach including both quantitative and qualitative methods.

While women living with HIV like any other women who are not HIV-positive share similar sexual and reproductive health rights that should be observed by all stakeholders. This study found that women living with HIV experience a wide range of sexual and reproductive health rights violations in clinical settings, their homes as well as in their communities. The violations range from misinformation regarding their Sexual Reproductive Health and Rights (SRHR), mistreatment/abuse during the process of seeking reproductive health services, especially maternal health services from health facilities, and coerced and/or forced sterilization.

There was consensus among all participants that women living with HIV have a right to conceive and bear children, engage in sexual relations with partners of their choice, and access SRH information especially family planning and use family planning methods of their choice. Contrary to the above consensus, over 90% of the participants (men and women) cautioned and held general perceptions that women living with HIV should not get pregnant without consulting health workers' guidance, planning for the pregnancy and enrolling on Prevention of Mother-to-Child Transmission/elimination of Mother-to-Child Transmission (PMTCT/eMTCT). The study participants were not aware of the existing guidelines on pre-conception counselling for women living with HIV.

Findings from qualitative interviews (KIs), case studies and Focus Group Discussions (FGDs) showed that women living with HIV had limited knowledge and awareness about their SRHR, which left them vulnerable and exposed to violations. For instance, the majority of women respondents in FGDs knew few options of family planning methods; they were not aware of the procedure of the long-term methods of family planning and consent. They were also not aware of their right to SRHR information and education, and determination of reproduction, among others. Further, women and men respondents reported unequal power relations between the health workers and women, with the former deemed more knowledgeable and experienced,

and the latter illiterate and uninformed. This was reported as a hindrance to women living with HIV realizing their SRHR, which also left women with limited choices.

The FGDs indicated that a number of women living with HIV experienced violations. For example, 72 out of 744 women in the study reported having undergone sterilization. Of these, 20 women had experienced SRHR violations of forced and coerced sterilization in clinical settings. Whereas three young women were forced to abort by their relatives, six women had consented to sterilization because of the difficult circumstances they were facing. Most violations, especially coerced and forced sterilization, occur during childbirth by C-section where the health workers have access to women's bodies and power to do what they feel is right for women living with HIV. The process of childbirth was reported as critical because one has limited choices and is at the mercy of health workers. Over 95% of forced/coerced sterilization occurred when women are undergoing C-section. A few of them were unaware that they had undergone sterilization until they failed to conceive years later. Other women believed that the procedure was a temporary measure, commonly referred to as "tying the tubes", which could be reversed to allow them have more children.

Other violations in clinical settings occurred while their Antenatal (ANC) cards are being marked. All women reported different forms of marginalization and stigmatization by health workers including negative comments and questioning their decision to get pregnant given their HIV status, and delays in receiving treatment. All these instilled fear and inhibited women's utilization of health facilities.

All respondents reported inadequacies in health care services that were characterized by inadequate supplies of essential drugs and equipment and late-coming and absenteeism of health workers. However, respondents acknowledged some improvement over the years.

The study further established that SRHR violations of women living with HIV were not confined to clinical settings but also occurred in homes and community settings. Such settings are characterized by socio-cultural and economic barriers including unequal power relations between men and women, and women's low education and economic status. The violations in the home manifested in form of restricted mobility to access care, gender-based violence, neglect, limited decision-making on re-

production (limited choice on when, how and the number of children) and use of family planning methods, and forced/coerced termination of pregnancy by relatives or spouses.

In terms of effects of forced/coerced sterilization, the women reported psycho-social (trauma), loss of identity as women, abandonment by spouses and gender-based violence due to inability to have children. A number of the women reported social isolation - inability to fit in the community and family. The demands from husbands for more children greatly impacted on their social wellbeing. A few (3) reported financial effects such as loss of a job and reduced productivity. While it was easy for women to disclose their HIV status (77% of the women interviewed), it was hard for women to disclose to their family members or spouses that they had been sterilized for fear of stigmatization and rejection. Contrary views from mainly men and key informants indicate that sterilization improves women's productivity and enhances the families' income because it leads to reduced family size and increases

time for engaging in productive activities.

All women who had undergone sterilization reported total lack of support system, both formal and informal, in their communities. All women were not aware of any legal options that could address their plight. Women choose to keep quiet and in a few cases were forced to disclose to their partners.

All women raised the need for extensive psycho-social support to raise their self-esteem and confidence, legal aid, and financial support for infertility treatment. They cited In vitro fertilization (IVF) – which is very expensive and inaccessible to most women.

The need for sensitization of communities and families about the SRHR violations of women living with HIV was raised as key to reducing different violations. The improvement of health service delivery through retraining and reorientation about SRHR needs of women living with HIV was also recommended as a means to eliminate all forms of SRHR violations.

Recommendations

Capacity building and sensitization

- Capacity building through training and sensitization of health workers on provision of quality and non-discriminatory care, encouraging them to provide right information to women living with HIV as well as adhere to the ethics of modern health care anchored in the principle of informed consent should be undertaken;
- Capacity building and skills enhancement and agency of women living with HIV should be undertaken by government and civil society to increase their ability to negotiate and resist the violations and seek legal redress whenever such violations occur;
- Regular provision of SRHR information and knowledge to women living with HIV should be inbuilt in all programmes on HIV&AIDS; and
- Conduct community dialogues involving massive campaign and sensitization of communities with particular focus on involving men to increase their knowledge and appreciation of the SRHR of women living with HIV.

Facilitate institutions and mechanisms for supporting women living with HIV

- An assessment of both formal and informal institutions that support or could support women living with HIV who have experienced SRHR violations and mechanisms should be put in place to revive the institutions or establish them in the respective communities where they are non-existent.
- Promote psychosocial support to women experiencing SRHR violations through establishment of counsel-

ling services at the community level.

Legal and Policy review and development

While Uganda has enacted number policies to address HIV vulnerabilities across the different groups of the population, SRHR violations of women living with HIV have not received adequate attention.

- There is need for review of HIV and SRH policies to adequately take into account SRHR violations for women living with HIV to ensure a good standard of health for all and effective management of HIV response in the country and ensure legal redress and access to justice;
- Review of tubal ligation consent protocols and procedures and ensure use of appropriate language of communication;
- Information on the protocols and procedures should be made available during antenatal clinics;
- Review guidelines for physicians on procedures for emergency tubal ligation; and
- Provide litigation and access to justice for women who have undergone coerced and/or forced sterilisation.

Provision of Comprehensive SRHR Options and choices for women

- Increased investment and funding in provision of more SRHR and family planning choices and options for women and including women living with HIV
- Civil Society Organisations including the women movement and organisations to scale up advocacy for funding, policy review and mass sensitisation of women and girls on their SRH and rights and protection.

INTRODUCTION

1.1 Background

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership-based organization for and by women living with HIV. It was founded in 2005 to give visibility to women living with HIV in the region. ICWEA's work focuses on influencing policy change and representing the voices of women living with HIV to ensure that appropriate policies are formulated and programmes funded and implemented.

ICWEA believes that gender inequalities and limited access to sexual, reproductive health services, information and rights violations experienced by women living with HIV is at the core of the HIV epidemic. Therefore, ICWEA aims to reduce the isolation of women living with HIV and overcome 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 builds capacities of its membership to understand policy, programming, human rights and gaps related to access and utilization of health services, issues and challenges that affect women living with HIV and cause women to demand for change and increased access to quality services. ICWEA aims to include women living with HIV in participating in policy-making processes; programming; service development and research at local, national and international levels.

ICWEA is implementing a project entitled Link Up: Better sexual and reproductive health and rights for young people most affected by HIV in Uganda, with support from STOP AIDS NOW! This research is part of the project. The research focused on sexual and reproductive health and rights (SRHR) violations experienced by women of reproductive age living with HIV within clinical and community settings focusing on coerced/forced sterilization in clinical settings.

The project development was informed by increased violations of SRHR of women living with HIV worldwide (International Community of Women living with HIV [ICW], 2009; Gatsi-Mallet, 2008; Stefiszyn et al, 2009; National Forum of People Living with HIV Networks in Uganda Stigma Index (NAFOPHANU), 2013). Women living with HIV have been reported to encounter hostile attitudes and discrimination from health care providers who refuse to provide them with services during pregnancy and child birth, with reported cases of coerced abortion and sterilization (Feldman, Jo Manchester and Maposhere, 2002). It is documented that up to 55% of the cases of vertical transmission of HIV that occur where prevention services are readily available may be due to stigma and discrimination; and that one of the most egregious rights violations occurring in maternal health care settings is forced sterilization. Coerced sterilization of women living with HIV

has been documented and litigated in Chile (Vidal and Carrasco, 2004) and Namibia (Gatsi, 2008; Nair, 2010); and reported by women living with HIV in other countries as wide-ranging as Indonesia (Sabarini, 2010), South Africa, Swaziland, Kenya, Uganda, and Zambia (Mamad, 2009; Anand et al, 2009).

1.2 Rationale

The recent Uganda AIDS Indicator Survey (2011/2012) shows that HIV prevalence has risen from 6.4% (2004/2005) to 7.3% with a higher rate (8.3%) reported among women (Ministry of Health, 2011). There is also a steady increase in the estimated number of new infections, from 124,000 in 2009 to 128,000 and 130,000 in 2010 and 2011, respectively (Nantulya, 2012). While the Uganda National HIV and AIDS Strategic Plan 2011/12-2014/15 (NSP) has committed to addressing stigma and discrimination, there is consistent evidence that HIV-related stigma is highly prevalent and so are the violations of human rights of people living with HIV. Irrespective of the form in which stigma is inflicted; its effects are largely negative and impact the quality of life of people living with HIV (PLHIV). In most cases, it restrains prevention, treatment, care and support interventions (NAFOPHANU, 2013).

There is growing evidence worldwide that women living with HIV experience more stigma and rights violations in health care settings than HIV-negative women. While implementing the Sexual and Reproductive Health Program in the five East African countries (i.e. Burundi, Kenya, Rwanda, Tanzania and Uganda), ICWEA engaged with women and young women living with HIV through capacity building sessions, dialogue meeting and FGDs who shared their experiences on accessing SRHR and maternal health services. For example, some women in Kenya and Uganda revealed that they had been coerced and forced into sterilisation at an early age in their lives because of their HIV positive status. One of the partners who had attended the dialogue meeting – Open Society Institute, EA (OSISEA) studied the experiences of Women living with HIV who had undergone forced and/or coerced sterilisation in Kenya. In Uganda, the people living with HIV (PLHIV) Stigma Index Survey Report (NAFOPHANU, 2013) indicates that 11% of the women respondents were coerced into sterilization by health care professionals because they were diagnosed HIV-positive. However, there is no comprehensive information on sexual and reproductive health and rights violations - in particular forced and/or coerced sterilization - of women living with HIV in Uganda. It is against this background that this study was undertaken to examine the insidious complex of stigma, gender-based prejudices, discrimination, and human rights violations, among others, that surround the incidence and severity of

forced/coerced sterilization of women living with HIV. This will not only reveal the drivers of the violations and how best to mitigate them, but also provide an informed basis for the initiation of evidence-based interventions including advocacy to address the plight of women living with HIV who seek SRH services at health facilities.

1.3 Purpose of the Study

The study sought to examine violations of rights of women of reproductive age living with HIV while seeking SRH services in clinical settings in Uganda.

1.3.1 Objectives of the study

1. To document the experiences of women of reproductive age who are living with HIV focusing on forced/coerced medical sterilization and other SRHR violations;
2. To identify the social, psychological and financial effects of coerced/forced sterilization and other SRHR violations of women living with HIV;
3. To identify the immediate and long-term support needs of women living with HIV who have experienced SRHR violations and;
4. To suggest policy and/or programme initiatives to promote SRHR of women living with HIV&AIDS in clinical settings in Uganda.

1.4 Scope of the Study

The study specifically focused on experiences of SRHR violations by women living with HIV in clinical and community settings in Uganda. Community perceptions on the violations were explored. The study covered nine districts of Uganda. The districts were purposively selected based on HIV-prevalence rates and the presence of health care facilities that provide SRHR services with long-term family planning methods.

1.5 Organization of the Report

The report comprises an introductory chapter; a review of literature on violations of SRHR of women living with HIV in respect to global, regional and national contexts. This is followed by the research approach and methodology section. The fourth section 4 presents the findings of the study with particular focus on the experiences of SRHR violations by women living with HIV. The section highlights forced and coerced sterilization and termination of pregnancy and other violations in clinical settings; violations at home and in the community; and participants views about these violations. The section further explores participants' awareness of SRHR of women living with HIV and the support needs of women living with HIV who experienced SRHR violation. The last section draws conclusions and provides recommendations.

SEXUAL REPRODUCTIVE HEALTH RIGHTS VIOLATIONS OF WOMEN LIVING WITH HIV: EVIDENCE FROM THE LITERATURE

There is a growing body of literature on SRHR violations of women living with HIV in clinical settings in sub-Saharan African. This review of literature explores the general SRHR issues; violations of SRHR especially coerced sterilization of women living with HIV in clinical settings; international and national legal frameworks for redress of SRHR violations; experiences of women living with HIV in Africa who have been forcefully sterilized; and the support needs for women living with HIV who have been subjected to forceful medical sterilization.

2.1 Sexual and Reproductive Health Rights of Women Living With HIV

Generally, the sexual and reproductive health needs of women living with HIV are not different from those of other women who are HIV negative. It has been observed that women living with HIV, like their HIV-free counterparts have sexual feelings and are sexually active (Feldman et al, 2002; NAFOPHANU, 2013; Essack and Strode, 2013; ICW nd). Furthermore, some studies have shown that society does not expect women living with HIV to be sexually active and have children; an attitude that has resulted into stigmatization and discrimination against women living with HIV who give birth (Feldman, Manchester and Maposhere, 2002). However, women living with HIV may have specific and unique SRH needs, including access to information and services to protect their own health as well as prevent infection to their infants (Feldman et al, 2002).

Sexual reproductive health and rights of women living with HIV include the right to information; family planning with options and choices; safe conception; maternal health care and safe motherhood; and diagnosis, prevention, care and treatment of sexually transmitted infections, cancers, HIV prevention and appropriate treatment of infertility. Others include prevention of abortion and management of the consequences of abortion; treatment of reproductive tract infections; prevention and surveillance of violence against women, care for survivors of violence and other actions to eliminate traditional harmful practices such as Genital Mutilation/Circumcisions; and appropriate referrals for further diagnosis and management of reproductive infections and the right to safe and satisfying sexual experience. Others are the right to legal or safe abortion (pro-

tection from forced abortions and sterilizations, obstruction of rape survivors to legal abortion and mental health services); the right to control reproductive functions; the right to quality gynaecological and obstetric health care; and the right to access SRHR information and education. The right to access SRHR information and education seeks to enable women living with HIV make informed reproductive care choices free from coercion, discrimination and violence as stipulated international human rights conventions.

2.1.1 Desire for children and access to fertility regulation services

Studies on reproductive choices among women living with HIV have yielded conflicting views: some have indicated that women living with HIV are less likely to desire to have more children than their HIV-negative counterparts (Population Council, 2006). However, other studies, from developed and developing countries, indicate that women living with HIV express desires to have children (Wagner and Wanyenze, 2013; Essack and Strode, 2012; Feldman, et al, 2002; Filipe and Santos, 2003; Cooper, Bracken and Myer, 2005; ICW, nd; Cooper et al, 2009; Nduna and Farlane, 2009). Desire for children among women living with HIV varies depending on whether one has children or not in the current relationship; payment of bride wealth; pleasing the partner; and death of child (Feldman et al, 2002). They also depend on having a complete family; feeling confident about childcare in future and the belief that the children would not be infected (ICW, nd). Feldman et al, (2002) observed that the desire to stop child-bearing increased sharply with the number of children the woman has. For instance, studies by Filipe and Santos (2003) and Cooper, Bracken and Myer (2005) show that a significant proportion of women living with HIV, especially those with no children, wanted to have children in the future. Cooper et al (2005) found that people living with HIV want children so as to “leave something of themselves behind” or because children represent “normality”. In Africa, studies conducted in Zimbabwe, Uganda, Kenya and Namibia, all testify that women living with HIV desire to have children and chose to become pregnant among others (Feldman, et al, 2002; Nakayiwa, et al, 2006 quoted in NAFOPHANU, 2013). In her study on “Fertility and HIV infection”, Beyeza-Kashesya (2010) reports that the majority of the young women living with HIV (57%) desire to have children but grapple with the dilemma of HIV transmission to their partners.

In Uganda, the majority of the women (56%) who participated in the HIV Stigma Index decided not to have children after being diagnosed HIV-positive (NAFOPHANU, 2013). Research conducted in Eastern Uganda (Nakayiwa et al, 2006, quoted in NAFOPHANU, 2013) reported low desire to have children among PLHIV. Only 18% of 1,092 PLHIV who were interviewed expressed the desire to have children, with males 4 times more likely to desire children than females. Some studies found out that women living with HIV are under pressure, often from families, community and health workers to have children or not to (Feldman et al, 2002; Paiva et al, 2002). HIV-positive men and women often report pressure and expectations that they should not be sexually active (Feldman et al, 2002). In Brazil, many women living with HIV do not voice their desire to have children to their health service provider for fear of a negative reaction (Paiva et al, 2002).

Contraceptive use among women living with HIV was reportedly variable, with some studies reporting limited use associated with frequent unplanned pregnancies (Wilson, 1997; Magalhaes, 2002); while other studies reported high contraceptive use. For instance, in a study conducted in Ireland revealed that 57% of the sexually active women living with HIV were using a reliable method of contraception (Murphy, 1993). Later on, research conducted in France on the impact of HIV diagnosis on sexual and contraceptive behaviour found out that 20% of the sexually active women living with HIV were not using any contraception; 24% became pregnant while 63% of conceptions ended in abortion (De Vincenzi, 1997). In West Africa (Burkina Faso, Ivory Coast and Cote D'Ivoire), 39% of women living with HIV used contraceptives with the incidence of further pregnancy estimated at 16.5% per 100 women at risk; 50% of these pregnancies were unplanned and one-third was terminated by abortion (Desgrées-du-Loû et al, 1995). An ICW study reported high contraceptive use (86%) among sexually-active women living with HIV. The most preferred contraceptive methods among them included condoms (52%) and sterilization (27%); others preferred pills and injections. Of those who used condoms, 61% used them consistently and 14% only occasionally.

In another study involving 59 women living with HIV, 60% reported the use of the barrier methods or dual protection to prevent conception; 87% used oral contraceptives; 75% used condoms to prevent STIs; while some women preferred using female condoms, they were often difficult to obtain (Feldman et al, 2002). After diagnosis, wom-

en became much more aware of methods to prevent STIs and HIV re-infection and were generally anxious to prevent conception (Ibid).

A number of studies have reported persistent engagement in unsafe sexual practices among women living with HIV, characterized by occasional and non-use of condoms (ICW, nd; Feldman et al, 2001; Jones, Weiss and Bhat, 2006). Occasional and non-use of condoms was attributed to husbands/partners dislike of condom use (42%); husbands/partners' ignorance of women's HIV sero status (8%); husbands being infected (6%); and husbands not fearing to be infected (3%). Unsafe sexual practices were also attributed to the use of other family planning methods (11%); condom stock-outs (11%); lack of knowledge about condom use (8%); non-familiarity with condom use (8%); and finding it inappropriate to use condoms in husband-wife sexual relationships (3%). Limited use of condoms and other contraceptive methods have been reported elsewhere in Africa among women living with HIV. For instance, a baseline assessment in Zambia found that only 30% of women living with HIV reported condom use in half of sexual encounters (Jones et al, 2006). Limited use of condoms among women living with HIV was attributed to partners' unwillingness; some did not know their wives/partners' HIV status while others did not fear the infection. Unavailability of condoms and lack of knowledge on how to use them were also contributory factors (ICW, 2006). Limited use of contraception has also been associated with marital status, level of education, death of the previous child, cessation of breast feeding and cessation of postpartum abstinence (Desgrées-du-Loû et al, 1995). Others include desire of children and limited couple communication on family planning matters (Feldman et al, 2002).

2.1.2 Maternal health

Globally, HIV and AIDS caused an estimated 56,100 maternal deaths in 2011 (UN MMEIAG, 2013; UN MDG Report, 2012; 2014; Lozano et al, 2011). In 2008, one in 10 maternal deaths in Sub-Saharan Africa resulted from HIV-related causes (WHO, 2010). It has been observed that if there had been no HIV and AIDS, the maternal mortality ratio (MMR) in Sub-Saharan Africa would have been 580 rather than 640 deaths per 100,000 live births in 2008 (Ibid). A recent estimate suggests that 24% of deaths in pregnant or postpartum women are attributable to HIV in Sub-Saharan Africa (Zaba et al, 2013). Just like other women, women living with HIV need a skilled attendant at birth to reduce the risk of maternal and new born morbidity and mortality. Literature shows that women living

with HIV may be more affected by certain reproductive health-related complications including miscarriage, post-partum haemorrhage, puerperal sepsis and complications of caesarean section compared to HIV-negative mothers (McIntyre, 2005). It has been noted that maternal mortality ratio in women living with HIV is about 10 times higher than in HIV negative women (Moran et al, 2012; Saving Mothers Report 2005-2007). The most common causes of maternal death among women living with HIV include pneumonia, tuberculosis; meningitis, sepsis and complications of abortion (Moran et al, 2012).

Studies have found out that while the majority of women living with HIV avoided becoming pregnant after diagnosis, over a half of those who got pregnant aborted due to fears of having an HIV-infected child and uncertainty of who would care for the child (ICW, nd). It further emerged that while women living with HIV who experienced unplanned pregnancies would chose to have safe abortions, abortion services were not available because abortion remains illegal in most developing countries (Feldman et al, 2002). Consequently, abortions were conducted in unsafe conditions by unqualified practitioners (ICW, nd; Feldman et al, 2002). Cases of abortion among women living with HIV have been reported in a number of studies (ICW, nd; De Vincenzi, 1997). Another ICW study reported that 28 out of 49 women living with HIV who became pregnant after being diagnosed with HIV, terminated the pregnancies because they feared that they would not be able to look after the baby due to poor health, that the pregnancy would deteriorate their health or that their babies would be born infected, become orphans, or lack care (ICW, nd). Anticipated inability to cope with motherhood and the risks of bearing HIV positive children were issues of major concern for many women living with HIV (ICW, nd; NAFOPHANU, 2013).

Studies have shown that the high maternal death prevalence among women living with HIV notwithstanding, their utilization of maternal health services is low. In a study of female adolescents living with HIV in Kenya, the rate of utilization of Prevention of Mother-to-Child Transmission (PMTCT) services was lower than use of prenatal care services, estimated at 67% and 84% of pregnancies, respectively (Gutmacher Institute, 2011). The study further reports that the adolescents made four or more prenatal care visits in only 45% of pregnancy cases. In addition, use of skilled care during or after abortion or miscarriage was low (20%) (Ibid).

2.1.3 HIV status and Termination of pregnancy

Globally, an unmet need for contraception persists, particularly in resource-poor settings (Wanyenze et al, 2010; King et al, 2011), leading to high rates of unplanned pregnancies (Groves et al, 2010). In sub-Saharan Africa, an estimated 39% of pregnancies are unintended and 33% of these ends in abortions, which are often unsafe (Sedgh et al, 2012; Singh, 2010). In Uganda, one in every five pregnancies is terminated (Susheela et al, 2005). A number of these abortions are unsafe, some of which are forced or coerced (Centre for Reproductive Rights et al, 2013). Susheela et al (2005) reveals that each year, an estimated 297,000 induced abortions occur in Uganda, with nearly 85,000 receiving treatment for complications of unsafe abortion. Similarly, Malinga and Mbonye (2008) observed that unsafe abortion remains a leading cause of maternal injuries and death in the country—causing as much as 26% of maternal deaths. According to the UDHS 2011, 34% of currently married women have an unmet need for family planning services, with 21% in need of spacing and 14% in need of limiting (UBOS and ICF International Inc, 2012).

Although there is limited literature on HIV status and abortion, there is evidence to show linkage between knowledge of HIV status and termination of pregnancy. Studies conducted in different parts of the world (Vietnam, Nigeria, Zambia) associated awareness of HIV-positive status to an increased likelihood of having an induced abortion (Chi et al, 2010; Bui et al, 2010; Akinrinola et al, 2014)). Florida et al (2010) found no association between pregnancy termination and HIV status; however, they noted that women living with HIV terminate pregnancies when they are unplanned; when they have had bad experiences during the previous pregnancies; and depending on the state of disease progression. According to Orner, de Bruyn and Cooper (2011) women living with HIV are often concerned about the heavy stigma and high risk associated with a clandestine abortion as well as the stigma of continuing a pregnancy. For many women in Africa, abortion decision-making is difficult because of widespread legal restrictions, social stigma, difficulties of access and provider bias (Cooper et al, 2007; Feldman, 2003). Akinrinola et al (2014) found out that among women in Nigeria and Zambia who had had an unintended pregnancy in the last five years, those who did not know their HIV status were more likely to report having had an abortion than those who were HIV-negative. HIV sero-positive women were 1.47 times more likely to have had a previous spontaneous abortion; this rose to 1.81 in women in Uganda who were sero-positive for both HIV and syphilis (Byabamazima, 1995). A three-fold increase in early spontaneous abortions in a prospective follow-up study has been reported in America (Langston, 1995; Shearer, 1997).

In a study conducted in Eastern Uganda among women living with HIV, the rate of induced abortion was twice the estimated figure for the region and many more attempts at abortion were made but not disclosed because elective abortions are illegal in Uganda (Leach-Lemens, 2010). Seeking an abortion was linked to women's fear of their own health. The need to inform women of the possibilities to access PMTCT and ART instead of abortion was emphasized. In South Africa, upon learning that they are pregnant, women on first-line antiretroviral treatment regimens containing efavirenz seek abortions (Laher et al, 2009).

2.1.4 Information, education and counselling

Adolescents, young girls and women living with HIV must have access to relevant information, counselling and services tailored to their sexual and reproductive health needs (Gruskin et al, 2007). Many women find out that they are HIV-positive while being screened during antenatal care or even at the time of delivery. Health services in all parts of the world need to provide information to women living with HIV when they are pregnant so that they can make an informed choice on the mode of delivery (Berer, 2004). Gruskin et al (2007) stress the need to provide appropriate pre- and post-test counselling, which must be ethical -- conducted with the primary aim of supporting positive people in staying connected to health services and helping negative people remain negative. Women living with HIV require information on reproductive options; the relative risks of breast and replacement feeding relevant to their living conditions; the preparation of replacement feeding by the mother/caregivers; costs of replacement feeding; possible obstacles to being able to continue their chosen feeding method if they become transient workers or refugees; and when and how to carry out abrupt weaning if they have been on exclusive breastfeeding (De Bruyn, 2004; Regional Centre for Quality of Health Care, 2006). However, many women lack such counselling and information (Feldman et al, 2002; NAFOPHA-NU, 2013). For example, in Zimbabwe, women living with HIV said that they did not receive adequate

pre-counselling information, although post-test counselling appeared to be more common (Feldman et al, 2002). In Uganda, the Stigma Index Survey of 2013 found out that of the 72% women living with HIV who received counselling about their reproductive options, 38% had been advised by health workers not to have children (NAFOPHANU, 2013).

2.1.5 Access to health services

Increased access to Sexual Reproductive Health services for women living with HIV is crucial not only for their own health needs but also for treatment and support to reduce the risk of HIV transmission to infants during childbirth and breastfeeding (Gruskin et al, 2007). The services include voluntary HIV testing and counselling; ANC, PNC, skilled attendance during child birth/delivery and obstetric care (basic, comprehensive and emergency); and PMTCT (Gruskin et al, 2007; Feldman et al, 2002). Women living with HIV need integrated services for sexual assault (support for contact with police); STI testing and treatment; emergency contraception or abortion if required; and access to safe and legal abortion (Epstein et al, 2006; UNHCR and UNAIDS, 1998). Where abortion services are illegal and unsafe, post-abortion care should be widely available to deal with complications (Ibid). Access to good-quality ANC is important to prevent other causes of poor pregnancy outcomes such as infections, anaemia and high blood pressure (Feldman et al, 2002).

It has been noted that only 57% of pregnant women living with HIV in developing regions receive antiretroviral treatment in 2011 (UN, 2013). In Africa, there is limited access of women living with HIV to quality health care including contraception, appropriate family planning services and safe abortion, ART to reduce the risk of HIV transmission to their infants, ANC, PNC and delivery care. The limited access to health care is associated with the high costs involved (consultation fees and medication, travel costs to larger hospitals); limited time given for examination; shortage of staff in the health facilities; negative attitudes of health workers (hostility and discriminatory treatment, breach of confidentiality); and discomfort with male nurses (Feldman et al, 2002).



In a study conducted in Zimbabwe, it was found out that none of the interviewed women had had access to ART; and only two had enrolled on a programme of short-course ART to reduce the risk of parent-to-child transmission in pregnancy as part of a clinical trial (Feldman et al, 2002). Discriminatory treatment was reported by nearly two-thirds of those interviewed, especially with maternity and ANC care. However, in Uganda, the HIV Stigma Index Survey shows that access to ART appears to be high where more females (95.6%) than males (94.2%) have access to ART (NAFOPHANU, 2013). Women's lack of autonomy in the household and economic disempowerment, especially the inability to purchase ARVs during pregnancy, has also constrained their ability to access health care (Feldman et al, 2002).

Access to free VCT has improved in many countries following the establishment of HIV sentinel surveillance sites for monitoring the rate of HIV infection. However, while HIV testing is expected to be undertaken after counselling, in some countries such as Zimbabwe, testing is done on an anonymous basis; thus women are not offered any counselling, informed of their status or offered practical support on how to reduce the risk of transmitting the infection to their unborn babies (Feldman et al, 2002). In addition, routine and free of charge ANC Voluntary Counselling and Testing (VCT) is limited; normally, it is recommended by a doctor with a few pilot ANC sites offering HIV testing and counselling and education on nevirapine therapy to pregnant mothers who test HIV- positive and their infants. The same study found out that because of the costs involved but also the low perception of risk, women rarely seek testing until their partners are sick or die, or when the women themselves or their child falls sick (see also ICW, nd).

Overall, Uganda faces poor coverage and access to health services, with only 50% of all public and private health facilities providing comprehensive HIV & AIDS care services (KMCC Initiative, 2012). Although overall PMTCT service coverage improved from 77% in 2009 to 90% in 2010, access to PMTCT remains limited. For instance, in 2013 only 39.6% of the women had access to PMTCT services: 18% were not aware of the existence of such services, 0.9% were refused the treatment while 12.1% did not have access to such services (NAFOPHANU, 2013). Access to ARVs by pregnant women living with HIV and their new-borns is estimated at 60% which is far from the universal target of 80% (Kivumbi, 2011; UAC, 2011). In addition, the integration of HIV&AIDS, EMTCT, maternal new-born and child health (MNCH) and other reproductive health and family planning services remains poor. Only 52% of HIV-positive pregnant women had access to ARVs for PMTCT in 2009 (MoH, 2009); about 30-40% of adults had ever tested for HIV and few of them knew the status of their partners. Furthermore, less than 10% of facilities had effective medical infection control procedures and PEP; 60% of the facilities had integrated STI case management, however access to STI services remained a challenge due to drug stock-outs (MoH and Macro, 2008).

2.1.6 Sexual health

Literature shows that while women living with HIV choose to abstain, others continue to have sex and enjoy sexual relationships; they also have the desire to have children. After receiving a positive diagnosis, some women withdraw from sexual activity because of fears of death, illness, loss of sexual desire, fear of spreading the disease, desperation and fear of re-infection and deterioration of health (Feldman et al, 2002; NAFOPHANU, 2013; ICW, nd). While 49% of the women in a study in Thailand had sexual relations after discovering they were HIV-positive, two and a half years later only 31% were still sexually active (ICW, 2006). According to NAFOPHANU (2013), 63% of the women living with HIV in Uganda, decided not to have sex and remain unmarried. However, in the Uganda Stigma Index Survey 2013, 80% of the men and 60.2% of the women living with HIV reported that they were sexually active. In Thailand, one in three women living with HIV remained sexually active; only 39% practiced safe sex and 51% stopped sexual relations^{1]} (ICW, nd). In Zimbabwe, 75% women living with HIV perceived themselves' as having limited control over sex within their relationships, both in terms of how sex is carried out and use of condoms. Incidents of forced sex were reported by 70% of the women.

Other studies report that reluctance to use condoms within marriage is attributed to a dominant feeling that condom use is strongly associated with extra-marital sex (Feldman et al, 2002; Bassett and

1 Due to boredom with family life, deteriorating health and concern for their children

Mhloyi, 1991; Meursing and Sibindi, 1995). Use of condoms was found to vary with age; type of relationship; number of surviving children; and experiences of pregnancy. Women in new relationships used no protection because they wanted a child, while others reported being forced by their partner to have unprotected sex after knowing their HIV status (Feldman et al, 2002). While women reported that men refused to use condoms, many of them also said that condoms were inappropriate within marriage and associated non-use with marital virtue in contrast with commercial sex work or other temporary sexual partnerships.

2.2 Gender and HIV& AIDS Prevalence

Since the start of the global HIV epidemic, women have remained at a much higher risk of HIV infection than men in many regions. Young women and adolescent girls in particular, account for a disproportionate number of new HIV infections among young people living with HIV. Every year, there are an estimated 380,000 new HIV infections among young women aged 15-24, accounting for 60% of all new HIV infections among young people in 2013. Approximately 80% of all young women living with HIV live in sub-Saharan Africa. Moreover, HIV remains the leading cause of death among women of reproductive age, yet access to HIV testing and treatment remains low (AVERTing HIV and AIDS 2015).

Globally, between 2002 and 2013, there was a 58% reduction in the number of new HIV infections among children (less than 15 years of age). Despite this, more than 240,000 children were infected with HIV during 2013, accounting for 700 new infections every day. In addition, millions more children every year are indirectly affected by the impact of the HIV epidemic on their families and communities. There were 3.2 million children living with HIV around the world at the end of 2013, 91% of these reside in sub-Saharan Africa. In the same year only 24% of children who needed antiretroviral treatment (ART) received it and 190,000 children died of AIDS-related illnesses (AVERTing HIV and AIDS 2015).

In high-prevalence countries such as Zimbabwe, data for 2000 showed that women living with HIV constituted between 24 (33%) and 7 (53%) in the urban and rural areas, respectively. For the 15-19 year-olds, HIV infection among young women was five times higher than that of young men (Feldman et al, 2002). In countries such as Thailand, more men are infected with HIV than women; however, the majority of the women living with HIV (95%) are women in the reproductive age bracket (15-49) (ICW, nd). According to UNAIDS (2013), women are more likely to acquire HIV at an early age, resulting in double HIV prevalence rate among girls and young women than their male counterparts in the same age bracket.

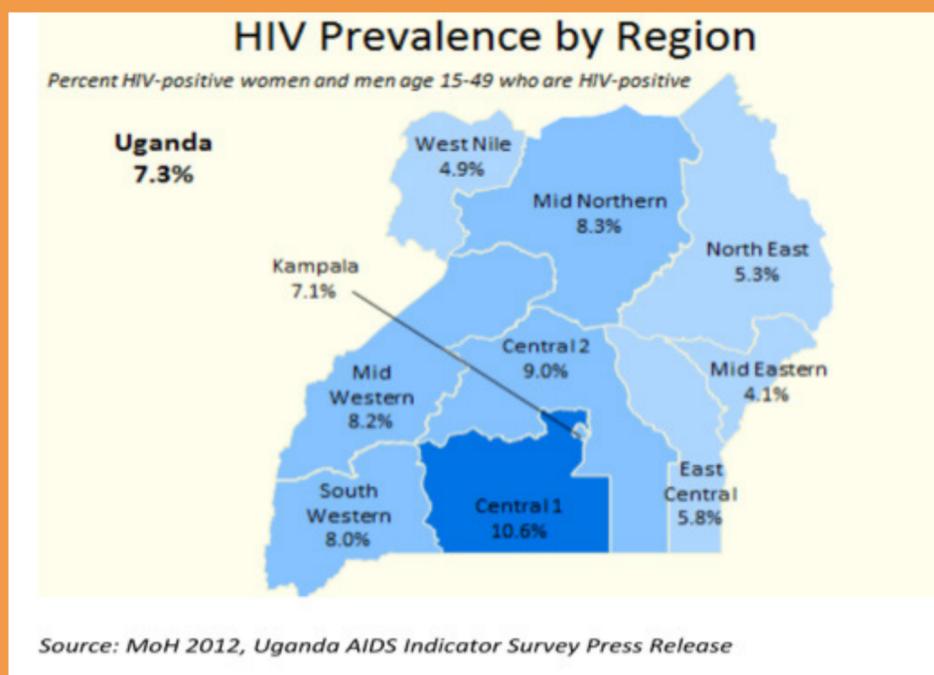
In Uganda, one of the most remarkable achievements in reducing new HIV infections has been among children below the age of 15 years. There has been a remarkable decline in the number of new infections among the children from about 31,000 infections in 2010 to about 9,000 by the end of 2014, representing a 70% decline. Uganda is among the 7 countries out of the 21 global plan countries that has a reduction rate of new infections among children above 60%. The world is on the edge of eliminating

new HIV infections among children. The rapid expansion of services to prevent MTCT has had a massive health impact on the world's children, and it has contributed to global efforts to reduce mortality in children under the age of five years (Country progress report 2014 – the Republic of Uganda).

Globally, gay men, sex workers and their clients and people who use drugs and their sexual partners are among an estimated 40–50% of adults who acquired HIV in 2014. HIV prevalence among men who have sex with men is highest in western and central Africa (15%) and eastern and southern Africa (14%). New infections are increasing in several countries across the Middle East and North Africa, Asia and the Pacific, and in cities in North America and Western Europe—primarily among men who have sex with men, transgender people, sex workers and their clients and drug addicts who use injections. HIV prevalence among sex workers is on average 12 times greater than the general population. In several southern African countries, more than 50% of sex workers are living with HIV. Transgender women are 49 times more likely to be living with HIV than other adults (UNAIDS Strategy 2016-2021).

The Uganda AIDS Indicator Survey (2011) shows that HIV prevalence has risen from 6.4% (2004/2005) to 7.3% (2009/2010), with higher rate among women at 8.3% (MoH, 2011).

There has also been a steady increase in the estimated number of new infections from 124,000 in 2009; 128,000 in 2010; and 130,000 in 2011 (Nantulya, 2012).



Like in many SSA countries, the major modes of transmission in Uganda include Mother-to-Child, sexual intercourse (among multiple sexual partners and commercial sex workers), unsafe medical injections and contaminated blood transfusion.

Girls and women's vulnerability to HIV infection is attributed to a complex interplay of physiological factors and gender inequality (UN, 2013). Across many Sub-Saharan Africa countries, women and girls have low economic and social status and their decision-making powers are limited; men control all aspects of decision-making (including control over women and girls' sexual and reproductive lives (UN, 2013; Quinn and Overbaugh, 2005). The unequal social and economic status often puts women and girls at a disadvantage in negotiating when, where and how to have sex (Ibid). For example, women often have less power to refuse sex or negotiate condom use (World Health Organization, 2006). Consequently, they are exposed to sexual violence, including rape and sex with older men (UNAIDS, 2013; WHO, 1995). Because of poverty and limited economic and employment opportunities, many women and girls engage in commercial sex work as a survival strategy which predisposes them to HIV infection (WHO, 1995). Societal construction of different sets of sexual rules for women and men and expectations that promote fidelity, which transmit messages of unquestionable male unfaithfulness as a form of masculine identity, render women even more vulnerable (Reid, 1994; Lee, 1994).

Despite the apparent gender dynamics associated with vulnerability to HIV infection, strategies to prevent the spread of HIV have focused on the promotion of condom use, reduction of numbers of sexual partners and treatment of STDs (Heise, 1995).

However, there is minimal focus on addressing social, economic and power relations between women and men. These relationships, together with physiological differences, to a great extent determine women and men's risk of infection, their ability to protect themselves effectively and their respective share of the burden of the epidemic (WHO, 1995).

2.3 Sexual and Reproductive Health Rights for Women: the International, Regional and National Legal Frameworks

2.3.1 Global and regional conventions and declarations that promote SRHR for WLHV

Sexual and reproductive health rights are defined as “the right for all people, regardless of age, gender and other characteristics, to make choices regarding their own sexuality and reproduction, provided that they respect the rights of others” (UN, 1994). This right is well articulated in the various global and regional human rights laws including international declarations, covenants and conventions^[1].

Globally, the Universal Declaration of Human Rights condemns discrimination on the grounds of sex and sets out a bill of rights relevant to the promotion of sexual and reproductive health. It lays a strong foundation for the development of international and national human rights laws for the promotion of the right to reproductive health (United Nations, 2009). The United Nations Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW), often described as the international bill of rights for women, commits state parties to comply with the CEDAW regulations by taking legislative and other appropriate measures to eliminate discrimination of women in public institutions or abolish discriminatory laws, customs and practices in all spheres of life (Foster, 1998). The International Conference on Population and Development (ICPD) held in Cairo in 1994 stressed the transformation of women's reproductive capacity from being an object of population control to a matter of women's empowerment to exercise personal autonomy in relation to their sexual and reproductive health (Shalev, 1998). ICPD acknowledges the right of women to personal reproductive autonomy and to collective gender equality as an important aspect of the development of reproductive health and population programmes. ICPD commitments are further amplified by the 1995 Beijing Declaration with explicit recognition of the need to promote sexual and reproductive health rights for all women. It further ensures the involvement of women living with HIV in all decision-making relating to development, implementation and monitoring HIV&AIDS policies and programmes. It also protects the rights of people living with HIV and ensures non-discriminatory practices and policies (United Nations, 1995). The International Planned Parenthood Foundation (IPPF) Charter on Sexual and Reproductive Rights makes reference to the “right to liberty and security of the person”, “the right to information and education”, the “right to healthcare and health protection” and most importantly, the “right to decide whether or when to have children” (ARASA, 2008).

The Millennium Development Goals (2000) stress respect and promotion of human rights for all and fight against all forms of violence against women as specified in CEDAW. For example, Goals 3, 5 and, namely empowerment of women as effective ways to ensure sustainable development, improving maternal health and combating HIV and AIDS with promotion of gender equality, respectively aim at combatting discrimination against women. While the global instruments do not make specific reference to women living with HIV, they provide a strong human rights framework for protection of SRHR of all women, including women living with HIV. In 2012, the International Federation of Gynaecology and Obstetrics (FIGO) issued informed consent guidelines on reproductive choice, particularly on sterilization, with emphasis on informed choice which must precede informed consent. The guidelines highlight proper counselling that includes the risks and benefits of the procedure and of its alternatives, communicating and interacting in accordance with ethical issues in obstetrics and gynaecology. The guidelines call for consideration of recognized available effective alternatives, especially reversible forms of family planning.

At the regional level, the African Charter on Human and People's Rights addresses human rights from an African perspective and calls on all state parties to eliminate discrimination against women. It provides for the right to be free from discrimination, the right to personal security and the right to liberty in Articles 6, 9 and 18, respectively. Attached to this Charter is the African Women's Rights Protocol which emphasizes the importance of women's right to control their fertility; the right to decide whether to have children with the family planning issues; the right to choose any method of contraception; and

¹ The United Nations Charter of Human Rights and Universal Declaration of Human Rights (1948), The International Convention on Civil and Political Rights (1966), the International Conference on Population and Development (ICPD) Declaration (1994), the Beijing Declaration (1995), the 1968 Teheran Human Rights Declaration, the African Charter on Human and People's Rights (1981), the Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979), the African Women's Protocol (2003) and the International Planned Parenthood Foundation (IPPF) Charter on Sexual and Reproductive Rights.

the right to care for prevention and treatment of sexually transmitted diseases. Both the African Court of Human and Peoples' Rights (ACHPR) has to receive complaints by individuals and NGOs with observer status in the African Commission. The Commission may institute action in the Court as authorized under Article 5(1) (a) of the Protocol. Within this mandate, the Commission is expected to raise questions on the measures taken to deal with all forms of discrimination, including forced sterilization, while analyzing state reports (Aligy, 2009).

The East African HIV and AIDS Prevention Management Act (2013), Article 15 (c) provides for access to counselling, information and education services to women living with HIV to enable them make informed and voluntary choices in matters affecting their health and reproduction as well as the health of their children. Currently, there is renewed global commitment to ending the vertical transmission of HIV, referred to as Virtual Elimination of Mother-to-Child Transmission of HIV (EMTCT) with a hope to have an HIV-free generation in the near future. EMTCT is expected to be realized through advances in prevention of unplanned pregnancies, HIV treatment, coverage and more effective regimens (KMCC, 2012). Achieving the EMTCT vision requires that the global commitments be followed through plans, frameworks and guidelines (KMCC, 2012). A number of strategies have been suggested, including increasing access to comprehensive HIV services, family planning among HIV positive women and antiretroviral therapy for Women living with HIV (WHO, 2010; UNAIDS, 2011; 2012).

Many of these conventions have been signed and ratified by African countries; therefore, they legally bound to protect women from any sexual and reproductive rights violations, including coerced sterilization irrespective of their sero status. Women living with HIV have a right to decide when to have children, with whom and when. In spite of the comprehensive global and regional commitments, Feldman et al (2002) note that the reproductive health goals are out-of-reach of many women because



of poverty, limited access to quality public health facilities, restrictive legal and institutional structures that restrict access to family planning services and abortion. These impediments are reinforced by the gender inequalities inherent in most societies, especially inequalities related to women's lack of productive resources (dependence on men), limited access to education and unemployment.

2.3.2 Uganda's commitment to addressing SRHR of women living with HIV

Uganda is party to the global and regional human rights laws. Uganda's commitment to the global agenda to promote and protect women's sexual and reproductive health and rights, in particular violation of SRHR of women living with HIV is reflected in the established legal and policy frameworks.

2.3.2.1 Legal framework

Uganda's commitment to address SRHR for women living with HIV is within the broad legal framework for addressing sexual and reproductive health rights founded on the principles of human dignity and equality provided for in the 1995 Uganda Constitution. SRHR for women living with HIV is a human rights issue in terms of the right to life (Article 22), liberty and security (Article 23); the right to health, respect for human dignity and protection from cruel, inhuman and degrading treatment or punishment (Article 24); the right to privacy of person (Article 27); the right to a fair hearing (Article 28); the right to education (Article 30); family rights (Article 31); the right to access information (Article 41); and the right to freedom from any harmful cultural practices (laws, customs, beliefs) that are against the dignity, welfare or interest of women or undermine their status (Article 33 (6)). The Constitution provides for non-discrimination and equality for all, as well as protection and promotion of women's rights (articles 20, 26, 30, 31, 40 (b and c) and 50 (Republic of Uganda, 1995). Under the National Objectives and Directive Principles of State Policy, the Constitution commits the state to take all practical measures to ensure the provision of basic medical services to the population (Objective XX).

These articles provide a firm foundation for promoting SRHR for women living with HIV in Uganda. Other legal instruments that protect SRHR of women living with HIV include the Penal Code Amendment Act (2006) – which provides for sexual violence including rape and defilement. The penal code is supplemented by the recently passed Uganda HIV Prevention and AIDS Control Act (2014). The law provides for protection of the sexual and reproductive health rights of people living with Women living with HIV in Article 37 (1) which calls upon every health institution public or private and every health management organization or medical insurance to facilitate access to healthcare services to people living with HIV without discrimination (Republic of Uganda, 2014). However, the clauses on criminalization of attempted HIV transmission and deliberate HIV transmission stipulated in articles 39 and 41 have significant negative implications for women living with HIV and will affect HIV prevention efforts in the country through increasing stigma and reducing disclosure. For instance, it will limit utilization of HIV services. Other clauses that potentially stigmatize and discriminate against women living with HIV include the article that permits non-consensual disclosure of one's status (Clause 19 (2d); 21 (e) and mandatory HIV testing without the patient's consent in certain circumstances. This clause contradicts the constitutional provision of the right to privacy (Article 27).

In 2009, the MoH developed The Patients Charter (2009) which provides for the right to redress where rights of patients and workers are violated (MoH, 2009). It also obliges all health facilities to have suggestion boxes where patients can provide feedback on the quality of health services. Article 19, particularly, requires every health facility to designate a person or committee to be responsible for the observance of patients' rights, whose duties include giving advice and assistance where rights are violated; receiving, investigating and processing complaints; and increasing awareness among hospital staff about patients' rights.

2.3.2.2 Policy commitments

The legal provisions are further enshrined in the National Development Plan (NDP) (2010 – 2015). One of the strategic objectives of the NDP is to promote gender equality and the empowerment of women in all sectors of the economy. The aim is improving quality and availability of maternal and reproductive healthcare for women and girls, targeting women in HIV prevention programmes, addressing prevention, treatment and access to legal redress in respect of SGBV (Republic of Uganda, 2010b). The National Gender Policy (2007) stresses government commitment to enacting and reforming laws

to eliminate gender discriminatory practices, norms and values; developing and implementing sexual and reproductive health rights programmes; and developing and implementing legal literacy programmes to improve women and men's awareness of their legal rights (Republic of Uganda, 2007). While Uganda has reviewed and developed policy guidelines to strengthen national response to HIV and AIDS transmission, the most relevant policies for the protection and promotion of SRHR of women living with HIV include the National Health Policy (2010), National HIV&AIDS Policy (2011), National Population Policy (2008), The Antiretroviral Treatment Policy, PMTCT guidelines and HCT policy.

Uganda's National Health Policy (2010c, page 10) goal is "to attain a good standard of health for all people in Uganda in order to promote healthy and productive lives". Emphasis is laid on health promotion, disease prevention and early diagnosis and treatment of disease with particular focus on vulnerable populations (Republic of Uganda, 2010c). The policy prioritizes the strengthening of health systems and pledges to ensure adequate financing of essential medicines and health supplies among others. It reaffirms government's commitment to the Uganda National Minimum Health Care Package (UNMH-CP) that prioritizes sexual and reproductive health rights issues. Uganda's Population Policy (2008) seeks to promote awareness among men, women and communities of their roles and responsibilities on sexual and reproductive health and rights (Republic of Uganda, 2008a). The policy pledges commitment to advocate linking of Reproductive Health (RH) with HIV&AIDS programmes.

The National AIDS Policy (2008) provides a strong basis for the promotion and protection of human rights for people living with HIV, those at risk of infection and those affected (Republic of Uganda, 2008b). The policy stresses the fact that the high incidence of HIV&AIDS compromises the sexual and reproductive health rights of women living with HIV. The policy commits to prevent transmission from mother to child, address all gender-based concerns that increase HIV vulnerability and impact on service access. The policy seeks to prohibit discrimination of PLHIV and promotes a rights-based response that emphasises greater involvement of PLHIV; equal rights for all people^[2]; non-discrimination on the basis of gender, sex and HIV status; and provision of AIDS-related information and services to all (Republic of Uganda, 2008b). The policy emphasizes individual consent, confidentiality and privacy in voluntary counselling and testing; control and management of STIs; and provision of information and counselling to women and men of child-bearing age on the implications of pregnancy when they are infected. It also stresses provision of appropriate services (counselling and treatment) for the PMTCT to women living with HIV and their partners; ethical and technical standards for safe medical care; and administration of ARVs and identification and addressing of all forms of discrimination against PLHIV. Women empowerment to safeguard against gender-based violence and unsafe sex is one of the priority areas of the policy.

The Anti-retroviral Treatment (ART) Policy (2003) is guided by the core values of equity and universal access. It is also based on a human rights approach that seeks to guarantee an improved quality of life for people living with HIV. The policy provides for "positive discrimination" for certain groups, by giving priority for free ARVs to women living with HIV identified through prevention of Mother-to-Child Transmission (PMTCT) programmes, as well as their HIV-infected family members (also known as "PMTCT-plus"), among other groups.

The HIV Counselling and Testing (HCT) Policy (2010), adopted after a review of the 2005 HCT policy aims to guide planning and implementation of HCT service delivery in the country. The overall goal of the HCT policy is "to contribute to reduction of HIV transmission and improving the quality of life by enabling persons to know their sero-status and linking them to prevention, care, treatment and support services" (Republic of Uganda 2010d, page ...). The policy emphasizes a human rights-based approach in all testing and counselling services and reduction of stigma and discrimination during HCT service delivery. It articulates the right to access quality HCT services for all people; provision of clear and accurate information, education and communication on HCT; and that all service providers shall observe the ethical requirements of confidentiality, informed consent, quality counselling and privacy. In situations where consent cannot be obtained from the client or next of kin, testing shall be done when necessary for clinical reasons. The policy provides for non-discrimination against HIV-positive persons, among other things.

² This implies that being at a higher risk of HIV infection or sero-status shall not be used as grounds for decisions that negatively impact on people's livelihood and well-being.

The Prevention of Mother-to-Child Transmission (PMTCT) Policy adopted in 2003 seeks to guide the different actors, set standards and ensure quality control in the prevention of Mother-to-Child transmission of HIV in Uganda. It aims to streamline and guide the process of initiating and implementing PMTCT interventions. The policy addresses a number of areas including provision of anti-retroviral therapy to pregnant women living with HIV and their infants; VCT within the antenatal clinic; infant feeding; routine administration of multivitamins in pregnancy and vitamin A to post-partum mothers and their children; routine iron and folate supplementation and safe blood transfusion; control and treatment of STIs and the use of barrier methods such as condoms during pregnancy and lactation; vaginal cleansing, and delayed rupture of membranes in labour; and limited use of episiotomy among pregnant women. Other interventions under PMTCT involve provision of VCT for the spouse or partner within the antenatal clinics or as conveniently as possible. The policy further states that every HIV-positive mother and her partner should be given information about the benefits and risks of breastfeeding and the use of alternative feeding options to enable them make informed choices on infant feeding; all women should be supported in a non-judgmental manner irrespective of their choices with regard to infant feeding; and that women living with HIV who choose not to breastfeed their infants should be supported to safely adopt replacement feeding options.

After a decade of implementation of PMTCT, Uganda has joined the rest of the world to eliminate Mother-to-Child transmission of HIV (EMTCT) and ensure an AIDS-free generation. The Government of Uganda has recently adopted Option B+ as the national policy for the biomedical health system response to EMTCT (KMCC, 2012). For effective EMTCT, Uganda has adopted the WHO four-pronged approach constituting primary prevention (Prong 1); prevention of unintended pregnancies (Prong 2); prevention of MTCT during pregnancy, delivery and breastfeeding (Prong 3); and HIV care, treatment and support for women and exposed children living with HIV and their families (UAC, 2011).

The commitment to address SRHR of all women irrespective of their HIV status is reaffirmed in the broad and specific national plans and strategies developed and adopted by the Ministry of Health and Uganda AIDS Commission. The Health Sector Strategic Plan (HSSP 2010/2011-2014-2015), which is the broad national strategy guiding in-

terventions within the health sector, emphasizes rights-based approaches to addressing health concerns. "Health is described as a fundamental human right - to be enjoyed by all without discrimination" (Ministry of Health, 2010, p. 38). The strategy emphasizes the right to health; and entitles individuals to information about their health, including diagnosis, treatment, costs and prognosis. It also requires that individuals make informed decisions regarding their health including making informed consent prior to undergoing any procedures (p. 39); and equal access to quality care. Sexual and reproductive health is one of the key priority areas in the HSSIP III with emphasis on maternal health and family planning.

The National HIV Prevention Strategy (NPS) 2011/12 – 2014/15 is premised on the principle of promotion, protection and respect for human rights of people living with HIV and emphasizes measures to eliminate all forms of stigma and discrimination (Uganda AIDS Commission (UAC), 2011). NPS's vision is "Zero new HIV infections, Zero discrimination and Zero-AIDS-related deaths" by 2015 to reduce HIV incidence by 30 per cent from the 2009 levels which will result into 40 per cent reduction of the projected number of new infections in 2015. NPS stresses the rights-based approach (especially for women) to all interventions, with strategies including SRH rights education; challenging HIV-related stigma and discrimination; male involvement in PMTCT, FP and other SRH services for women; and increasing effectiveness of PMTCT services. This will be achieved through strengthening the four prongs of PMTCT recommended by WHO (2010), which are mentioned above. The NPS seeks to:

- Increase number of pregnant mothers attending ANC and delivering in health units;
- Expand PMTCT to all facilities to ensure access to all pregnant mothers;
- Enrol all HIV-positive pregnant mothers on to ARVs on Option B+;
- Roll out guidelines and increase access supplies;
- Ensure that MOH (ACP) provides adequate supplies to all health units;
- Encourage men to come for HCT and be involved in the prevention of HIV to their unborn children and internalize prevention of transmission of HIV to the child as a responsibility of both parents;
- Ensure that Ministry of Health puts in place PMTCT-related programmes for men;
- Increase maternal and infant uptake of ARVs;
- Strengthen referrals and linkages with several related services such as adult/paediatric AIDS care and ART, home-based care, immuniza-

- tion and Early Infant Diagnosis of HIV (EID); and provide comprehensive PMTCT that includes child health services such as cotrimoxazole prophylaxis, TB screening, referrals, and insecticide-treated nets promotion;
- Promote educational and BCC efforts that stress demand creation, parent-to-child transmission, family responsibility and planning, women and men's role in PMTCT, and couple counselling and testing with focus on risk reduction counselling and post-delivery risk reduction for infants through modified breastfeeding practices;
 - Simultaneously address structural barriers for PMTCT including gender barriers, stigma and discrimination of mothers that do not breastfeed and limited male involvement;
 - Ensure that every health facility providing antenatal care services tests pregnant women for HIV, and that at least 95 per cent of HIV-exposed infants receive combination ARV therapy; and
 - Improve uptake & efficiency of PMTCT & prioritize it at district level as a key District Health Team (DHT) performance indicator; identify districts that need urgent attention for action.

Gaps in policies

In line with the global commitment to address sexual reproductive health and rights within the context of HIV, Uganda has developed a number of policies, guidelines and strategic plans towards achieving good standard of health for all the people. However most of the policies do not explicitly address the unique SRHR issues of women living with HIV. Whereas the policies have largely focused on PMTCT/eMTCT as a strategy for ensuring an HIV-free future generation, they are silent on the multitude of SRHR violations that women living with HIV routinely endure. Such silence has significant implications on effective delivery and management of HIV response interventions.

2.4 Informed Consent to Medical Interventions and the Right to Freedom from Coercion in Accepting Contraception

Informed consent is one of the ethical cornerstones of modern healthcare. The phrase 'informed consent' refers to, "the right of every competent patient to be told about any proposed intervention before it is performed" (Faden and Beauchamp, 1986). The reason for informed consent is that any

foreseeable consequences of accepting or rejecting, existence and nature of available alternatives and the fact that an individual is free to accept or reject the intervention. Valid informed consent therefore incorporates five elements: voluntarism, capacity, disclosure, understanding, and decision making (De Carmen and Joffe, 2005). Voluntarism requires that the patient be free from coercion and from unfair persuasions and inducements. To deprive someone of decision-making power regarding themselves is effectively to deny them their status as an autonomous being (Kluge, 2007). Informed consent is therefore grounded in the principle of autonomy which implies that everyone has a right to self-determination as reflected in the Universal Declaration of Human Rights.

Ideally, individuals living with HIV (like any other human being) who wish to use a permanent contraceptive method should have access to female sterilization and vasectomy in an informed manner, free from coercion (Delvaux and Nostlinger, 2007). A study in Brazil to assess personal wishes and medical prescription on women living with HIV found that women's own preferences took a secondary place (Knauth, et al, 2003).

Informed consent guidelines issued by the International Federation of Gynaecology and Obstetrics (FIGO) emphasize that the process of informed choice must precede informed consent to surgical sterilization. Recognized available alternatives, especially reversible forms of family planning which may be equally effective, must be given due consideration. The physician performing sterilization has the responsibility of ensuring that the person has been properly counselled concerning the risks and benefits of the procedure and its alternatives. FIGO guidelines also specifically note that the difficulty or time-consuming nature of providing the necessary information for a woman's informed consent does not absolve medical providers from striving to fulfil these criteria for informed consent.

2.5 Violation of Sexual and Reproductive Health Rights

2.5.1 Forced and coerced sterilization

In spite of the existence of a comprehensive global and local legal and policy framework for human rights protection, violation of sexual and reproductive health rights, especially forced/coerced sterilization among women living with HIV, is a global concern. The first coerced sterilization cases were reported in Namibia in 2007 when three of the 30

participants in a training project involving young women living with HIV stated that they had been sterilized without their informed consent (ICW, 2009). Since February 2008 to-date, the Legal Assistance Centre (LAC) in Namibia has documented fifteen individual cases in which women seeking medical care at state hospitals, in two of the thirteen regions of the country, were subjected to sterilization without informed consent. Most of the clients did not even know that they were sterilized until they consulted medical personnel (Gatsi-Mallet, 2008). Research carried out by ICW documented 40 cases of coerced or forced sterilization in Namibia, whereby informed consent was not adequately obtained. It emerged that 'consent' was obtained under duress and was regarded as invalid because the women were not informed of the contents of the documents they signed (Stefiszyn et al, 2009).

In Uganda, cases of forced/coerced sterilization have been reported (National Community of Women living with HIV&AIDS [NACWOLA], 2008; NAFOPHANU, 2013). In the HIV Stigma Index Report 2013, it was reported that at least 11% of the respondents were coerced by a healthcare professional into being sterilized after an HIV-positive diagnosis (NAFOPHANU, 2013). A similar study in Kenya revealed that 9.6% of the respondents reported that they had been coerced into considering sterilization (National Empowerment Network of People Living With HIV and AIDS in Kenya [NEPHAK] and Global Network of People Living with HIV [GNP+], 2011); while in Ethiopia, 7.2% reported that they had been coerced by healthcare professionals into being sterilized since they had been diagnosed with HIV (Network of Networks of HIV Positives in Ethiopia [NEP+], 2011).

Kalambi (2008) observes that in all the documented cases; informed consent was not adequately obtained. Where it was obtained, it was under duress, ignorance regarding sterilization procedure, and deceit since the women were not explained the contents of the documents they signed. In other cases, the subjects were given the impression that they had to consent to sterilization in order to obtain another medical procedure such as an abortion or caesarean section. As noted by Jennifer Gatsi-Mallet (2009), "these women were in pain, they were told to sign, and they did not know what it was. They thought it was part of their HIV treatment. None of them knew what sterilization was, including those from urban areas because it was never explained to them" (Gatsi-Mal-

let 2009). The reported cases in Namibia were of women who could not read, write or speak English; were black and used public healthcare services; who were poor and came from disadvantaged backgrounds or informal settlements; who did not know what sterilization meant or entailed; or who did not know what informed consent entailed (Dumba, 2009).

A study in Zimbabwe revealed negative experiences of women living with HIV when seeking child birth and other reproductive health services in health facilities. The experiences included scolding by health workers for getting pregnant (Feldman and Maposhere, 2003); being neglected by health workers, and denied information on HIV and pregnancy (ICW, 2009).

2.5.2 General SRHR violations

In spite of the existence of a comprehensive global and local legal and policy framework for human rights protection and promotion, violation of sexual and reproductive health rights of women living with HIV has remained a global concern. These violations range from discrimination and trauma in the family, community and health facilities; breach of confidentiality; denial of health care services and information; and hostility ranging from physical to verbal abuse (Petretti, 2009; Welbourn, 2008; Lester et al., 1995; Feldman and Maposhere, 2003; ICW, 2009; De Bruyn, 2004; Human Rights Watch, 2006). These violations reportedly have locus in clinical, family and community settings.

There is a growing body of evidence to show that health facilities are among the settings where women living with HIV experience most violence, abuse and lack of respect in violation of their sexual and reproductive health rights in both developed and developing countries. In some contexts, there has been official recognition of these violations as violence against women. In Venezuela's 2006 laws on violence against women, for instance, such violations are referred to as 'obstetric' or 'gynaecological violence' (United Nations Population Fund, 2008). Studies conducted in the United Kingdom and USA report that pregnant Women living with HIV often experience judgemental treatment and breach of confidentiality and are denied antenatal care services (Petretti, 2009; Welbourn, 2008). In a study conducted in the US, 35% of women who tested HIV-positive in pregnancy reported experience of discrimination in healthcare facilities while those who tested HIV

negative in pregnancy did not experience such discrimination (Lester et al, 1995).

Studies conducted in developing countries report similar violations of SRHR of women living with HIV. Research investigations conducted in Africa, India and Thailand have shown that women living with HIV experience stigma and discrimination in health care settings (ICW, 2006). It is revealed that the stigma often takes the form of disparaging remarks and substandard service provision (Ibid). In India and Nepal (ICW, 2009) women living with HIV attending reproductive health services were pinched and scolded by health workers during procedures and denied services such as abortion, sterilization and delivery care until after other women had been attended to. Similar discriminatory practices of physical and verbal abuse by health workers, lack of proper care during childbirth, and breach of confidentiality by disclosing HIV status to relatives and spouses have been reported in Zimbabwe (Feldman and Maposhere, 2003; Feldman et al, 2002); Namibia (ICW, 2009); and South Africa (De Bruyn, 2004; Mthembu et al, 2011). Another study in India found out that five out of seven women living with HIV interviewed in Delhi were denied abortion or sterilization services in government hospitals and were told that the operation would negatively affect their brain (ICW, 2009). Medical personnel were reported to ignore birthing requests from women living with HIV and consequently, in some cases, they were forced to deliver without medical assistance in healthcare settings (ICW, 2009).

Rights violations related to poor attitudes and lack of interpersonal communication skills among health providers have been reported in studies conducted in other countries such as Thailand (ICW, nd) and South Africa (Mthembu et al, 2011). In Uganda, many of the women living with HIV (64%) who participated in the 2013 Stigma Index Survey reported having constructive discussions with health workers on SRHR; however, stigma and discrimination remain major issues in sexual and reproductive healthcare settings with reported cases of violations related to forced submission to medical health procedures including HIV testing (NAFOPHANU, 2013).

Women living with HIV are not only denied care but also information related to family planning and PMTCT; they are also provided with inaccurate in-

formation about HIV infection to influence their fertility decisions. A Human Rights Watch (2006) study in Ukraine documents how health workers (doctors) failed to inform pregnant women living with HIV about prevention of Mother-to-Child HIV transmission; they also exaggerated the risk of HIV transmission to the foetus and attempted to unduly influence their independent decisions regarding having children. Women living with HIV's difficulty in accessing information on HIV and pregnancy, as well as information on available contraceptive options, have also been reported in South Africa (De Bruyn, 2004). In Namibia, reports experiences of neglect by health workers, including refusal to provide information on HIV and pregnancy have been documented (ICW, 2009).

Recently, in Uganda, women living with HIV reported having been coerced by a health professional to terminate pregnancy (12%), and unduly influenced on birthing procedure (26%) and infant feeding practices (25%) (NAFOPHANU, 2013). In addition, Wagner and Wanyenze (2013) observe that over 27% of women living with HIV were told by a health provider not to have children. While service providers are expected to ensure confidentiality of test results and provide support to women living with HIV who wish to disclose their status to their partners or other family members, health service providers have been implicated in disclosing women's HIV status to other staff or community members (ICW, 2006). Many health professionals perceive the pregnancy-related needs of women living with HIV to be almost exclusively related to the prevention of Mother-to-Child transmission of HIV (Oliveira and Junior, 2003). This has led to insufficient attention being paid to other needs in relation to child-bearing.

Healthworkers' negative attitudes, breach of women's confidentiality and discriminatory practices reported in numerous studies have been noted to discourage women from seeking healthcare services (ICW, nd; Feldman et al, 2002; Petretti, 2009; Gatsi et al, 2010). Such practices can severely undermine the government's public health initiatives around HIV and reproductive health (Gatsi et al, 2010). Feldman et al (2002) report prejudices that women living with HIV should not be sexually active – which makes it difficult for them to disclose their status to family planning service providers and other health workers. A study conducted in the United Kingdom found out that the majority of



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women living with HIV would not tell their doctors about their HIV status because of fear of judgemental treatment or breaches of confidentiality (60%) while others felt their HIV status prevented them from utilizing health facilities (33%) (Petretti, 2009). In Zimbabwe, women living with HIV admitted to non-disclosure of their HIV status to health workers in order to avoid discrimination (Feldman and Maposhere, 2003).

Feldman et al (2002) note that discrimination of women living with HIV in health facilities prevented women from disclosing their status to health workers when seeking ANC and maternity services. This implies that they could not get appropriate care for their health needs especially when seeking treatment for opportunistic infections. Consequently, most women resorted to consulting traditional healers who were more accessible and willing to provide services not easily accessible through conventional health units such as abortion, treatment of chronic STIs and menstrual problems.

Violation of SRHR of women living with HIV has also been reported in family and community contexts. In the family, women were reported to experience blame, hostility, violence and desertion from partners, and accusations of infidelity upon disclosure (Feldman et al, 2002; Welbourn, 2008; De Bruyn, 2004). These studies note that women living with HIV are sexually abused or coerced into unprotected sex when they try to insist on safe sex use. In Zimbabwe, women do not only face rejection and hostility from husbands but also from their relatives, especially the in-laws (Feldman et al., 2002). Women living with HIV have also reported experience of abuse and ostracism from other community members (Welbourn, 2008; De Bruyn, 2004). Such hostility, blame and rejection is noted to cause sexual double standards and stigma which are sustained by women's economic dependence on men for their own and their children's well-being, especially in rural areas where women's rights to land are often derived from husbands (Feldman et al, 2002).

Discrimination and stigma are common experiences for women living with HIV who become pregnant (Rochon, 2009; Macquarrie and Nyblade; 2006; Feldman et al, 2002; Sean and Zydenek, 2010; Parker et al, 2002). In Uganda, while the AIDS Indicator Survey (2011) shows changing attitudes towards people living with HIV and AIDS, stigma and discrimination were reported among 22% of the men and 17% of the women who asserted that PLHIV should be ashamed of themselves; while 22% of the men and 18.3% of the women blamed HIV infection and spread in the community on PLHIV (MoH, 2011). While both men and women are stigmatized and discriminated against, the HIV Stigma^[3] Index Survey indicated that women living with HIV face more stigma and discrimination than men (NAFOPHANU, 2013). However, internal stigma characterized by feelings of shame, guilt, self-blame, low self-esteem, suicide, and seeking punitive revenge by infecting others were found to be higher among men than women.

2.6 Psycho-socio and Financial Consequences of Forced Sterilization on Women Living With HIV

The impact of involuntary sterilization can be devastating, affecting a woman's mental and physical health and her relationship with her partner, family and society at large. Some women who have been sterilized have disclosed that their families, husbands or male partners have abandoned them due to their infertility. In many developing nations and Africa, in particular, child-bearing is perceived as central to women's role, purpose and identity. Giving birth is often described as a unique attribute which nature has endowed women with (Hartman, 1995). Consequently inability to reproduce is in many cases viewed as the greatest calamity that can befall any society, community, household, family and each individual human being (Ibid). For instance, children are viewed as tremendously important in the life of women, families and communities. They are considered as guarantors of the future of the human race, sources of hope for the survival of the family name and history and key links between the present and the future; and women who choose to control their fertility or are incapable of child-bearing are viewed negatively (Limputtom, 2007). Hence, in a culture that immensely values having children for sustenance of posterity, sterilization will not be tolerated because it undermines the maintenance of the social fabric.

Inability to bear children has negative implications for women because they are unable to fulfil cultural and personal expectations, resulting in stigma and discrimination (Alonzo and Reynolds, 1995). Since there are very many stigmatizing circumstances that can affect multiple domains of people's lives, stigmatization probably has a dramatic bearing on the distribution of life chances in such areas as earnings, housing, criminal involvement, health, and life itself (Springen, 2008). Women's internalization of stigma related to sterilization can also have grave social consequences on the sterilized woman. Expectations of rejection can lead to reduced confidence and impaired social interactions, constricted social networks, low self-esteem, depressive symptoms, and unemployment and income loss (Pamela, 2008).

Childlessness can also be an enormous economic problem in developing countries where social security, pensions and retirement savings plans are not the norm. "If you don't have your children, no one looks after you," says Guido Pennings, professor of philosophy and moral science at Belgium's Ghent University. Therefore, it is not only a question of values and perception of the society but also that of sustainability of the family which is ensured by bearing children (Bantebya et al, 2014). The impact of sterilization without consent on women's overall well-being and health status has serious implications for the healthcare system as a whole because the fear of discrimination and mistreatment can discourage women from seeking healthcare services, and can severely undermine the government's public health initiatives on HIV and reproductive health (Gatsi et al, 2010).

The socio-cultural expectations of womanhood and motherhood greatly impact the extent to which women are in position to cope with the implications of sterilization after returning to their communities (Gatsi et al, 2010). These expectations are influenced by religious teaching about God's purpose for

3 Internal stigma is where one has negative feelings based on her/his HIV positive status (NAFOPHANU, 2013: 21).

man and woman that “go out and populate the earth”, Genesis chapter 22, verses 15-19. In the Hindu religion, it is believed that a woman without a child, particularly a son, cannot go to heaven. Infertile couples worry that without a child, there will be no one to mourn for them and bury them. In China and Vietnam, the traditional belief is that the souls of childless people cannot rest easily. In India, the eldest son traditionally lights the funeral pyre. In Muslim culture, the stigma follows childless women even after death: women without children are not always allowed to be buried in graveyards or sacred grounds (Springen, 2008).

2.7 Support Needs for Women living with HIV that have undergone forced and/or coerced sterilisation

Evidence from the literature shows limited support mechanisms or systems for women living with HIV, whose sexual and reproductive rights have been violated. Once forced sterilization has been undertaken, the only remedy available to the victim is reparation for the loss she suffered (Mamad, 2009). In this context, victims must have domestic recourse mechanisms first and then move on to regional or international mechanism, if dissatisfied or the domestic recourse mechanism proves inefficient (Mamad, 2009). In some countries such as Zimbabwe, there are HIV support groups which have been reported to be a vital source of information, material, emotional and social support for many women living with HIV; the groups help women to come to terms with the HIV status; learn from each other on how to live with HIV, how to eat well, look after their sexual health, feed their babies and provide collective strength and a sense of identity (Feldman et al, 2002). In addition, women living with HIV are able to engage with other members of the community to challenge discrimination and traditional practices such as widow inheritance and get help from government agencies or get free medicine (Ibid). Similar support groups have been reported by other studies conducted in Uganda, Thailand (ICW, nd; ICW, 2007; NAFOPHANU, 2013). The Uganda HIV Stigma Index Survey indicates existence of a number of support groups and networks for PLHIV, including PLHIV associations and networks; local NGOs; however, those that focus specifically on SRHR matters for women living with HIV are not identified (NAFOPHANU, 2013).

Some studies (Mthembu et al, 2011) found out that women living with HIV who had been forcefully sterilized need support in terms of compensation; provision of free psychological support, information on the nature of the procedures they have undergone, pain relief for the physical side effects of the sterilization procedure, and sterilization reversal procedures where possible. Some women living with HIV in Thailand expressed the need to have a specific hospital, or at least a specific sterile building on the hospital grounds, to protect people living with HIV from contracting other diseases; and the HIV clinic to be open on a daily basis (ICW, 2010). Other needs include provision of information on reproductive rights and options for family planning as well as clear laws to stop men from making reproductive health decisions on behalf of their wives (African Gender and Media Initiative, 2012).

2.8 Lessons from the Literature

It is clear that documentation relating to SRHR violations, especially coerced sterilization of women living with HIV in Uganda is scanty. The literature reveals common experiences of stigma and discrimination in both health care settings and community. There is limited documentation on forced and coerced sterilizations and the associated violations of the right to dignity, personal security and right to liberty. Sterilization has, however, been discussed in international litigation cases from the perspective of the right to informed consent. Unfortunately, the cases do not explore the other related rights that are being violated such as the right to dignity, personal security and liberty (Hungary, 2006).

Freedom of decision-making is linked to informed consent. It is required when permanent procedures such as sterilization are being performed. Informed consent is not merely saying “yes” to a procedure but a discussion and most importantly, it involves communication between a patient and a healthcare provider. In sterilizing clients without their informed consent, medical personnel involved violate the clients’ rights. Failing to warn the patient of the risks involved or possible alternatives to the procedure is a breach of professional ethics of the health workers and the latter could be held legally liable under negligence principles. Coercive practices relating to family planning, including forced sterilization, violate the integrity and autonomy of women’s bodies.

APPROACH AND METHODOLOGY

The research adopted a cross-sectional study design with a participatory approach employing both quantitative and qualitative methods of data collection. A quantitative field survey was conducted in all the eight regions of Uganda to generate data on the socio-demographic information and access to SRHR services. The qualitative methods included extensive desk review of relevant government and NGO policy documents, research reports, refereed journals and texts. It also entailed use of focused group discussions; key informant interviews; and selected case studies to capture the experiences of women living with HIV who had undergone forced and/or coerced sterilization. We also sought community and leaders' knowledge and perceptions related to SRHR violations and needs of women living with HIV. The triangulation of methods facilitated the collection of comprehensive data on SRHR violations.

3.1 Study sites and selection

The study was conducted in eight regions of Uganda covering nine districts (Table 3.1). The selection of districts was based on two main criteria: high HIV prevalence rates and availability of a district or regional referral hospital which offered comprehensive family planning services, including long-term and permanent methods of family planning. The selected health facilities had requisite structures, facilities and human resources to handle SRH services.

Table 1: Selected study districts

Region	% of women living with HIV by regions	Selected district
Central 1	12.5	Masaka
Kampala	9.5	Kampala
Mid Eastern	4.4	Mbale
North East	5.2	Soroti
West Nile	4.7	Arua
Mid Nothern	10.1	Gulu
South Western	9.0	Mbarara and Kabale
Mid Western	9.1	Hoima

3.2 Study Participants

The study participants included women aged between 15 and 49 who had used family planning; and those who had experienced SRHR violations and coerced and/or forced sterilization in health facility settings and in the community. About 25.3% of study participants were young women aged between 26 and 30; followed by those aged 41 – 45 (23%); 31 – 40 years (22%); 46-49 years (16%), while 13% were aged 21-25 and 2.4% aged between 15 and 20. Most of the women were married (40%); 18.4% were single; 18% were cohabiting, 15.1% were widowed and 9% were either separated or divorced. Women with primary-level education constituted over half of the study participants (54%) while 28% had attained secondary education. Eleven per cent (11%) had never been to school, and a small proportion (2.3%) had been to high school; 4% had tertiary education and 2% had vocational education. Across all the districts, there were slightly more women selected from the rural areas constituting 39.2%, followed by those from peri-urban or small towns in the villages constituted 31.8%. Twenty nine percent (29%) of the respondents were Urban-based women. The main occupation for a large proportion of the women interviewed was farming (34.4%) and retail business (22.6%); civil servants (4.3%); housewives (8.4%); engaged in cross-border trade (2.3%); employed (9.1%); casual workers (11.2%); students (6.1%) and volunteers in organizations (1.6%). More than half of the interviewed women (52.6%) knew their sero-status more than five years prior to the study and 11.6% had known five years before the study. Very few women had just tested in the less than 6 months by the time of the interview (4.2%) and 31.5% had lived with HIV for one to four years. Study participants for the qualitative interviews included men who had lived with women living with HIV as husbands/sexual partners and representatives of NGOs and government institutions working on SRHR and HIV&AIDS issues at national and district levels.

3.3 Sampling Strategy and Size

3.3.1 Survey participants

Selection of study participants was largely purposive, using the Snowball method. The strategy was preferred because of the specific target group who were mainly women living with HIV within the reproductive age (15 – 49 years). It also targeted those who had used family planning and had experienced coerced sterilization or other SRHR violations in health facility settings and in the community. Other participants included health workers, policy makers, and representatives of CSOs working on HIV and AIDS and local leaders. They were identified through the networks of ICWEA and other similar organizations. There was limited documentation and data on the numbers of women living with HIV who were accessing SRH services in the selected districts and the country at large. Given the fact that we had no idea about the target population, we used Slovin's formula to determine the sample size (Ariola, 2006). The formula is as follows;

$$n = \frac{N}{1 + Ne^2}$$

where n is the desired sample size; N is the population value and e is error tolerance/level of significance desired or acceptable margin of error.

The calculation was based on the total adult population of 780,000 women living with HIV in Uganda aged 15+ (UNGASS, 2012) which figure will be taken as N (the population) in the given equation.

The error term was fixed between 1 and 5% depending on the available resources (financial or otherwise). We opted to use the upper limit of 5%, with a 95% confidence level. Taking into consideration a possibility of response rate of about 90% and design effect of 2, and by substituting it in the given formulae, we had a sample computation as:

$$\begin{aligned} N &= 780,000 / (1 + 780,000 * 0.05 * 0.05) \\ &= 399.79 \\ n &= 400 \end{aligned}$$

The sample size of 400 was increased by 75% (300) to reduce the margin error and increase the confidence level. This gave us the total sample of 700 respondents. The districts were given equal share of respondents, large enough to allow representation of women living with HIV who were accessing SRH services. In each of the selected districts, 100 women living with HIV, aged between 15 and 49, were selected randomly from the list of those who were purposively selected from partner organizations of PLHIV in the study districts. This was followed by a screening process aimed at identifying women who had been sexually active and had ever used any form of family planning method. To increase the level of representativeness, more women living with HIV who met the criteria were selected raising the total to 744 respondents. Selection of survey respondents by district is shown in Table 2.

3.3.2 Selection of Focus Group Discussions (FGDs) participants

Some of the women living with HIV who did not participate in the survey but met the study criteria, age and marital status, were purposively selected to participate in FGDs to provide qualitative insights of their SRHR violation experiences in clinical settings. A total of 18 FGDs (9 for young women aged –15-30, and 9 for older women aged 31-49) were respectively conducted (Table 2). In addition, 14 focus group discussions for men were conducted to solicit their views on their perceptions about SRHR violations of women living with HIV. Using the snowball sampling method, men who had lived with women living with HIV as husbands/sexual partners were identified to participate in the FGDs. A total of 14 FGDs composed of 8-11 men participants in each group were conducted (Table 2).

3.3.3 Selection of case study participants

Case study participants included women living with HIV who had been coerced or forced into sterilization and termination of pregnancy. These were selected purposively through a screening process where all women who had undergone sterilization and/or abortion were identified. From this sample, women living with HIV who had been coerced or forcefully sterilized were selected. Other women living with HIV in this category were identified using the Snowball sampling method. A total of 28 eligible women were identified and interviewed as case studies.

3.3.4 Selection of key informants

These were purposively selected based on their position and nature of work on SRH and HIV&AIDS. They included representatives of NGOs working on HIV and AIDS and SRH issues – in particular provision of SRH education and family planning services and were engaged in advocacy and promotion of PLHIV rights both at national and district levels. They included Marie Stopes Uganda, Reproductive Health Uganda (RHU), Pace Uganda, The AIDS Support Organizations (TASO), Uganda Young Positives, Nabyoya Positives, Uganda Cares, Soroti Network of AIDS Organizations (SONASO), National Community of Women living with HIV (NACWOLA), and National Forum of People Living with HIV&AIDS Networks in Uganda (NAFOPHANU). Others were District HIV Consortium Arua, Baylor Uganda, Uganda Network on Law, Ethics and HIV&AIDS (UGANET), AIDS Information Centre (AIC), Kabale HIV&AIDS Forum (KIHEFU), Kitovu Mobile Clinic (Masaka District), and Makerere University Joint AIDS Programme (MJAP). The study also considered health workers from the District Health Offices and Maternal Health and Family Planning units in the Regional Referral^[1] Hospitals. The study also included district leaders including HIV district focal persons, Maternal and Child Health supervisors, District Health Officers, chairpersons and secretaries of District HIV&AIDS Committees (DACs); secretaries of Social Services – Health Affairs, as well as development partners including UNFPA, UNAIDS and government officials from the Ministry of Health (MOH) – Reproductive Health Division. Representatives of PLHIV at district levels participated in the study. A total of 63 key informants were interviewed (Table 2).

¹ Hoima, Kabale, Mbarara, Masaka, Mbale, Soroti, Arua, Gulu, Lira hospitals

Table 2: Total number of interviews by data collection method and study site

District	Quantitative semi-structured interviews with women living with HIV	Focus Groups						Case Studies	Key informant interviews
		Young Women aged 15-30 and No. of participants	Older women aged 31-49 and No. of participants	Adult men and No. of participants					
Arua	88	1	8	1	9	1	9	3	9
Mbale	84	1	8	1	5	2	9	2	5
Soroti	76	1	9	1	8	1	9	3	8
Gulu	96	1	7	1	10	1	8	--	5
Hoima	78	1	10	1	11	1	10	2	6
Kabale	78	1	9	1	10	2	17	1	7
Masaka	73	1	13	1	11	2	16	4	7
Mbarara	79	1	10	1	11	1	9	2	9
Kampala	92	1	11	1	10	2	18	3	7
TOTAL	744	9	85	9	84	13	105	20	63

3.4 Data Collection Methods and Tools

Semi-structured Interviews: Semi-structured questionnaires were administered to selected women living with HIV in the reproductive age group (15 – 49 years) in the selected districts. All these women were first subjected to a screening process using a screening interview guide (Annex 1a). The interviews were conducted mainly at hospitals, places where support groups were located, community centers and their homes. For those who felt uncomfortable to be interviewed at their homes, they were interviewed in places of their convenience. The semi-structured questionnaire (Annex 1b) captured women’s socio-economic and demographic characteristics; household data; experiences in testing and diagnosis; sexual relationships; health status; health service utilization; and participation in clinical or antiretroviral drug trials.

The semi-structured questionnaire and screening guide were adopted from those used in other countries (South Africa and Kenya) that had conducted similar studies.

In-depth Interviews (IDI): In-depth interviews were conducted using case study interview guide (Annex 1c) with five women (case studies) for each of the study sites. The women were interviewed about their personal histories and experiences as well as their concerns about their sexual wellbeing, reproduction, access to reproductive health services and SRHR violations and forced or coerced sterilization.

Key Informant Interviews (KII): To obtain information from key resource persons, local leaders, representatives of civil society organizations working on HIV and AIDS and related matters (including ICWEA staff and partner organizations), healthcare workers, policy makers at district and national levels (members of the District AIDS Committees, members of the sub-county HIV&AIDS Committees, local leaders, officials from Ministry of Health - AIDS Control Program and members of Parliament on the HIV&AIDS committee) were interviewed - using KII interview guide (Annex 1d).

Focus Group Discussions (FGDs): A total of 18 focus group discussions for women and 14 for men were conducted with men who had lived or were living with women living with HIV or had been spouses/ caretakers in the selected districts. Each focus group comprised 8 to 10 members to ensure that they were manageable and that all participants contribute to the discussions. The FGDs were guided by a moderator and a note taker – using an FGD guide for women and men (Annex 1e). The FGDs for men explored men’s norms, values, and attitudes towards SRHR of women living with HIV.

All tools were pre-tested in a pilot survey and later refined.

3.5 Field Team Composition

All research assistants were women living with HIV, majority being young women living with HIV. The purpose was to instill confidence in the respondents (women living with HIV). It was also an opportunity to enhance the capacity of young women living with HIV in data collection and analysis.

3.6 Data Management and Analysis

Qualitative data from case studies, FGDs and KIs were voice-recorded and later transcribed. In addition, field notes for all the interviews were prepared. Using the voice-recorded data and field notes, a data summary sheet was prepared. Content analysis was then used to identify emerging themes of interest. Desk review of documents was undertaken to identify gaps in policies and programming for women living with HIV in Uganda and elsewhere. Quantitative survey data was cleaned, coded and analyzed using the SPSS software package. It generated frequency tables in respect of variables and/or themes, particularly the background variables of study participants, access and utilization of health services by women living with HIV. The two data sets were then corroborated to provide quantitative and qualitative backup where necessary in the analysis and interpretation of the findings. However, the report largely draws on qualitative data to present women's experiences of SRHR violations.

3.7 Ethical Considerations

Like all studies targeting women living with HIV, this research was approached with great sensitivity in respect of the respondents' privacy, sexual and emotional life. Clearance to carry out the research at national level was obtained from the Uganda National Council for Science and Technology (UNCST). Clearance was also sought from the TASO Institutional Review Board (IRB) and district civic leaderships. Participation in the research was voluntary. At the beginning of each interview participants were assured of confidentiality, the manner in which responses would be recorded was also explained and their consent to record the interviews and discussions was sought. Where participants were uncomfortable with recording, the recorder was not used and instead handwritten notes were made in a notebook. Participants also had the liberty to refuse to answer some questions they felt uncomfortable with. To ensure reliable and valid information, research tools were pre-tested.

Confidentiality was maintained throughout the data collection, analysis and report writing processes. Only pseudonyms have been 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 cause them any harm, lead to denial of services or access to resources in the organizations where they worked or were affiliated.

Written consent forms (Annex II) were explained in the various languages and given to the study participants to sign before the interview. All data collectors were trained to ensure that they protect the confidentiality of research subjects and ensure their safety. In cases where study participants were emotional, the researchers had been trained to offer counselling and give advice where to seek further support.

Limitations of the Study

- Using research assistants who were women living with HIV in data collection could have introduced bias. However, before data collection they were trained and cautioned to be aware of their position in the study and avoid introducing bias in the interviews.
- Purposive sampling limited the coverage of respondents to only those who had disclosed their HIV status, leaving out those women who had not disclosed.
- The study exclusively focussed on women living with HIV and therefore missed understanding whether the practice is widespread among all women of reproductive age.
- The case studies presented were women's experiences and were not verified with the respective health facilities.

FINDINGS OF THE STUDY

4.1 SRHR Violation Experiences of Women Living With HIV

This section presents Sexual Reproductive Health Rights violation experiences of women living with HIV in both clinical settings and home environments. Women's right to family planning was reaffirmed by all respondents. This notwithstanding, a total of 17 women experienced either forced or coerced sterilization in clinical settings, 6 consented under difficult circumstances and 3 young adolescents experienced violation of forced abortion by their close relatives.

4.1.1 *The right to family planning and women's experiences of coerced and/or forced sterilization in clinical settings*

There was consensus across all categories of the study participants that using family planning is a birth control right for every woman, including women living with HIV. Indeed, all the women living with HIV interviewed were using family planning at the time of the interview. The majority of the women in both the quantitative interviews and FGDs observed the need for women living with HIV to use family planning for child spacing, with the health workers' advice. Over 88% of the women interviewed had ever received SRH guidance and counselling services from health workers. Only 11% had not received any form of counselling on SRH. The main source of counselling was health workers (89.6%) and social workers (13.5%).

Counselling was mainly offered after testing for HIV & AIDs. The majority of women (71%) reported that the counselling was mainly focused on family planning and 15% were advised to stop having children altogether. Other pieces of advice included prevention of MTCT and encouragement to access PMTCT/eMTCT and deliver from the health facility/hospital; avoiding multiple partners and protecting themselves; going for cancer screening; ensuring nutrition and good feeding; and living positively and adhering to treatment. A few had been advised to avoid FP because it reduces the effectiveness of ART drugs. The main family planning methods women were advised to use was injectables (33%), condoms (25%) and pills (12%) (Table 3).

Table 3: Main type of Family planning method advised to use

Type of Family Planning Method	Frequency	Validity Percent
Injection	202	33.1
Pills	72	11.8
Condoms	155	25.4
IUD	38	6.2
All the methods but was advised to make a choice	59	9.7
Norplant	41	6.7
Sterilization	16	2.6
Abstinence	6	1
Breastfeeding continuously	1	0.2
Moon beeding	1	0.2
Others	20	3.3
TOTAL	611	100

The findings show that the most popular method of family planning was the injection as reported by the majority of the participants, followed by implant and sterilization. While women living with HIV observed that there were multiple methods of family planning, they noted a number of challenges that limited their right to reproduction and family planning use. These challenges were mainly associated with refusal by spouse, gender-based factors and limited information provided by health workers in clinical settings.

4.1.2 Women's experiences of coerced and forced sterilization in clinical settings

Sterilization is one of the permanent methods of family planning available to women who have had the number of children they desire or if there is a serious medical condition that requires a permanent method. It is normally a choice made by women and their partners and a consent form must be signed as evidence that the person has consented. However, the literature across the different countries in Africa reveals that a number of women are sterilized without their consent. The findings from this study confirm this literature because 20 of the 72 women interviewed who had been sterilized, were either forced or coerced to undergo sterilization while 3 were forced to abort. Of the 20 women, 8 were forced; 8 were coerced by health workers, while 4 were sterilized before they knew their HIV status. Three were forced by relatives to abort. However, it is important to note that in most of the cases, the link between HIV status and the circumstances of sterilization was not direct.

The age of the women who had undergone forced and /or coerced sterilization ranged from 19 to 44 years, with an average age of 29. All except one had ever given birth and the number of children ranged from 2 to 6. Of these, 3 who were forced to abort had low levels of education -- with the majority having primary education -- and only 2 had completed secondary level. All were low-income earners with only one with a professional job (HIV counsellor); others were engaged in casual work and small retail business. All were sterilized in government hospitals, except two women who were sterilized in private health facilities. The age at which they were sterilized ranged between 19 and 39 years, with the average age being 29.

Most of the forced and coerced sterilization occurred during child birth, and two had gone for treatment. The violations manifested in form of misinformation, where the women were told that their fallopian tubes would be tied and later untied when they needed to give birth; not being consulted at all; and relatives having signed on their behalf. Two of the women were not informed and only discovered years later when they failed to conceive. The power dynamics between the health workers and the women and the dire situation of childbirth through C-section left women with no option. The forcing and coercion in all the three abortions were by family members/relatives.

4.1.3 Forced and coerced sterilization during pregnancy and childbirth

Forced sterilization during childbirth was the most common form of violation that women living with HIV experienced. In such circumstances, women were under pain, and were taken to the theatre without

being given an opportunity to make informed consent. They were neither given information about the procedure nor did they sign a consent form. Others were not given any opportunity to ask questions because of the language barrier (they could not speak or understand English which the doctors used). For some, the relatives consented on their behalf. Such cases of forced sterilization are illustrated in Box 1.

For purposes of confidentiality, all names used under this section are pseudonym names

Box 1: Cases of Forced Sterilization during pregnancy and childbirth

**Case 1:
Rose Gauda
(not real name):
Neither my
husband nor
any relative
consented**

I was sterilized in 1993 at the age of 25 when I had gone to the hospital to give birth. They knew I was HIV positive because my file was clearly marked HIV positive. I was not told anything about sterilization and I did not sign any consent form. Neither had my husband or relative signed any consent form. When I gained consciousness, I heard the doctors quarrelling mentioning tubes. I became suspicious that something bad had happened but was not told what exactly had happened. Later I waited for pregnancy but was unable to conceive. I tried following up my case with a doctor friend and we found that my tubes had been cut. I didn't disclose it to anybody, only people started guessing that by this time I should have given birth but I think my mother knew about it.

**Case 2:
Babirye Joy
(not real name):
My uncle
consented on
her behalf**

I was sterilized in 2003, when I was 21 years old and it was done at the hospital. I was admitted at the hospital with fever and was pregnant and going to deliver. They told me after birth that they would give me an injection so that I would not give birth until after five years - which I accepted. I did not know until later that I had been sterilized when I visited a nearby Clinic, because of frequent stomach pains. The doctor at the Clinic asked for the medical form and I told him it was with my uncle. I went and picked the form from my uncle. It is at that point that I learned that my fallopian tubes were operated. My uncle had signed the consent form. Upon hearing that, I started shedding tears. This has greatly affected my health. I just struggle to accept the situation.

**Case 3:
Kyakuwa Jus-
tine (not real
name): My sister
colluded with
doctors**

I was sterilized in 2010 at the age of 23 years in the hospital. My sister took me to the doctor when I was due to give birth. My sister met the doctor and they talked in private. I did not request sterilization but my sister told me the doctor recommended it. I was not given any information about the procedure and I did not have an opportunity to ask any questions. I found out later what was done to me when I went to Joint Clinic Research Centre for a check-up; the machine showed that my fallopian tubes were cut. I had not been told and did not sign a consent form.

**Case 4:
Nakayiwa
Brenda (not real
name):
I was never
given an
opportunity to
decide**

I underwent sterilization in 2008 at the age of 33 at a private hospital when I went to give birth. I had complications during the pregnancy. I was operated, and in the process my fallopian tubes were cut. I was experiencing a lot of abdominal pain and sometimes I had difficulty urinating. They had earlier told me I had a tumour on my uterus. They wanted to operate me immediately but I refused, as I had no one to take care of me. I went back home and returned a few days later and they operated me. They found that the baby was still alive, but unfortunately the baby died after 3 days. After I left the hospital I still had a lot of pain, which lasted for over a year. When I went back for review I met a new doctor who examined me and told me that my fallopian tubes were cut and I will never give birth again. The doctor who had cut my fallopian tubes did not ask for my permission and neither for my mother's consent because I was with her in the hospital; she did not sign and neither did my husband. I wasn't given an opportunity to decide for myself. Even when I was leaving, they did not give me a letter that shows that I had been their patient. It has been hard for me.

**Case 5:
Mayimuna
Naomi (not real
name): Health
workers
removed my
uterus without
consent**

My uterus was removed in 2007. When I got pregnant and went for medical check-up, the doctor asked me why I was pregnant. I told him I want to have a third child. The doctor said, "you people living with HIV at times annoy us because you understand your situations but you come to disturb us." Then, I said to the doctor – I am very sorry, I have a problem and cannot go anywhere else. The doctor said that they would begin to decide on our behalf. I was admitted and had the baby delivered by C-section. At that time I did not know they had removed my uterus. The time came when I wanted another baby because I had few children. I waited for one, two years but did not conceive. Then they directed me to Mulago, Ward 5, to check why I was not conceiving. That was where they told me that my uterus was removed! I was hurt and wondered why the doctors did not inform me or give me an explanation. I tried following up the case but failed to get help or answers; my file disappeared. Though I knew my rights had been violated I did not take legal action. My husband and I accepted it and we know we shall never have another child.

**Case 6:
Nyanjoki Pricilla
(not real name):
Got information
from a caretaker
that she was
sterilized**

I was sterilized in 2000 at the age of 32 years in a government hospital when I had gone to deliver my third child. The doctor did not inform me that he was going to cut my fallopian tubes or stop me from giving birth. I did not know what was happening to me because I had gone to give birth. I knew that I had been sterilized when I had regained conscience after the operation. I asked the person that was around me and he told me that he had heard the doctors saying they were going to stop me from giving birth again. It was hard to ask the doctor any question because I was in much pain. They just wrote things and most of the time they were talking in English, which I did not understand. I do not remember whether or not I signed because I was alone during that time and had no one to sign for me and I was experiencing severe pain. Since then I have never given birth.

**Case 7:
Nanfuka Hope
(not real name):
M Aunt
consented on
my behalf**

My fallopian tubes were cut when I was 27 in a government hospital. I was in a bad condition when I was pregnant. They then operated on me. I lost a lot of blood, so they decided to cut my fallopian tubes. I did not know anything about it but my aunt knew. She decided for me. After the operation when I gained consciousness, she told me that they cut my fallopian tubes. She told me I should take care of my baby because I will never give birth again. I wanted to find out why the doctor cut my fallopian tubes without my permission. I told them that I was not aware of what they had done. My husband abandoned me, in the house with my children, so I decided to live with my aunt. The decision that was made pains me so much because these days men want women who can give them children. It was wrong for my aunt to decide for me. Perhaps I would have suggested using better family planning methods.

**Case 8:
Kamusiime Ivas
(not real name):
My husband
colluded with
doctors**

I was sterilized in 2005, at the age of 39 in the government hospital. My husband told the doctors to sterilize me, without my knowledge, after I gave birth to my last born. I had talked about it before with my husband and he wanted me to do it but I refused because I wanted to continue with injections. I even asked why he wanted me sterilized, whether he wanted to get children outside our marriage but he said it was fine if I did not like. I don't know when and how they sterilized me; I came to know it later after 4 years when I developed abdominal pain and went for a medical check-up. I felt bad and wondered why my husband had not informed me. Did he want to get children with other women? I did not take any legal action because it was already done. I consoled myself because there was nothing else I could do.

4.1.4 Experiences of women living with HIV who were coerced to undergo sterilization

Four of the women interviewed were coerced to undergo sterilization. The health workers reportedly either misinformed mothers or convinced them to give their consent, because the only option to save their lives would be sterilization. They did not provide adequate information about the other options of long-term family planning so that women could make informed decisions and choices. Box 2 presents testimonies of women who were coerced into sterilization.

Box 2: Cases of Coerced sterilization

**Case 9:
Ahoka Faith (not
real name):
The nurse
coerced me to
be sterilized**

I was sterilized in 2009 at the age of 39 in a public health centre in Arua. I had had a difficult pregnancy and went through very tough times. The nurse asked me very difficult questions that gave me a single option of sterilization. I was frightened. I really don't know why they sterilized me. May be, to them, I looked like I had given birth to too many children. They asked me how many children I had and told them I had had seven children they told me that the best thing was to undergo sterilization. I had to accept out of fear. I was informed that after sterilization I would not give birth again. They did not tell me about any complications and I did not ask any question because of the experience of embarrassment from the nurse. I did not sign any consent.

**Case 10:
Nyakishiki
Brenda (not real
name):
Coerced into
sterilization**

I was sterilized in June 2013 at the age of 33 in a government hospital where I had gone to give birth. Due to many complications I experienced during pregnancy and childbirth that led to miscarriages and still birth I was advised to undergo sterilization for fear that I would die. I did not want it [sterilization] but because of complications, I had to do it. After giving birth, my child died immediately. I was in a very critical condition, the doctors talked about sterilizing me. I did not like it but doctors told me that my condition would result into death if I did not sterilize, forced me to accept to be sterilized. The doctor informed me about the procedure and that after sterilization I would never conceive again. It is only when he took me to the theatre that he told me that he had forgotten to give me the form to sign. He gave me the form to sign which I signed. I was aware of other family planning methods such as injector plan, IUD, pills and condoms but I was not given a chance to decide on other options of family planning methods. They only told me that my uterus was weak and that if I continued giving birth I would die. When they told me the repercussions if I didn't sterilize, I had to agree. At first I feared because I used to hear that when they sterilize you, you become weak. I have received counselling that has helped me to come to terms with sterilization.

**Case 11:
Adururu Peace
(not real name):**

In 2009 at the age of 38, I had gone to the health centre in Arua district to access a Depo Provera injection and found the nurse talking about sterilization. The nurse recommended that I should undergo sterilization because taking Depo for a long time would lead me into problems. I was also told about Injecta plan. She told me that after one week of sterilisation I would be okay. I decided to be sterilized because I thought about the suffering I would go through if I conceived again given that my other child was HIV positive. I was given a chance to ask questions and I understood that I would not give birth again. I did not discuss this with my husband; it was done secretly. I informed him later on. I was told verbally and never signed anything. I feel I was coerced into sterilization because I had actually only gone for Depo Provera. I have thought about giving birth but have let it go because I know I can't conceive. If there was a possibility of reversing it I would do so.

**Case 12:
Nakijjoba Ida
(not real name):
Was never told
about the
procedure**

I was sterilized in 2008 at the age of 29 in a hospital. I went to the hospital to get treatment because my fallopian tubes were causing me pain and I had a bad discharge. The doctor decided to test me for HIV and found that I was HIV positive. I was in a lot of pain and the situation was bad. They told me they were going to clean my womb. They took me to the examination room and asked me how many children I had. I told them I had four. They were using English. I did not understand what they were saying because I never studied English. They told me they were going to give me treatment. Later when I gained consciousness I saw a plaster on my stomach, but because I was in great pain, I couldn't ask questions. They gave me drugs to take and told me I would be fine and that if I get any problem I should come back. After sometime, I wanted to reproduce but I was not conceiving and I went to another hospital where they told me my fallopian tubes had been cut. Yet the hospital doctor did not tell me that they had sterilized me. I felt very bad.

**Case 13:
Mutabwire Joy
(not real name):
Sterilization
without her
knowledge**

I was sterilized in 2007 at the age of 23 in a government hospital, where I had gone to get treatment, after I had an abortion. The doctors first asked me whether they should cut my fallopian tubes, I refused. They told me that “why do you get pregnancies and abort?” I told them I was a prostitute so I didn’t know the men responsible for the pregnancies and I cannot give birth for them; even the children I have, some were HIV positive except one child. They told me about other options of family planning but I had already used some like a coil [IUD] and got pregnant. When I explained all this to them, they told me that they were going to insert Norplant. They talked about sterilization but I said that I was not ready to have my fallopian tubes cut because I might want to give birth to another child who might be HIV-negative. They agreed but advised me that the work I was engaged in was bad and exposing my life to danger. Although I had heard about sterilization, I did not want it. But the doctors decided to cut my fallopian tubes because of the many abortions I had had. By then I had aborted four times and they told me that I was putting my life in danger. They advised me to stop giving birth. When I asked what I should do, they said they were going to insert a coil [IUD] and I accepted but I didn’t know that they were going to cut my tubes. They took me to the theatre and I couldn’t understand anything. By the time I gained consciousness I found myself on a drip. When I asked what had happened, the doctor said I was sick and would get well soon and could go home. I got to know two later that my fallopian tubes had been cut. I went for treatment for stomach pains, but was informed by the doctors that I had a coil, she then examined and informed me that there was no coil; my fallopian tubes had been cut. It felt bad but I had no option.

There were also four cases of women who were sterilized without consent before they knew their HIV status.

Box 3: Cases of women who were sterilized before testing for HIV

**Case 14:
Naki Florence
(not real name):**

I was sterilized in 1991 at the age of 22 from private hospital when I had gone to give birth. I did not find out at the beginning because I had lost my child. I thought that since my child had died, I would give birth to another child again. But it was all in vain. So, I started wondering why I was unable to conceive. After some time, I was not conceiving; my husband and I got so much concerned and worried about the matter. It was really unusual that’s why I went to the hospital to consult the doctors. When I went to the hospital they gave me medicine to take for three years then some doctor told me to look for the documents that they used where I gave birth. I went and brought the documents, when the doctor read the documents, he told me that they had cut my fallopian tubes and that I would never give birth again. “And nobody should ever lie to you nor take your money that you can ever give birth again”. So I gave up on giving birth and I remained with the pain for cutting of my fallopian tubes. I even went to the hospital, where I met some white doctor, who told me that he could operate me and I could give birth again but I refused.

**Case 15:
Nawazzi Sifa
(not real name):
Spouse
consented on
her behalf**

I was sterilized in 2007 at the age of 31 in a government hospital when I had gone to deliver my sixth baby. By the time I regained consciousness, tubal ligation had already been done. I think my husband signed to show that he had consented. Maybe the doctors could have discovered a problem that compelled them to do it or maybe it could have been a result of my terrible labour pains and complications.

**Case 16:
Mulondo Rita
(not real name):**

I was sterilized in 1999 at the age of 29 from a private clinic. My husband, from whom I separated, took me to a clinic for medical care. He told me that the doctor in that clinic was good and would cure the persistent abdominal pains I had. I used to hear from healthy talks about sterilization, it wasn't new to me but I was shocked to learn that it was done to me. No mother of one kid can ever suggest sterilization. I started imagining whether my husband might have been behind it. Maybe he had already found out that he was HIV positive and decided to malice me. During those days if you were HIV-positive you were not allowed to give birth but today things have improved and much has changed. That is how it all came about. I wish it had not happened to me, I would give birth to another child. Since it hurts me, what about that child who is lonely, with no brother or sister? What about my current husband? I've not been able to give him a child. This situation equally affects both my child and my husband. I can't deny the obvious; it keeps on traumatizing me; however, I cannot do anything about it.

**Case 17:
Barya Christine
(not real name):**

I was sterilized in 2002 at the age of 26 in a government hospital. I had gone for family planning clinic. Sterilization was recommended by the doctor after I had gone there several times for post-abortion care. I accepted to be sterilized because that was where I got treatment from. I did not feel bad about being sterilized, but later I did. At one moment, I wanted to give birth again and it was not possible. When I had hardships with survival, I got married. I could deceive the man that I was pregnant yet it was not possible for me to conceive since I had been sterilized and later the man chased me away and I started paying rent for myself.

**Case 18:
Nakato Katrina
(not real name):
Coerced by a
Health worker**

I was sterilized at the age of 19 at Mulago National Referral Hospital, Family Planning Unit, when I went to access post abortion care. This is when the health worker told me to go for the sterilization, because I had carried out two abortions in the past and became very sick. I did not refuse because this was the Clinic where I would get my HIV medication and the health worker also knew that I was a sex worker, and didn't have a permanent partner. At first I thought it was okay, but there was a time when I got married to a man after one year, and he wanted a child that I could not give him. I had lied to him that I would one day give birth, but when he discovered the truth, he beat me and chased me from his home. I signed the consent form but this pained me since my two kids are HIV-positive and yet I now see other women living with HIV giving birth to HIV free babies.

**Case 19:
(not real name):
Igoye Anna:
Coerced into
sterilisation by
the nurse as the
best option**

I was sterilized in 2012 at the age of 28 at Arua Hospital, Family planning Unit. I had gone for treatment for Epilepsy but continued to the Family Planning Unit for contraception services. The nurse told me that since I was on strong drugs of epilepsy, sterilization was the best method of family planning. I decided to take it since I didn't want to suffer since I was sick. I was just told that if I felt any pain after sterilization, I should go back to them. I was also told that the process was irreversible but I didn't get a chance to ask any questions. Before I got sterilized, I was given a paper that I signed but I never kept a copy.

**Case 20:
(not real name):
Chandiru
Grace:
Depo had
longtime side
effects**

I got sterilized in 2009 at the age of 38 from Wandu Health Centre where I had gone to get my family planning injection (DEPO). While at the centre, I found the sterilization program which was introduced to me by a nurse. She told me that taking DEPO for a long time had side effects. She advised me to go for sterilization. I didn't request for it myself but opted for it after thinking about how I would suffer if I conceived again. I have a son who had been found HIV-positive. I was only told about injectables as the other options of family planning. The nurse told me that after one week of sterilization, I would be okay but I wasn't told of any dangers. I asked whether I wouldn't be badly affected and I was assured that I would not. I did it secretly and informed my husband later.

It is important to note that the majority of the case studies occurred more than five years ago before the study commenced and only six case studies happened in the last five years. It is not possible to establish that sterilization remains a major problem to date given that most of the cases happened more than five years ago. Findings in this study show that health services had greatly improved as reported by women in section 4.2.2.

Women in the FGDs also reported cases of forced and coerced sterilization by some health workers. They reported that forced sterilization is mostly done when the women are in pain and cannot help themselves. They also spoke of cases where spouses conspire with health workers for the operation to be done. They emphasized the need to give the women an opportunity to decide whether to be sterilized or not or use other methods of family planning.

There are those who have had difficult childbirths and when they tell their husbands, their husbands decide that they should sterilize them and this happens when the women are still unconscious. Therefore, the women may wish to continue to give birth but the husband says no! You have difficult birth, just cut! When the woman is in labour, the husband tells the nurses we have four children, just cut. (FGD Young Women, Mbale)

It would be better if this woman is the one that has requested for it [sterilization] and not deciding for her what is best. She should be left to decide depending on the situation she may be in, maybe, she is always ill, maybe she delivers children consecutively one after another, or even their financial status may be poor. They should discuss all this, and agree but not force her to stop giving birth when she has not decided that herself. Everyone has a right to make their own decisions. (FGD Adult Women, Masaka)

Male participants had this to say;

There are those who are sterilized without their knowledge. In that case the doctors are doing injustice to the women... if the woman is HIV-positive and has no child, it is her right to give birth... It is not right to sterilize a woman; instead they should use a condom... Even if they sterilize, still they will get AIDS, the only option is to use condoms... If you sterilize, the children you have might all die and you cannot give birth to others, but if you have not sterilized, you can give birth to other children. (FGD Men, Kabale)

Some men also spoke of how spouses connive with doctors to have their wives sterilized:

You may find a man having a family which he cannot manage, so you find that he orders the doctor to sterilize one of his wives and leave the other to give birth. In that process the sterilized woman's rights are not respected" (FGD Men, Kabale)

Women in the FGDs were concerned about misinformation about the procedure - where women are told that the tubes would be tied and later be untied to enable them conceive when they need to have more children as this voice illustrates:

What is funny is that they use the word "tie". They can never tell you that they will sterilize you. They do not explain to them what exactly sterilization is. So, for her she will not know that she was sterilized. She will think that she was only tied and once she needs another baby, she will be untied. They don't differentiate for them tying the fallopian tubes from cutting them. Cutting is the permanent method of family planning where one does not expect to have a baby again, but tying can give a chance to give birth again. But they don't explain to us exactly what they are going to do so that we know how to decide. (FGD Adult Women, Masaka)

You go to the hospital when you need to tie the fallopian tubes they instead cut them when you only wanted to tie them so that you may untie them in case you get the desire to give birth. This brings misunderstandings in a family because what you asked for is not what you got. (FGD Young Women, Masaka)

The misunderstanding of sterilization to mean tying the fallopian tubes and untying them when one desires to have a child was also reported by one of the key informants as a big issue in Masaka District. It created misunderstanding of what tubal ligation meant as illustrated in this quote:

The issue was like when they tell them "Tuzisiba" (we tie them – fallopian tubes) the women understand it to mean that they can be opened at a later date; so, it is the communication gap. They should actually be telling them "tuzisala busazi" [we cut them] because when they tell them "tuzisiba" [we tie them), the women think may be when they want to give birth they can be untied. The medical personnel should tell them what cutting, "kusiba", is. You will not be able to give birth unless maybe God intervenes. So it should be explained clearly so that they know what they are going into better still they could choose another method of Family Planning that is not permanent. (KII, Masaka)

The above extract was raised by women who had been sterilized. The majority of the men also concurred with the women that sterilization should not be undertaken unless the woman has requested for it. They recommended use of other family planning methods. According to all health workers, forced and or coerced sterilization is a violation of women's sexual and reproductive rights irrespective of their HIV status. Consequently, they were aware of the legal implications of the procedure and emphasized that sterilization in clinical settings be only done with consent of the mother and on medical grounds.

4.1.5 Circumstances under which sterilization for women living with HIV is recommended

Participants were asked their opinions on the circumstances under which women living with HIV should be sterilized. All the participants stressed that sterilization is a woman's right and shouldn't be carried out without her consent. All the women and men recommended that it should be done by consent. While women and men reported that there were cases of forced or coerced sterilization, the circumstances remained unclear even to the women themselves. The health workers and officials argued that there should be no forced sterilization unless it was a matter of life or death. Even under those circumstances, they argued consent should always be sought. However, evidence from the case studies show that a number of women underwent sterilization without their knowledge, were misinformed or were coerced by their spouses or health workers who in most cases left them with a single option of sterilization. The women noted:

It is important not to sterilize; your reproductive parts should be there because you can get some very good man. For example, my neighbour who had lived for ten years without a man [husband], met some man who came from abroad and married her. So, if you remove your reproductive parts, how then will you conceive? (FG Discussant -Young Women, Gulu)

I would not support sterilization because rumours have it that it weakens the women... unless when you have failed all the family planning methods. Forced sterilization is not good at all; women need to opt for sterilization at their own will (FGD Young Women, Hoima).

... person to sterilize, you should first know that the children you have are enough you cannot add on...if

you have the number of children you want, you can sterilize...if you have a problem that whenever you give birth, it is by C-section, you should not exceed four children and you should accept to be sterilized... (FGD Young Women, Kabale).

The men expressed similar views thus:

If the doctor wants to cut the tubes of the woman or the reproductive parts of the woman, they should inform this person suffering from HIV that they will cut their tubes, they shouldn't do it without her knowledge because she might still want to give birth to children. (FGD Men, Gulu)

A woman has a right to decide whether to sterilize or not... the woman has a right to sterilize depending on the number of children she feels comfortable with. This helps her to plan for her family. Both a woman and a man should make their own decisions on whether to sterilize or not, and if they agree, none of them should look for children outside their marriage; it should be a woman's decision to be sterilized not a man. But if she is, she should not stop a man from going outside the marriage to get other women... (FGD Men, Kabale)

A woman living with HIV can go for sterilization, if she has already produced at least above three children but if she has only one child, it would not be good for her to go for it. (FGD Men, Soroti)

Opinion on the desired number of children one should have before they opt for a permanent family planning method such as sterilization varied across the different study participants. While some men emphasized the husband's consent as crucial before BTL is done, others pointed to a woman's consent as important.

Some participants observed that there are circumstances where a doctor may have to do it, for example, when the woman has an infection that cannot be treated which may affect the other parts of the body or if there are complications that threaten the life of the mother. These findings concurred with the views from the key informants who stressed that sterilization is normally done and should be done on medical grounds but with the consent of the woman. Sufficient information, discussion and dialogue with the women should be carried out; once it is ascertained that the life of the mother is in danger – in cases where the mother has an ectopic pregnancy – then sterilization can be carried out. Other circumstances that may demand a woman living with HIV to undergo BTL include when a woman has attained the number of children she desires – between two to six children, when her CD4 count is low, when in terminal stages of illness and getting pregnant would accelerate her death, inability to take care of the baby because of poverty, or mental illness and severe disability. It was revealed that the women who request for the method are usually given time to reflect on the method before it is done. Their views are illustrated below.

Sterilization can only be done if the doctor recommends that her life is in danger or the life of the foetus is in danger. However, her consent must be sought. (KII, Mbale)

Sterilization is not good at all because sometimes people make decisions when they are desperate due to lack of enough resources to take care of their family. (KII, Gulu)

According to our records, we don't have many people who had sterilization. However, in some other circumstances, where we advise women to use sterilization due to medical complications, [for example] when a mother is very weak and can't afford, especially those with many children or if they are hypertensive, diabetic. (KII, Arua)

I think if a service provider reaches a consensus with a client of course after giving them information. And then the client decides then it is a right if she has decided. It is a two-way dialogue. They need information, they need to be supported, they need not to be forced on some decisions which they will regret in future because they are human beings they have their rights. (KII, Hoima)

It's okay for women to be sterilized only if there is consent. Women should only be sterilized if they are no longer interested in having children; if they have multiple partners some of whom they may not get consent to use condoms or may not be willing to take responsibility of the pregnancy. Women should not be forced to terminate pregnancies unless they get ectopic pregnancies or if the CD4 of the woman is too low and may put the health of both the child and the mother at risk. (KII, Kabale)

I am treating them as human beings, I have not bothered with whether you are positive or negative; the issue is that you have made a decision to permanently stop giving birth. It is the highest level of decision-making for a woman to know the number of children she desires vis-a-vis the amount of risk to transmit HIV to the baby and then she decides to stop. (KII, Mbarara)

However, one of the health workers in Arua District felt that coercion is done under the following circumstances:

A mother having more than 10 children, it is believed that at that number of pregnancies really there should be no reason to explain much especially if the last pregnancy is C-section; it is an emergency. [We] Also consider the social economic wellbeing of the couple, when it is an emergency you take up a decision as a medical officer you carry out Tubal Ligation, whether someone is HIV-positive or not. (KII, Arua)

4.2 Other Sexual Reproductive Health & Rights Violations in Clinical Settings

4.2.1 Health workers' attitudes and practices

Respect for human dignity and protection from cruel, inhuman and degrading treatment are provided for in the 1995 Ugandan Constitution (Article 24). Furthermore, Article 21 provides for non-discrimination and equality for all in all spheres of life; the HIV Prevention and AIDS Control ACT (2014) (Articles 37 & 39) explicitly calls for non-discrimination in provision of healthcare services for all the people living with HIV. Over 90% of women studied reported receiving different forms of support from the health facilities, ranging from medical, material such as mosquito nets and food to financial support as illustrated below. Only less than 10% did not get any form of support. The support received at the health facilities was mainly psycho-social (67.3%) and medical support in form of drugs (66.7%). Other support included material, referral and spiritual (Table 4).

Table 4: Support obtained from the health facility

Support received at the facility	Frequency	Per cent of cases
Psycho-social	452	67.3
Medical	448	66.7
Material	168	25.0
Referral	126	18.8
Spiritual	19	2.8
Financial	23	3.4
All the above	9	1.3

Note: Percentages do not add up to 100% because of multiple answers

On psycho-social support, the majority of the women (93.6%) had received sufficient information and they felt that confidentiality was maintained.

In spite of these provisions and the support received, findings from the qualitative interviews reveal that healthcare facilities remain spaces of discrimination and marginalization, where women living with HIV experience cruel, inhuman and degrading treatment from health workers. According to women participants in FGDs, violations occur during childbirth, in the labour wards. They noted that, in most instances, the health workers are fearful and reluctant to attend to them. Below are some of the voices to illustrate this:

When you go to give birth at the health facility, the nurses tend to be rude and accuse us that people who are living with HIV have come to infect them with their disease. So, we are discriminated against and marginalized all the time when we are at the health facility, therefore, we do not get peace of mind and urgent treatment since we are always frustrated. (FGD Young Women, Soroti)



The nurses are reluctant to help; they take their time to put on gloves and are very proud. As a result, the nurses injure the baby due to neglect and others are told to give birth from their homes. Irrespective of how serious the condition one is in, even to the point of death, no one is willing to help you, not even getting you water to drink arguing that it was not them who infected us with the HIV virus. (FGD, Young Women, Soroti)

The problem we have is the poor treatment from the nurses. They [nurses] chase the woman out of the labour ward when she is in pain and weak. When she enters the labour ward, you see the nurses telling her to first get out... if you are pregnant, they tell you to get out and when you are in labour pain (about to give birth) that is when they allow you to go inside the labour ward... (FGD, Young Women, Kabale)

There were also concerns regarding delays for medical treatment.

We have few counsellors who have limited or no time for counselling the people.... what annoys me is that you come early in the morning like at 9:00 a.m. and leave late in the evening like at 5:00 pm when you are very hungry. (FGD, Young Women, Hoima)

The male participants noted:

Some nurses are not professional and go on to talk rudely to these women implying that they shouldn't have conceived if they knew they had the virus. They reason that this could endanger the child. (FGD Men, Kampala)

The health workers blame the women for getting pregnant:

If the client has been a longstanding client at the facility, when she becomes pregnant without consulting this service provider, it now becomes a discrimination entry point. In the first place she is blamed for getting pregnant without consulting the service provider. She is subjected to many questions to answer before she receives support and treatment. In the end, one is traumatized. (KII, Hoima)

We have a challenge especially for women living with HIV and most people believe that after discovering that they are HIV positive, they lose the right to have children. People believe that when someone is HIV-positive, they should not bear children. This is a bad perception that is common even among health workers. (KII, Kabale)

Although government has put in place the elimination of Mother-to-Child Transmission (eMTCT) program, some of the interviewed women (2%) testified to having been denied access to the services while others have not been enrolled on the program. While the majority are advised to use family planning (71%) to limit their births, 15% of the women reported having been advised to stop having children because they were HIV positive others were discouraged from using family planning because it interferes with the ART drugs. However, the majority of the women (85.6%) were on ART treatment. The majority of those who were not on ART said the CD4 count was still high (53.8%) and had been advised to wait.

4.2.2 Poor health facilities

Provision of adequate health care services for people living with HIV is a human right. However, across all study districts, women reported that the health facilities were not easily accessible to many rural women, and those that are accessible do not have adequate supplies as blood, ambulance for emergencies and essential drugs, which often results into giving under-doses. Furthermore, the facilities are characterized by late-coming and absenteeism among health workers and provision of limited psycho-social support. The findings from the study further reveal concerns relating to human resource capacity and skills limitations to support women living with HIV. Health workers were reported to have limited knowledge on SRHR for women living with HIV; consequently, do not provide sufficient information to help women make informed decisions.

The people who work in health centres in our communities arrive late, then they work on some people and others go back home without receiving any treatment. ... sometimes, the health workers give us under-doses especially in Health centres II, III and IV; they are mean with their medicines and give us under-dose. They sometimes tell you that there is only Paracetamol, so they send you to buy the other medicines that are prescribed for you. They don't usually give you a full dose... (FGD Adult Women Masaka)

Access to services especially for women living with HIV in our communities would be good but it lacks counselling, people living with HIV need to be counselled. When you are tested and found to be HIV-positive, they only tell you that we found you with the virus and you are supposed to begin treatment. But they don't give us any kind of psycho-social support to encourage you or guide you on what to do next. With regard to delivering women, you may find that neither the in-charge nor the senior midwife is present. Sometimes when one bleeds a lot, they don't even have blood for transfusion. Accessing services here is really very demotivating. You know government things, for example, the ambulance may have gone on other errands and is not at the unit ..., which also brings about more problems. (FGD, Adult Women, Masaka)

Poor health service delivery was also reported by health workers who observed that some health workers lack SRH information to give to the women; they are not aware of the SRHR of people living with HIV and discourage women. Other facility-related issues identified by health workers include poor access to health centres (long distances); poor quality care characterized by shortage of drugs and testing kits; mandatory HIV testing for pregnant women; and lack of long-term FP methods. Consequently, one of the key informants noted that some of the violations may not be intentional but are due to poor healthcare facilities.

Some of the violations are not intended, but they exist because of the health system challenges that we have. For example, inaccessibility occurs when one does not have an appointment, and she is not attended to. Another violation could be that we are not giving them enough information, because of the work load. For example, you have very many people, we have to give them a health talk and carry out demonstrations. I do not think we give them adequate time, so mainly the services they need are not given. (KII, Mbarara)

However, there was an acknowledgment that healthcare services have improved. Women were asked to evaluate the quality of the health services received when they went for HIV testing, whether the services were friendly and not. The majority of the women (87.1%) were happy with the services provided during the testing because of the good psycho-social support provided by friendly, caring and supportive health workers. Others were pleased with the material and medical support such as drugs and food, among others. Only 12.9% noted that the services were bad largely because of the poor psycho-social support provided (33.6%), bad health workers (26.2%), poor services and overcrowding at the health facilities.

Table 5: Assessment of services received during HIV testing

Respondents' assessment of the health facility	Frequency	Valid Per cent
Friendly and good	643	87.1
Bad and terrible	95	12.9
Reasons for friendly services		
Good psycho-social support	433	68.2
Good and caring health workers	127	20.0
Material and medical support	85	13.4
Good services and facilities	75	11.8
Good information	19	3.0
Confidentiality was observed	4	0.6
Others	16	2.5
Reasons for bad services		
Poor psycho-social support	36	36.4
Bad health workers	28	28.3
No material and medical support was given	10	10.1
Too crowded and delays	8	8.1
Poor and bad services and facilities	8	8.1
Lack of information	3	3.0
Confidentiality was not kept	1	1.0
Others	13	13.1

87.1% of women were happy with the services provided during the testing because of the good psycho-social support provided by friendly, caring and supportive health workers.

Note: Percentages in respect of reasons for friendly services do not add up to 100% because of multiple answers.

4.3 Violation of Sexual Reproductive Health Rights of Women Living With HIV at the Household and community level

The findings reveal that women's SRH rights are violated not only in clinical settings but also in the home and the community. The violations are diverse, particularly relating to the right to family planning and access to quality healthcare services. The violations include coerced and forced abortion; restricted mobility to access health services and information; gender-based violence; neglect by spouses, among others. Most men and women in the FGDs observed that social and cultural factors remain barriers to the realization of women's reproductive rights or women accessing their rights. Some of the factors mentioned include unequal power relations leading to women's low bargaining power; limited education; and low economic status. The majority of the men in FGDs noted that when men get to know that their women are HIV-positive, they mistreat and sometimes chase or abandon them with their children. However, they said there were some good men who upon learning that their spouses are HIV-positive, give extra care and do not let them do heavy work or walk long distances.

4.3.1 Young women's experiences of violations at home: cases of forced abortion

Sexual and reproductive health and rights violations do not only occur in clinical settings but also at home. Women reported violations of forced termination of pregnancy often driven by their spouses and sometimes their relatives especially parents or sisters (Box 4).

Box 4: Cases of coerced and forced abortion in communities

Case 1: Nantume Faus- ta: Forced abortion – “It is my mum who decided for me

My pregnancy was removed at home after I had tested HIV positive. It is my mother who decided that I should abort. Then, I went with her to the herbalist who removed it. It was three months old. We did it without anyone knowing. The problem is the parents; if had it not been for the parents I would have waited and given birth because there are some girls who are 16 years and have given birth. But because I was still schooling and my father was harsh, he constantly warned us against getting pregnant; I had to remove it. The person who gave me the medicine was paid money. My boyfriend knew about it but he said that he was not ready for the baby because he was still in school.

Case 2: Nakalema Be- atrice: She was forced to abort by her sister

I was forced to abort by my sister when I was 20 years old in 1990. The abortion was done at home. I was leaving with my sister and due to fear when my sister told me to abort I just accepted. My sister told me, “If you don’t abort, who will provide soap and other requirements for the child? It will be difficult for you to access the requirements for a baby after your delivery”. I was not told about the dangers of abortion and was not given an opportunity to ask any question. I could not ask any question because I was living with my sister and I feared to ask. You know living under the authority of someone..., you can’t ask questions!

Case 3: Nakiriga Susan: The mother co- erced her to abort

I was forced to abort in 2012 by my mother. At that time I was in Senior 3. When I got pregnant; I told my mother about it. She told me that I have to terminate the pregnancy because I had to finish my studies. I never wanted to abort but I had to do it. After aborting, I decided to go for the family planning. I did it from home using the local medicines. She told me that if I am pregnant, I do not have enough for support ... that my baby could easily get the same disease [HIV&AIDS] I had and I could not manage it. So, I decided to abort. After abortion I did not feel good because I spent almost one month sick; I started gaining strength again after going to the family planning. I did not feel good myself I wanted a child so my mother just forced me to abort.

Key informants associated forced abortions with women in temporary and unstable relationships – where men are not ready to take responsibility for the pregnancies. The abortions are in most cases forced by spouses/partners or relatives. All key informants testified that they were not aware of such cases happening in health facilities, given that abortion is illegal in Uganda.

In Uganda, abortion is considered to be illegal. If a woman is forced to terminate a pregnancy based on her HIV status, it is illegal. Sometimes women are influenced by their sexual partners to terminate a pregnancy or some women choose to terminate the pregnancy due to misunderstanding with the sexual partner. (KII, Kampala).

Issues of unsafe abortions at community level are also a challenge, because some of these women really do not seek for safe abortions. You know that safe abortions are generally illegal in Uganda. So, they tend to go to unqualified professionals and only come out to seek medical care once they get complications. Sometimes they go there but maybe the quality and the care [is lacking], and most of the facilities are not able to offer post-abortion care because the providers on the ground may not have the [requisite] skills to provide such care. Most of the facilities like Health Centre IIs and IIIs and the cadres there do not have supporting staff or nursing aids. (KII, Kabale)

Other SRHR violations at the household level were linked to the right to family planning use, where women are forced to give birth beyond the number of children they desire. Women in Gulu District noted that as women, they may not have the desire to conceive or get pregnant but the person they are living with, for example, one's husband will force them to get pregnant. In Kampala some of the women expressed the dilemma of men who do not respect women's rights as illustrated by some of the participants:

On the rights of whether women should use condoms or not, it is something new to us because we, married women, know that it's the man to use a condom. If you don't take him to the counsellor and he accepts, it is hard to use a condom. Remember we take drugs in different clinics" (FGD, Adult Women, Kampala).

Women in Hoima also emphasized the fact that although they may know their rights; their spouses do not allow them to enjoy these rights.

Men put [impose] their restrictions and rules [on us], which becomes a problem. When you tell the man that you want to use family planning, the man refuses and says for him he wants to have children. (FGD, Adult Women, Hoima)

Women are forced to give birth to many children against their will, they cannot decide on the number of children. For example, women are refused to start family planning methods by their husbands. Women do it out of their husbands' consent ... When we go to hospitals, doctors advise us to use condoms but some husbands refuse. We wonder why they [husbands] refuse yet we get the advice together with our husbands. My husband does not like family planning. I do it without his knowledge so that I can space well my children. (FGD, Young Women, Hoima)

Women living with HIV in our areas are traumatized, people point fingers at them. Once anybody knows that you are HIV-positive, the marriage will break, the husband will chase you away, the community will begin backbiting you and pinpointing at you. (FGD, Young Women, Masaka)

Women with HIV AIDS have many problems when they become pregnant; there is stigmatization and discrimination amongst women in the community, at home and elsewhere. At times when they go to the hospital and the doctor requests them to go with their husbands when they are going for antenatal care, they find it difficult especially if they have never told their husbands about their HIV status. (FGD, Men, Kampala)

While most men would want women to have many children, some men restrict their spouses from giving birth as these women illustrated.

Some women in our communities face challenges, there are family breakages, women are chased from their homes because of giving birth every year, which implies that he is denying you the right to produce. (FGD, Adult Women, Masaka)

On coerced sex and restricted mobility, the men noted as follows:

For example, for discordant couples, especially when the man is the one who is HIV-positive, he will always say that he married the woman for sex and forces her into having sex without using a condom. (FGD, Men, Soroti)

Women experience very many kinds of STIs but they fear to come out and reveal this to their husbands; for example, that I want to go to the health facility. The men restrict their wives from moving out of home including going to visit health facilities for medical care. The men should give women freedom to go and access treatment. (FGD, Men, Gulu)

Other sexual and reproductive health rights challenges faced by women living with HIV were associated with the effects of pregnancy on their health, poor drug adherence, heavy workload at home and poverty.

According to the key informants, women experience a myriad of SRH violations at the household level – all associated with unequal power relations that limit women's decision making, social cultural perceptions about motherhood, economic constraints, gender-based violence, and property grabbing among others.

Most of our societies demand a woman to be submissive to her husband and decision-making is not a choice especially for her. This has perpetuated the issue of denying women rights in reproductive health, delayed decision-making since the woman thinks that the husband must give her permission to go for antenatal care and decide on how many children she wants to have. (Kil, Arua)

Even if women don't want to produce, men want to produce. Culturally, if you don't have children you don't fit in society. When women test and find they are HIV-positive, it is very difficult for them to reveal their status to their husbands because they fear that the man will automatically say she is the one who brought it [became infected first]. The next day, she will be chased away from the home. Men do not want to accompany their wives for antenatal care. To them, they see it as wastage of time and they don't see it as very beneficial. Even if she is on PMTCT, in most cases, she hides while she is taking the drugs. When she produces, there are various options: to exclusively breastfeed for three or six months, to put the child on supplements or milk. However, she is forced to breastfeed because the moment she does not do it [breastfeed], the family members and the community will question her. (KII, Kabale)

Majority of women living with HIV have limited economic strength, yet accessing SRH services requires some money for transport and other requirements. As I have told you, majority of the TASO clients are women and are economically dependent on their partners. If their partners do not support them economically to access the services, they won't come for the services. (KII, Kampala)

One of the biggest challenges among women living with HIV is gender-based violence which is crosscutting in both family planning service provision and uptake. Men are the major problem; they lack information and do not even turn up for services. They say that it is the role of the woman to go for a family planning method. When it comes to gender-based violence and HIV, men usually want to live in denial. They do not want to show that they are HIV-positive even if you go to ART clinics; the number of men receiving drugs is just a handful. So you find that even these drugs these women take home, the men want to share. So, this kind of denial is actually fuelling some violence. (KII, Hoima)

We have received information about rape which occurs in the process of women negotiating safer sex. Women have limited control over the use of male condoms. Actually, some women are raped/ forced into unprotected sex by their own partners while they negotiate for safer sex. We have received a case of defilement of a 13-year-old girl living with HIV. (KII, Kampala)

They also noted that women lack information about their rights and therefore cannot demand for them. Disclosure of one's HIV status appeared to be a significant issue causing marital instabilities. The findings reveal that all the interviewed women had disclosed their HIV test results. A large proportion of the women (45%) disclosed to an adult family member; 37% disclosed to a parent; and 35% disclosed to a spouse. Other women disclosed to friends (23%), children (7%) and religious leaders (Table 6).

Table 6: HIV disclosure among the interviewed women

Person disclosed to	Frequency	Per cent of cases
Spouse	248	34.5
Parent	265	36.9
Adult family member	324	45.1
Friends	168	23.4
Children	52	7.2
Religious leader	33	4.6
In-laws	22	3.1
Relatives	13	1.8
Neighbour	5	0.7
Local council leader	2	0.3
Media	1	0.1
All the above, the public and community	8	1.1

45% of women disclosed their HIV status to an adult family member; 37% disclosed to a parent; and 35% disclosed to a spouse.

Note: Percentages do not equal 100% because of multiple answers

The majority of the women disclosed at will (77%) while the rest (23%) felt they were pressurized. Thirty six percent were pressured to disclose by health workers (36%), and family members (31%). Others were pressured to disclose by people living with HIV (12%), non-HIV people (7.2%), neighbours (2.7%), spouse (9%) and friends (5.4%) (Table 7).

Table 7: Person who pressured for disclosure

Category of person	Frequency	Per cent of Cases
Family member	34	30.6
From spouse	10	9.0
Health worker	40	36.0
People living with HIV	13	11.7
Yes, from people not living with HIV	8	7.2
Friend and colleagues at the work place	6	5.4
Neighbour	3	2.7
Relatives of partner	2	1.8

36% were pressured to disclose by health workers (36%), and family members (31%)

Note: Percentages do not equal 100% because of multiple answers

Disclosure was associated with abandonment, discrimination and stigma as illustrated in the following voice:

Stigma is a major issue; they do not access health services, so they might not very well follow what you are telling them. They might continue breastfeeding up to two years, because they do not want their spouses to know that they are HIV-positive. Some of them might fear disclosing to their sexual partner because they fear that they will be abandoned or blamed for infecting their partners. So, there is also some bit of gender-based violence in their homes. She wants to use a condom and the other one does not want; so, in that process, they might fight. She might want the husband to go for testing and he does not want, they fight over it. (KII, Mbarara)

4.4 Factors that Inhibit Realization of SRHR by Women Living With HIV

Findings reveal a number of factors leading to the violations ranging from women's lack of information about their rights; limited decision-making/lack of agency; low self-esteem -- all of which make them vulnerable to a number of SRHR violations. Due to ignorance, women reportedly accept whatever advice they are given and do not even ask or raise any questions.

Some people don't know their rights; when they test her and she is HIV-positive, she takes whatever advice they give her; she cannot decide on her own and that is the biggest number [most women fall under this category]. On the other hand, most people are still naïve about the reproductive health. For instance, a woman might go to the local health facility, when they are being educated, most of them say yes but they don't ask what will be the effects on that. So, we still need more awareness on these matters. (FGD Young Women, Kampala)

Most women are not aware of these rights because of culture, and they have low self-esteem. Therefore they don't know what they want because they are vulnerable, with the exception of those who are educated but in some cases being educated does not mean being learned, that is why I say we have got a huge knowledge gap. (KII, Arua)

These reproductive health rights are not known to some of our women; we just have a few, a handful who knows that reproductive health is a right that a woman should actually have. What I have seen, our women want to seek the opinion of their husbands and most of them are not assertive. They don't know what to say, they don't know what to do unless the husband tells her that I want you to do it like this; others shy away. They don't want to share some of these problems. I have seen women suffer from side effects, they don't want to share them with people; they just keep silent with the problem, at times some have even died because of over-bleeding. (KII, Gulu)

Women give birth to infected children because some women do not have this kind of information that we come together to share with like today; they don't get it. Many women living with HIV don't know their rights. They don't have adequate information. For some who know their rights, the problem is that when they come to hospitals they pretend not to know anything because they fear to be neglected by the nurses. They fear to be identified as people living with HIV. (FGD, Adult Women, Masaka)

The reproductive health rights of women are not so much executed; they have been abused because of lack of knowledge. They do not have much information about their rights, and because of that, they are not being given the services in the context of their rights. This is again made worse by HIV. At times, people think that reproductive health rights are not an obligation for people who have HIV, maybe because they are already sick and [for now] do not have a clear future. (KII, Arua)

All these challenges are associated with women's low education levels and economic status. For instance, over a half of the women interviewed (54%) had only primary level education, only 28% had attained secondary education; 11% had never been to school, and a small proportion had been to high school (2.3%); 4% had tertiary education and 2% had vocational education. The main occupation for a large proportion of the women interviewed was farming (34.4%) and retail business (22.6%). A large proportion of the women lived in rural areas (39.2%), followed by those from peri-urban or small towns in the villages (31.8%). Urban-based women comprised 29%.

4.5 Effects of Violations of Sexual Reproductive Health Rights and coerced and Forced Sterilization on Women Living With HIV

The effects of forced and/or coerced sterilization on women living with HIV can be devastating, and are bound to affect a woman's psycho-social and physical relationship with her husband, family and community at large. Evidence from the case studies of women who had experienced forced and/or coerced sterilization, interviews and discussions with other women and men and key informants revealed a number of effects of forced/coerced sterilization on women and their families. These effects are attributed to their inability to give birth which is negatively perceived by the communities. As pointed out by Olonzo and Raymond (1995), inability to bear children has implications for women because they are unable to fulfil cultural and personal expectations, resulting in stigma and discrimination. Evidence from the study identified the following effects of SRHR violations and forced and/or coerced sterilization on women living with HIV as presented in four categories - psycho-social, diminished desire for sex, and family conflicts including domestic violence and separation and financial and economic effects.



4.5.1 *Psycho-social effects*

All the case studies reported psycho-social effects in form of anxiety due to failure to conceive, feeling of worthlessness and out-of-place in a family and community. These feelings were echoed by the respective women and men in a number of FGDs and interviews:

Sometimes when I remember what I have been through and what caused it all; I burst in tears and cry. I feel I should separate from my husband. If it was possible, I would leave him because of the pain I am going through. I don't want him to suffer because of my problems; besides, I have lost sexual desire. (Case 10)

The man I had been married to died and I got another one who does not know about the sterilization and is demanding for a child. I have never disclosed it to him but if the worst comes to the worst, I will. It has disturbed me. (Case 1)

I feel what they did was wrong and they should have told me about other family planning methods and I choose the best method for myself. It has affected me because I also wanted to have a girl in my life. I only have boys. At times I bleed a lot and I fear going to the hospital because I don't know whether this time they will remove my uterus. I fear that they might tell me that I have cancer and they do what they want on my body. (Case 12)

What he has done caused me a lot of trouble; my husband rejected me with all my children and I didn't get any form of support because I was going through this situation. I have no feeling for men given what I have gone through. (Case 2)

Sterilization comes with other problems including psychological problems, emotional problems because the mere thinking that your tubes are nowhere, it also puts you down. It can cause psycho-social breakdown and reduces your productivity. (FGD, young women, Kampala)

I have not seen my periods since the operation. I worry a lot because of not seeing my periods that I'll become weak. I used to worry about not having another child but now I am used. I feel it was wrong for the health workers to cut my tubes without telling me. (Case 4).

In the villages when you are walking, you will no longer have that respect and people will begin talking about you saying see that woman was sterilized. (FGD women, Masaka)

It is evident from the above voices that women have internalized stigma arising out of their inability to bear children. This has social consequences and acceptability as proper women. The finding has been confirmed in other studies (Alonzo and Reynolds, 1995; Springen, 2008). It erodes their agency and capacity to access reproductive health services and engage in productive activities.

4.5.2 *Sexual relationships: diminished desire for sex*

Evidence from the case studies and FGDs shows that sterilization affects sexual relations including reduced sexual desire, painful sexual intercourse and feeling weak.

My sexual relationship is no longer the same; I am no longer happy. All the time we are quarrelling and at times I ask myself: do others feel the same? (Case 1)

I am not sexually active. It has affected me because my body is very weak. (Case 12)

Similar sentiments came from some participants from FGDs and KII interviews.

Some do not feel like having sex with their men. No interest at all. Some become weak, their bodies pain with backache; so everyone has her side of it. (FGD, Young women, Mbale)

If the woman is not well counselled she may be depressed and this may affect her sexual life and if it is not done well, it may affect her health. (KII Kabale)

If your husband is not aware that you removed or cut the tubes, it can destroy your marriage because he might want children, yet you can't bear him children anymore. In this case he will refuse to have sex with you and get another woman whom he can have sex with to bear him children. (FGD Adult Women, Gulu)

You reach [There is] a time when you feel that having sexual intercourse is a waste of time because you will never have children again. This is worse when you discover that your partner did it when you didn't know. But if both [of you] consented, then there is no problem. (FGD Men, Kampala)

Sterilization is very painful; therefore, it affects the sexual urge of a woman. As a result, she may deny her husband sex and this will lead to issues of domestic violence. (FGD Adult Women, Soroti)

Sterilization makes some women lose their sexual desire for men, which in most cases leads to family breakdown. Some become weak and one cannot have children anymore (FGD Women, Mbale)

4.5.3 Expectations and family conflicts

Family conflicts were reported among couples because of the silence and stigma associated with sterilization. Yet the majority of the women who had been either forced or coerced into sterilization did not know that they had been sterilized until much later. Among those who got to know their situation, only two had informed their husbands, the rest did not disclose because of uncertainty about their spouse's response. The findings reveal that conflicts arose when husbands got to know that their wives had been sterilized leading to violence and divorce or separation.

I no longer work the way I used to work. My husband abandoned us with the children. When you have a man, he might want you to give birth and so if you have been sterilized he will leave you for another woman who can give birth. (Case 12)

It is really very bad because we have seen many marriages break as a result of sterilization. There is a way it [sterilization] spoils the relationship in a family. It causes problems in the family because one changes a lot in their own health. (FGD women, Masaka)

Sterilization can cause conflicts at home and it can also lead to divorce because the man wants a child but the woman's tubes were removed, and this is not good and may breed conflicts. (FGD, Men, Gulu)

In our culture, one gets married to bear children and once you are sterilized, then you will have forced a man to go out and look for children. It creates polygamous relationships. It stresses the woman, actually both of them. (KII Arua)

If women do it [sterilization] without the consent of the spouse, they fight, separate and in most cases, the man moves out and brings another woman. (KII, Mbarara)

In the Acholi culture, once you bring a woman or a girl in your home, in the first three months, you have to see her picking raw mangoes or vomiting, if not that is already a problem. There will be no respect for that woman and the man. The relationship at home becomes unstable and you know our mothers can be so inquisitive and they will start asking questions like, "My child you have been in the house for three months, how come this woman has not gotten pregnant?" (FGD Men Gulu)

Everyone's pride is a child so you cannot get happiness without a child. No matter how rich you are or how many plazas you own in town, you can never get happiness without a child. When you don't have a child, they don't respect you even when you are married to a Member of Parliament. (FGD, Young Women, Kampala)

4.5.4 Financial and economic effects

Evidence from the case studies shows that sterilization affected their economic opportunities and welfare. It leads to losing jobs, body weakness that hinders them from engaging in productive activities and abandonment by the breadwinners leaving the women to fend for themselves. Participants from FGDs and KIIs also demonstrate that women living with HIV who have undergone sterilization experience financial and economic loss. Because of inability to work due to body weaknesses, women noted as follows:

My work has been affected I used to sell bales of cloth for someone but now they are too heavy, I quit the job. (Case 2)

If the women get serious effects that need serious medical attention it may affect her capability to work yet treating the after effects may be expensive. (KII, Kabale)

Sterilization affects women farmers because they will not be able to do farming as they used to since they have become weak. (FGD Women, Mbale)

Once these fallopian tubes are cut, that means she has become disabled. There is no way she can be as strong as she was before. She won't be able to take care of her family very well and she won't be able to handle some chores at home, do any hard work. (FGDs women, Masaka)

Loss of a breadwinner due to divorce or separation causes poverty and loss of livelihoods among women living with HIV.

If a woman has all along been depending on her husband, after him knowing that she cut her tubes without his knowledge, he may chase her and marries another woman. This causes a big financial problem on the side of the woman because she cannot support herself. This is coupled with psychological torture on this lady and if she is tortured then she will no longer work like she used before; so financial income decreases. (FGD Men, Kampala)

The process of sterilization is painful and some women go for it without the consent of their husbands, yet the husbands may still want to have more children and this may lead to divorce in the long run which may cause the woman to become poor especially if they were dependant on their husbands for their own sustainability and that of their children. (FDG, Adult Women, Soroti)

However, there were opposing views that sterilization has no financial and economic effects but rather gains for the family. While some women and men in the communities believed that sterilization has financial and economic effects on women's lives, a significant number of participants from the FGDs and KIIs observed that there are no direct effects of sterilization on the financial and economic situation of women. They argued that there are instead economic and financial gains after undergoing the sterilization. Most of the key informants took a medical view and argued that there are no effects referring to the process as simple and having nothing to do with body weakness and inability to work or productivity.

Some participants, especially the KIIs, argued that sterilization has economic gains due to reduced number of children, reduced child care budgets, freedom from the burdens of pregnancy and childbirth.

4.6 Awareness of Sexual Reproductive Health Rights for Women Living With HIV

Study participants' knowledge about SRHR for women living with HIV mirrors presumptions about the SRHRs of women living with HIV. In spite of indisputable consensus that women living with HIV have SRH rights, the misconception of the latter is overtly clear among both FGD and KII respondents, irrespective of gender. In fact good maternal health practices like seeking pre-natal care, fertility regulation, men's involvement in their partners/wives' maternal care-seeking activities such as escorting them to the health centre, and practicing protected sex both for the prevention of STIs (including HIV and AIDS) and birth control among others, are overtly perceived as the SRH rights of women living with HIV. The responses of most respondents indeed do not reflect factual knowledge and/or awareness about SRHRs of women living with HIV. However, they are apparently more of mental debates as to what is morally right or wrong in respect of self-conscience and/or conduct of women living with HIV or how they are seen by others in their society. Their zeal about SRHRs of women living with HIV notwithstanding, none of the participants in the FGDs and KIIs was able to state with certainty their source of knowledge about the rights of women living with HIV. Some admitted that the behaviours they are counselled to adopt as part of positive living with HIV such as avoiding engaging in casual sexual relationships, or getting pregnant and bearing children among others, do not rhyme with what they believe to be de facto SRHRs of women living with HIV.

Some of the participants went to the extreme of asserting that what they perceived to be the SRHR of women living with HIV are also divine rights, granted by the almighty God and documented in the Holy Bible. In this context it is rational to argue, basing on the insights from FGDs data, that most PLHIV irrespective of gender do not understand the concept of human rights, let alone the SRHRs of women living with HIV and how they are promoted or violated in clinical settings and perhaps elsewhere. The responses of the Key Informants suggest that they do not fare any better than the rest of the study participants in terms of knowledge and/or awareness of SRHRs of women living with HIV in spite of being relatively better educated and presumably informed about HIV and AIDs. Evidence from the literature shows that SRHRs of women living with HIV are enshrined in diverse government, UN and other regional and international organizations' HIV and AIDs policy and programme documents. Therefore, accessing and understanding of this documentation would require not only possession of capacities such as knowledge about HIV but also exposure to HIV and AIDS work. In the quantitative survey, most respondents lacked even adequate basic education, for example, 54% were primary school drop-outs while 28% claimed to have secondary school education. In essence therefore, this cohort that represents 82% of the PLHIV are constrained by inadequate education, lack of relevant exposure and definitely lack of opportunity to get acquainted with knowledge or correct information about the SRHRs of women living with HIV; and the latter is clearly discernible in their responses. It should also be reiterated that ignorance about the rights is tantamount to ignorance about the rights violations in any setting. The level of knowledge of the SRH rights of women living with HIV among FGD participants is shown by the verbatim excerpts below.

When you get pregnant and go to the health centre they tell you about things like family planning and child spacing as good practices. So, I know these are my rights and I enjoy them. I solely determine how to space my children; and plan for my family in case I pass away. I decided to join family planning to enable me produce children that I can care for well and also look after the rest of my family. (FGD, Older women, Hoima)

I am a man but I am aware of women's rights. For instance, the woman has a right to be escorted by the husband to the health centre for check-up during pregnancy... the woman has a right to give birth when and where she wants,... the woman has a right to have sex with the husband when she is willing and to deny it when she is not in moods,... the woman has a right to demand for use of a condom or not during sexual intercourse,... the woman has a right to decide the number of children to give birth to,... the woman has a right to family planning. (FGD Men, Kabale)

This thing about women's rights is confusing. When you are HIV-positive and you go for counselling the first piece of advice they give you is to avoid by any means getting pregnant and producing children. Then other people come and tell you that catching HIV is not the end of the world; that you are free to enjoy sex, get pregnant and have children - because these are your rights. Now whom should we take seriously? For me, I learnt my HIV-positive status before getting pregnant and producing a child and that is how I will remain - childless unless an HIV cure is found.' (FGD Young women, Gulu)

Lonely life is not good. If you get someone who can help you meet some problems, you can get married again even if he is HIV-positive. It is your right. When I lost my husband, I got married to an HIV-positive man and he rented for me a house somewhere. I'm contented because we are both HIV-positive and love each other. (FGD, Older women, Kampala)

I don't know if it is my right but the way I see, it's good for a woman, especially who is widowed and HIV-positive to get another man because if she remains alone or single, life becomes very difficult for her, especially when she gets admitted in hospital. Someone must be at her bed-side to help her. (FGD Young women, Soroti)

I have HIV but also have rights like other women. When I get pregnant and go to the health unit, I'm entitled to get treatment and care to ensure that I give birth to a child who is HIV-free. If you are HIV-positive and have never given birth, you should produce because these days the services are available. It is not like in the past, where you would give birth and both the child and mother would die. (FGD Young women, Kabale)

If a woman has HIV it does not mean that she has no human feelings. She has the right to choose a husband or sexual partner; and if they get along well and know each other's HIV status they can have unprotected sex, and remind each other to take ARVs ... (FGD older women, Masaka)

I'm HIV-positive and my wife is HIV-negative. I married her after the death of my first wife to AIDS, and she



Some of the participants went to the extreme of asserting that what they perceived to be the SRHR of women living with HIV are also divine rights, granted by the almighty God and documented in the Holy Bible.

knew my HIV status. We are living comfortably in the house so there is no reason why an HIV-positive widow or widower should not remarry. Whether or not to spread HIV is just a matter of understanding each other. (FGD Men, Soroti)

When I was diagnosed HIV-positive and I went for counselling, I was strongly advised to live positively and practice safe sex to avoid re-infection. I was not told anything about the rights of people living with HIV and sincerely I do not know them. (FGD men, Kabale)

4.6.1 Key Informants' knowledge and perceptions of SRHR of women living with HIV

In the qualitative survey, purposively selected individuals believed to have a wealth of knowledge and/or information about the SRHR of women living with HIV by virtue of their long-term experience with HIV and AIDS work, or position in political/civic leadership, among other factors, were interviewed. Below are some of their verbatim responses.

Women living with HIV have rights like those who are not infected. They have a right to marry, to family planning, and to have sex with a partner of their choice. They also have a right to protect themselves from re-infection with HIV or other STIs. However, many of them are not aware of their rights or violations. (KII, Arua)

Of course everybody knows that PLHIV have rights but this does not necessarily mean that these rights are respected by everybody. In most cases, when people know that a person is HIV-positive, they prefer to isolate that person and in the process indirectly violating his/her rights. So PLHIV find it easier to conceal their status.' (KII, Kabale)

Women living with HIV have a right to access SRH services such as antenatal, ARV therapy, routine medical treatment and access to correct information, among others. However, women living with HIV are very sensitive and need to be handled carefully. They are always on their guard and many health workers do not understand them. Some prefer to avoid them, in the process, they deny them access to services which is a violation of their rights. (KII, Mbarara)

Some women living with HIV are responsible for their SRH rights violations. Even if it is your right to have sex and conceive, why should you do it when your CD4 count is so low? If a health worker disapproves of such behavior and tries to counsel the woman, telling her the risks associated with her reckless behavior, she will become indignant and say her right to behave as she wants is being violated! She may even decide to seek services elsewhere including traditional herbalists in total disregard of the risks associated with such options. So we just leave such women to do what they want. (KII, Hoima)

Analysis of the above excerpts shows that there is variation in the knowledge and awareness about SRHRs for women living with HIV among Key Informants; some are knowledgeable while others lack adequate information about the SRHR of women living with HIV.



4.7 Support Needs of Women Living With HIV who have Experienced Sexual Reproductive Health Rights violations

Participants were asked to identify both immediate and long-term support needs of women living with HIV who have experienced SRHR violations especially forced and/or coerced sterilization. There was consensus among respondents that in general there was no support for the women's needs. The needs were categorized into two, legal and psycho-social support. The respondents however noted that there was limited awareness about these needs among women and the community at large.

A number of institutions that could address the above needs of women who have been coerced or forced into sterilization were suggested. These included the courts of law, LC system and the police. There was consensus that although these institutions exist, their capacities and modalities of work are wanting and cannot address the above needs.

4.7.1 Awareness of legal implications and redress

There was widespread awareness, especially among Klls, of the legal implication of forced and coerced sterilization. It was pointed out that it was wrong and if it is established that forced and/or coerced sterilization was done, legal redress should be sought. This was not the case among women, especially those who experienced SRHR violations like forced and/or coerced sterilization. None of the 20 women interviewed who did not consent to sterilization sought legal redress.

To do Bilateral Tubal Ligation (BTL), they normally come both. When the woman comes, she brings her husband; both of them have to consent. The agreement has to be documented, they have to sign ... if it is verbal, it will bring in legal implications. (Kll, Arua)

BTL is done under the consent of a woman through a written document. We mainly encourage her to come with her husband. However, on medical grounds, depending on the condition of the mother, we may encourage her to do BTL but still under her consent. This is especially if her life is in danger; however, some refuse to consent and continue giving birth risking their lives. These medical conditions include heart conditions, chronic diseases, even diabetes and cancer. (Kll, Mbale)

Sometimes the woman may be the only one who has consented especially when she comes alone and from very far, so as long as they tell us they have agreed with the husband. The woman is the most important person because she consents. (Kll, Gulu)

Due to the legal implications regarding sterilization, I don't think someone can really do sterilization to someone without this person's consent. Because if this person takes it up, I don't think he [medical practitioner] can survive it. So we do not usually hear of this forced sterilization. They (health workers) are very careful about it. (Kll, Hoima)

4.7.2 Social support networks for women living with HIV

Majority of the women (52%) value social networking as a support mechanism of empowerment and were members of various local groups. The networks ranged from single-sex groups to mixed groups constituting people living with HIV. Forty-eight per cent of the women did not have any group affiliation. Support from the groups was largely psychosocial (25%), savings and credit (23%) and financial (23%).

Table 8: Support received from the social networks

Support obtained	Frequency	Per cent of Cases
Education	68	17.7
Financial and income	89	23.2
Savings and credit or getting loans	89	23.2
Psychosocial	98	25.5
Material and wellbeing	44	11.5
Support towards agricultural development	38	9.9
No support	19	4.9
Medical	23	6.0
Information and education	50	13
Networking and sharing of experiences	25	6.5
Assistance with funeral arrangements	4	1.0
Child care	4	1.0
Spiritual guidance	4	1.0

52% women value social networking as a support mechanism of empowerment & were members of various local groups.

Note: Percentages do not equal 100% because of multiple answers

Some of the reasons advanced for not being in a support group included the non-existent of such groups in the locality, time constraints, lack of information about the groups, financial constraints, and lack of serious and active groups in the area. Other reasons included sickness, lack of cooperation among women in groups, having retired from the groups, not being called to join a group, having been recently tested and non-disclosure.

4.7.3 Psycho -Social needs and support

Evidence from the respondents suggests that although the women who had undergone forced sterilization had a lot of psycho-social support needs such as counselling, confidence building, there were limited institutions or systems for addressing their needs. Women suffered in isolation and bore the brunt when their condition, inability to conceive, was revealed or established.

Women do not get enough counselling and advice. Government should send and facilitate more counselling aides in the villages because most counselling aides are found in urban and trading centres. (FGD, Young women, Hoima)

Women living with HIV who could have experienced forced sterilization and forced abortion need a lot of psychosocial support. TASO provides psychosocial support services for those who need it. These are services that are needed by our clients which we do not provide directly. (KII, Kampala)

4.8 Institutions and Mechanisms of Support for Women Living With HIV who have Experienced Sexual Reproductive Health Rights violations

All the case studies and majority of the female and male study participants were not aware of redress mechanisms, though some possible institutions like police, courts of law, local councils, community and family protection unit at the district, Human Rights Commission and FIDA were mentioned as possible places to seek redress. Most of the women were helpless and had not sought support; they were not aware of the laws and institutions that could support them to attain redress. Personal attempts of some women to follow up the health workers always yielded nothing. Seeking redress meant they had evidence, which most women could not obtain. One woman's (Case 1) attempt is evidenced by this

quote:

I told the doctor that they cut my tubes but I have no evidence unless you help me and get the evidence. The doctor friend offered help and established that indeed I had been sterilized by an intern doctor at Mulago hospital during child birth of the last child. I did not have a discharge letter; they told me it was taken by the nurse, a wife to the intern doctor who operated me. (Case 1)

Others testified the limited availability of support institutions and mechanisms; one of the women explains:

I have not heard of any organization or laws for addressing my problem. I think the government should put in place a law and sensitize women about the issues related to sterilization and the laws that can support women living with HIV. (FGD, Woman Participant, Kabale)

Lack of redress mechanisms was echoed in the FGDs across all the study districts with complaints of the legal process being difficult, tricky, too long, corrupt and expensive, yet most of these women are poor; therefore, they suffer silently. Furthermore, it was noted that there are no specific programmes in place to address such issues related to sterilization and reproductive health services were generalized.

4.9 Recommendations to Support Women Living With HIV who have Experienced Sexual Reproductive Health Rights Violations

The study participants made a number of recommendations that would increase support to women living with HIV who have experienced SRHR violations especially forced and/or coerced sterilization. They include provision of legal aid, community sensitization, legal education and improvement of the existing systems such as Local Councils and non-government organizations. Below are some of these recommendations:

Avail affordable legal services to women victims of coerced and forced sterilization and other SRHR violations. (KII, Kabale)

NGOs should come out to communicate these issues to the community, not only one person but also an agency to come out. (FGD Men, Gulu)

We need more education on these issues, more seminars on reproductive health. Awareness should include many people, men and even lawmakers themselves are sick [sic], they need it. Also doctors should have seminars to learn about these issues especially how to handle women living with HIV. (FGD Women, Kampala)

Women should join support groups where they will get advice, counselling and share experiences. Have community dialogues at all levels including sub-county. Different professionals could be invited for these dialogues to educate the community. (FGD, Young women Mbale)

I would strongly appeal to your organization to come down to the grassroots and sensitize the rural women on their sexual and reproductive rights because that is where the majority of women are and are ill-informed about their rights, even in town here. I believe there are some that are not aware of what is happening or what is there for them. (FGD, Men Soroti)

The only thing we can do is to have a source of support for these people who have been coerced into sterilisation so that we take legal action against those who coerced them. (KII Arua)

We need peer support, expert in that field, to talk about these issues of sterilization. However, they can seek redress from the police at community level, [for example, they can contact] community leaders, cultural leaders who handle cases, and paralegals in the community. We have heads of clans; we also need support from health service providers. (KII, Arua)

CONCLUSIONS RECOMMENDATIONS

5.1 Conclusions

There is evidence from the study that while women living with HIV, like any other women who are HIV negative share similar sexual and reproductive health rights that should be observed by all stakeholders. Women living with HIV experienced a wide range of sexual and reproductive health rights violations in clinical settings, home as well as in their communities. The violations range from misinformation regarding their SRHR, mistreatment/abuse during the process of seeking reproductive health services, especially maternal health services from health facilities to coerced and/or forced sterilization.

There was consensus among all participants that women living with HIV have a right to become pregnant and have children; engage in sexual relations with the men of their choice; access SRH information especially family planning and use family planning methods of their choice. Contrary to the above consensus, over 90% of the participants, men and women respondents, cautioned and held general perceptions that women living with HIV should not get pregnant without consulting health workers' guidance and planning for the pregnancy and enrolment on PMTCT/eMTCT. The study participants were not aware of the existing guidelines on pre-conception counselling for women living with HIV.

The findings from qualitative interviews (Kills and case studies) and FGDs show that women living with HIV have limited knowledge and awareness about their SRHR, which leaves them vulnerable and exposed to violations. For instance, the majority of women respondents in FGDs knew few options of family planning methods; they were not aware of the procedure of the long-term methods of family planning and consent and their right to SRHR information and education and determination of reproduction. In addition, women and men respondents reported unequal power relations between the health workers and women; the former seemed more knowledgeable and experienced while the latter were generally illiterate and uninformed. This was reported as a hindrance to women living with HIV realizing their SRHR and left women with limited choices.

The study established that a number of women living with HIV experienced violations as demonstrated by the documented individual case studies and were confirmed by women and men in the focus group discussions;

for example 72 out of 744 women in the study reported having undergone sterilization. Of these, 20 women had experienced SRHR violations of forced and coerced sterilization in clinical settings. Whereas three young women were forced to abort by their relatives, six women had consented to sterilization because of the difficult circumstances they were facing. Most violations, especially coerced and forced sterilization, occur during childbirth by C-section where the health workers have access to women's bodies and power to do what they feel is right for women living with HIV. The process of childbirth was reported as critical because one has limited choices and is at the mercy of health workers.

Over 95% of forced/coerced sterilization occurred when women are undergoing C-section. A few of them were unaware that they had undergone sterilization until they failed to conceive years later.

Other women believed that the procedure was a temporary measure, commonly referred to as “tying the tubes”, which could be reversed to allow them have more children.

Other violations in clinical settings occurred as a result of their ANC card being marked. All women reported different forms of marginalization and stigmatization by health workers characterized by negative comments and questioning their decision to get pregnant given the women's HIV status, and delays in receiving treatment. Such actions instilled fear and inhibited women's utilization of health facilities.

All respondents reported inadequacies in health care services such as poor quality services characterized by inadequate supplies of essential drugs and equipment, late-coming and absenteeism of health workers. However, there was an acknowledgement of an improvement over the years. The inadequacies were reported to greatly contribute to the above SRHR violations.

The study further established that SRHR violations of women living with HIV were not confined to clinical settings but also occurred at home and community settings. In these contexts, socio-cultural and economic barriers characterized by unequal power relations between men and women, women's low education and economic status are a hindrance to women's realization of their SRHR. The violations in the home manifested in form of restricted mobility to access care, gender-based violence, neglect, limited decision-making on reproduction (limited choice on when, how and the number of children to produce) and use of family planning and forced and/or coerced termination of pregnancy by relatives or spouses.

In terms of the effects of forced and/or coerced sterilization, women living with HIV reported a wide range of effects. The most common and significant effects were psycho-social (trauma); loss of identity as women; neglect by spouses and gender-based violence due to inability to have children. Others reported social isolation - inability to fit in the community and family. The demands from husbands for more children greatly impacted on their social wellbeing. A few (3) reported financial effects such loss of a job and reduced productivity. While it was easy for women to disclose their HIV status (77% of the women interviewed), it was hard for women to tell their family members or spouses that they had undergone sterilization for fear of stigmatization and abandonment. Contrary views, mainly from men and key informants, indicate that sterilization improves women's productivity and enhances the families' income because of reduced family size and increased time for engaging in productive activities.

All women who had undergone sterilization reported total lack of support system both formal and informal in their communities. All women were not aware of any legal options that could address their plight. Women chose to keep quiet and a few times forced to disclose to their partners. They need

extensive psycho-social support to raise their self-esteem and confidence as women, legal aid and financial support for infertility treatment – in particular In vitro fertilization (IVF), which is very expensive and inaccessible to most women.

The need for sensitization of communities and families about the SRHR violations of women living with HIV was raised as key to reducing the respective violations. All respondents recommended legal education and aid to support women who have experienced SRHR violations; and improving health service delivery. Retraining and re-orientation about SRHR needs of women living with HIV /AIDs was recommended by all respondents to eliminate all forms of SRHR violations of women living with HIV /AIDS.

5.2 Recommendations

Capacity building and sensitization

- Capacity building through training and sensitization of health workers on provision of quality and non-discriminatory care, encouraging them to provide right information to women living with HIV as well as adhere to the ethics of modern health care anchored in the principle of informed consent should be undertaken;
- Capacity building and skills enhancement and agency of women living with HIV should be undertaken by government and civil society to increase their ability to negotiate and resist the violations and seek legal redress whenever such violations occur;
- Regular provision of SRHR information and knowledge to women living with HIV should be inbuilt in all programmes on HIV&AIDS; and
- Conduct community dialogues involving massive campaign and sensitization of communities with particular focus on involving men to increase their knowledge and appreciation of the SRHR of women living with HIV.

Facilitate institutions and mechanisms for supporting women living with HIV

- An assessment of both formal and informal institutions that support or could support women living with HIV who have experienced SRHR violations and mechanisms should be put in place to revive the institutions or establish them in the respective communities where they are non-existent.

Promote psychosocial support to women experiencing SRHR violations through establishment of counselling services at the community level.

Legal and Policy review and development

While Uganda has enacted number policies to address HIV vulnerabilities across the different groups of the population, SRHR violations of women living with HIV have not received adequate attention.

- There is need for review of HIV and SRH policies to adequately take into account SRHR violations for women living with HIV to ensure a good standard of health for all and effective management of HIV response in the country and ensure legal redress and access to justice;
- Review of tubal ligation consent protocols and procedures and ensure use of appropriate language of communication;
- Information on the protocols and procedures should be made available during antenatal clinics;
- Review guidelines for physicians on procedures for emergency tubal ligation; and
- Provide litigation and access to justice for women who have undergone coerced and/or forced sterilisation.

Provision of Comprehensive SRHR Options and choices for women

- Increased investment and funding in provision of more SRHR and family planning choices and options for women and including women living with HIV
- Civil Society Organisations including the women movement and organisations to scale up advocacy for funding, policy review and mass sensitisation of women and girls on their SRH and rights and protection

References

- Akinrinola, Bankole, Sarah Keogh, Odunayo, Akinyemi, Kumbutso, Dzekedzeke, Olutosin, Awolude and Isaac Adewole. 2014. Differences in Unintended Pregnancy, Contraceptive Use and Abortion by HIV Status among Women in Nigeria and Zambia. *International Perspectives on Sexual and Reproductive Health*, 40 (1) Aligy Farida UssenMamad. 2009. Human Rights and Democratization in Africa
- 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.
- ARASA. 2008. Sexual and Reproductive Health Rights Advocacy Workshop Report. 21 to 22 October 2008, Johannesburg, South Africa.
- Bui, K.C., Gammeltoft, T, Nguyen, T.T., et al. Induced abortion among Women living with HIV in Quang Ninh and HaiPhong, Vietnam. *Tropical Medicine and International Health* (10):1172–78.
- Byabamazima C.R., Asiimwe, O.G., Malamba, S. et al. 1995. HIV/Syphilis serology as an indicator of past pregnancy outcomes among antenatal attendees in Kampala. IXth International Conference on AIDS and STD in Africa, Kampala.
- Center for Reproductive Rights, the International Women's Human Rights Clinic and the O'Neill Institute for National and Global Health Law, 2013 The stakes are high: The impact of unsafe abortion and inadequate access to contraception in Uganda, Centre for Reproductive health Nairobi.
- Centre for Reproductive Rights, 2006. The Protocol on the Rights of Women in Africa: An Instrument for Advancing Reproductive and Sexual Rights. Briefing Paper www.reproductiverights.org Accessed 02 March 2014
- Chi B, Hanh N, Rasch V, et al. 2010. Induced abortion among Women living with HIV in northern Vietnam: exploring reproductive dilemmas. *Culture, Health and Sexuality* 12 (Suppl 1):41–54.
- Del Carmen M, Joffe S. 2005. Informed Consent for Medical Treatment and Research: A Review *The Oncologist*, 10 (8) pp636-641
- Delvaux T, Nostlinger 2007. C. Reproductive choice for women and men living with HIV: contraception, abortion, and fertility. *Reprod Health Matters*. 2007; 15(29 suppl):46–66
- Dumba, L 2009. Litigating the cases of sterilisation without informed consent of HIV positive women in Namibia: The Process. Presentation at the ARASA Sexual Health and Reproductive Rights (SHRH) Seminar. Kopanong Conference Centre Johannesburg 12 – 13 August 2009
- Faden RR, and Beauchamp TL 1986. A History and Theory of Informed Consent. New York: Oxford University Press
- Feldman, R & Maposhere, C 2003) 'Safer sex and reproductive choice: Findings from 63 "Positive women: Voices and choices" in Zimbabwe' 11(22) *Reproductive Health Matters* 162.
- Feldman, R., Jo Manchester and C. Maposhere, 2002. Positive Women: Voices and Choices. Zimbabwe Report. International Community of Women living with HIV & AIDS: Harare.
- Floridia M, Tamburrini E, Tibaldi C, et al. Voluntary pregnancy termination among women with HIV in the HAART era (2002–2008): a case series from a national study. *AIDS Care* 22(1):50–53.
- Gatsi, J. 2008. "Denying us the rights to reproduce", ALQ.
- Gatsi, J, Kehler, J. Crone. J 2010. Make it Everybody's Business: Lessons Learned from Addressing the Coerced Sterilisation of Women living with HIV in Namibia: A Best Practice Model. Athene Network: Namibia.
- 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
- Gnaore E, De Cock KM, Gayle H et al. 1989. Prevalence and mortality from HIV Type 2 in Guinea Bissau, West Africa. *Lancet*, 1989, 334 (ii):513.
- Groves AK, Kagee A, Maman S, et al. 2010. Associations between partner violence and symptoms of anxiety and depression among pregnant women in Durban, South Africa and the implications for PMTCT. XVIII International AIDS Conference; July 18–23; Vienna

- Hallgren, R 1983. West Africa Childbirth Tradition (1983) 96(11) *Jordemodern*, 96
- Interagency Coalition on AIDS and Development, 2001. HIV and AIDS: Mother-to-Child Transmission. Available at: www.icad-cisd.com
- International Community of Women living with HIV [ICW] 2009. 'Overview of ICW's work to end the forced and coerced',
- 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
- King, R, Khana, K, Nakayiwa, S, et al. 2011. "Pregnancy comes accidentally – like it did with me": reproductive decisions among women on ART and their partners in rural Uganda. *BMC Public Health* 11(530).
- Knauth, D.R, Barbosa, R.M and Hopkins, K. 2003. Between Personal Wishes and Medical "Prescription": Mode of Delivery and Post-Partum Sterilisation among Women with HIV in Brazil. *Reproductive Health Matters* 11 (22)
- Mukasa, R. S 2008. The African Women's Protocol: Harnessing a Potential Force for Positive Change. Fanele. South Africa
- Laher, F. et al. 2009. Efavirenz conceptions in Soweto, South Africa. 5th International AIDS Society Conference on Pathogenesis, Treatment and Prevention. Cape Town, abstract TUPECO4. July 2009.
- Langston, C., Lewis, D.E., Hammill, H.A. et al. 1995. Excess intrauterine fetal demise associated with maternal human immunodeficiency virus infection. *Journal of Infectious Disease*, 172:1451-1460.
- Leach-Lemens, C. 2010. Preventing unintended pregnancies in women living with HIV in resource-poor settings.
- Malliga, S. and Mbonye, A. 2008. Maternal Morbidity and Mortality in Uganda (Dec. 8–9, 2008) (submission to All -Party Parliamentary group on Population Development and reproductive Health International - UK).
- Mamad, F. A. U. 2009. Forced sterilisation of women living with HIV & AIDS in Africa: A dissertation submitted in partial fulfilment of the requirements for the degree LL.M. (Human rights and democratisation in Africa), Faculty of Law and Management, University of Mauritius: Mauritius. available at: <http://137.215.9.22/bitstream/handle/2263/12645/mamad.pdf> accessed April 25, 2012.
- Ministry of Health. 2012. Uganda AIDS indicator Survey 2011. Kampala: Ministry of Health
- NAFOPHANU [National Forum of People Living with HIV Networks in Uganda] 2013). The People Living with HIV: Stigma Index, Uganda. Kampala: NAFOPHANU.
- Nair, P. 2010. Litigating against the forced sterilisation of Women living with HIV: Recent Developments in Chile and Namibia. *Harvard Human Rights Journal*, 23(1): 223-31
- Nantulya, V. 2012. Our HIV/AIDS epidemic. What each of us must do.
- National Empowerment Network of People Living With HIV and AIDS in Kenya [NEPHAK] and Global Network of People Living with HIV [GNP+], 2011. The People Living with HIV: Stigma Index Kenyan Country Assessment, Nairobi: NEPHAK.
- Network of Networks of HIV Positives in Ethiopia (NEP+), 2011. The People Living with HIV: Stigma Index, Ethiopia. Addis Ababa: NEP+.
- Pamela, C. 2008. Church ladies, good girls, and local stigma and the intersection of gender, ethnicity, mental illness, and sexual in relation to HIV risk. *Social science & Medicine*, Vol 67/3 398-408
- Sabarini, P. 2010 "Women living with HIV resent sterilisation advise", *Jakarta Post*: Jarkata, available at: <http://www.thejakartapost.com/news/2010/11/10/hivpositive-women-resent>; accessed April 25, 2012.
- Sedgh, G. et al., 2012. Induced abortion: incidence and trends worldwide from 1995 to 2008, *Lancet*, 379(9816):625–632.
- Shalev, C. 1998. Rights to Sexual and Reproductive Health-the ICPD and the Convention on the Elimination of All Forms of Discrimination Against Women. Paper Presented at the International Conference on Reproductive Health, Mumbai (India), 15 to 19 March 1998.
- Shearer, W.T., Langston, C, Lewis, D.E. et al. 1997. Early spontaneous abortion and fetalthymic abnormalities in maternal-to-fetal HIV infection. *ActaPediatr*, 421:60-64.
- Singh, S., Sedgh, G. and Hussain, R. 2010. Unintended pregnancy: worldwide levels, trends and outcomes, *Studies in Family Planning*, 41(4):241–250.

- Springen, K. 2008. 'What it mean to be a woman' Newsweek health Available at: Newsweek-com.html Accessed 2nd March, 2014.
- Stefiszyn, K., Mooki, K. and Tesfagabir, Y. 2009. "Addressing the reproductive health rights of women living with HIV in Southern.
- Susheela, S. et al., 2006. Unintended Pregnancy and induced abortion in Uganda: Causes and consequences, Guttmacher Institute, available at <http://www.guttmacher.org/pubs/2006/11/27/UgandaUPIA.pdf>.
- Susheela, Singh et al., 2005. The Incidence of Induced Abortion in Uganda, International Family Planning Perspectives, 31(4): 183 – 188.
- UN [United Nations Division for the Advancement of Women]. 2009. <http://www.un.org/womenwatch/daw/cedaw>The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). Accessed 05 August 2009
- United Nations. 1994. The International Conference on Population and Development Declaration, 1994, Cairo.
- United Nations. 1995. Beijing Declaration and Platform for Action (1995) Fourth World Conference on Women (15 September 1995) UN Documents A/CONF.177/20 (1995).
- Vidal, F. and Carrasco, M. 2004. Mujeres Chilenas Viviendo Con VIH/SIDA: Derechos Sexuales Reproductivos. Un Estudio de Correlaciones en Ocho Regiones del Pais. Available at http://www.feim.org.ar/pdf/blog_violencia/chile/MujeresChilenas_con_VIH_y_DSyR.pdf; Accessed April 25, 2012
- Wanyenze, R., Kindyomunda, R., Beyeza, J, et al. 2010. Uptake of contraceptives and unplanned pregnancies among HIV-infected patients in Uganda. XVIII International AIDS Conference. July 18–23; Vienna.

Annexes

Annex 1a

SCREENING QUESTIONNAIRE

Self-introduction

The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS NOW (SAN), a partner of the Link-Up Project is conducting a study to understand the experiences of women living with HIV in Uganda who have been coerced into sterilization.

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership based organization founded in 2005 that exists to give visibility to women living with HIV. ICWEA believes that gender inequalities and the limited access to sexual and reproductive health and rights for women are at the heart of the HIV epidemic. Our advocacy is based on evidence of our daily lived experiences complemented by research through participatory processes to address the priorities of women living with HIV including young women.

ICWEA's vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels; local, national, regional, and international, where decisions that affect our lives are being made;
- Have full access to care and treatment services; and
- Enjoy full rights, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders but more especially Women living with HIV. Your participation in this exercise is important in improving service delivery for Women living with HIV and for protection of their Sexual and Reproductive Health and rights. We request you to participate in responding to the questions in this questionnaire. We shall take your name for follow up where necessary but will not record it in the report and no one will penalize you for your opinions. Your views will be treated with utmost confidentiality. Please feel free to ask me anything about this study before we proceed.

1. Let the respondent introduce herself.
2. Request for consent to participate in the study.

Do you agree to participate in the interview?

1. Yes
2. No (if No, discontinue interview)

Name of Interviewer _____

Name of Respondent _____

Age _____

Instructions for Completing the Questionnaire

Please read through the questions below and answer YES or NO by placing an X in the correct box.

QUESTION		YES	NO
1	Have you ever taken an HIV test? (if No , end interview)		
2	Have you ever used any family planning methods? (Go to 4)		
3.	If yes which type? 1. Pills 2. Injectables 3. Intra-uterine device (IUD) 4. Condoms 5. Sterilization (Tubal Ligation) 6. Others (specify)-----		
4.	If No, why not? (Go to 23)		
5.	Are you currently using any family planning method? (Go to 7)		
6.	1. Pills 2. Injecta plan 3. Intra-uterine device (IUD) 4. Condoms 5. Sterilization (Tubal Ligation) 6. Others (specify)-----		
7	If NO, why not? (Go to 23) ----- -----		
8	For the method you are using, would you say it was your decision to use that method?		
9	If NO, what happened?		
If the respondent was sterilized ask:			
10	Did you approach a health care worker or doctor and ask for information on sterilization?		
11	Did a health care worker approach you to tell you about sterilization as a form of birth control?		
12	Did anyone give you any information on the procedure, how it would be done and what implications it would have on you in the future?		
13	Did you have an opportunity to ask any questions?		
14	Were you given time to think about the procedure?		
15	Did you understand what was told to you?		
16	Did you agree to the sterilization verbally?		
17	Did you sign an informed consent form?		
18	Was the consent form in English?		
19	Do you read and understand English?		
20	Did anyone explain the form to you?		
21	Did you feel pressurized into signing?		
22	What services had you gone to access at the time?		
Abortion			
23	Have you experienced any termination of pregnancy (If NO, end interview)		
24	Under what circumstances was the termination done? 1. Medical 2. Forced		
25	Where was it done? -----		
26	By who? -----		
27	Did you agree to termination of your pregnancy?		
28	If at health facility ask the following:		
29	Did anyone give you any information on the procedure, how it would be done and what implications it would have for you in the future?		
30	Did you have an opportunity to ask any questions?		
31	Were you given time to think about the procedure?		
32	Did you understand what was told to you?		
33	Did you agree to the abortion verbally?		
34	Did you sign an informed consent form?		
35	Was the consent form in English?		
36	Do you read and understand English?		
37	Did anyone explain the form to you?		
38	Did you feel pressurized into signing?		
39	What services had you gone to access at the time?		

Annex 1b

SOCIAL DEMOGRAPHIC SURVEY

IDENTIFICATION (OFFICIAL USE ONLY)

Date :	Interviewer:
Time started:	Time Ended:
District:	County:
Sub-county:	Parish:
Village:	Name of Respondent.....

INFORMED CONSENT

My name is I am part of a team from the International Community of Women living with HIV Eastern Africa (ICWEA).

The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS NOW (SAN), a partner of the Link-Up Project is conducting a study to understand the experiences of women living with HIV in Uganda who have been coerced into sterilization.

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ICWEA's vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels; local, national, regional, and international, where decisions that affect our lives are being made;
- Have full access to care and treatment services; and
- Enjoy full rights particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders. Your participation in this study is important in improving service delivery for women living with HIV and for protection of their Sexual and Reproductive Health and rights. We request you to participate in responding to the questions in this questionnaire. We shall take your name for follow up where necessary but will not record it in the report and no one will penalize you for your opinions. Your views will be treated with utmost confidentiality. Please feel free to ask me anything about this study before we proceed.

Do you agree to participate in the interview?

1. Yes
2. No (if NO, discontinue interview)

Ask respondent to introduce herself

Section A: Background Information of the Respondent (Please tick and write the appropriate answer in the codes column)

1.	Age of Respondent	Code
	1. 15- 20 2. 21- 25 3. 26-30 4. 31-35 5. 36-40 6. 41-49 7. 50 and above	
2.	Marital Status	
	1. Married 2. Single 3. Separated/Divorced 4. Widowed 5. Cohabiting 6. Others (specify).....	
3.	Education: What is your highest education level attained?	
	1. Never been to School 2. Primary 3. Secondary (Ordinary) 4. High School (Advanced level) 5. Technical/College/Vocational level 6. Tertiary/University Degree 7. Other (Specify)	
4.	Residence: Where do you live?	
	1. Rural 2. Urban area 3. Small town/village (Peri-Urban)	
5.	Occupation: What has been your MAIN occupation for the last twelve months (an activity you were involved in most of the time)?	
	1. Civil Servant 2. Farming 3. Housewife 4. Retail business 5. Cross-border trader 6. Fish folk 7. Other (Specify).....	
6.	Employment Status	
6.1	What kind of employment are you involved in?	
	1. Fulltime(employee) 2. Part time (employee) 3. Self-employed (fulltime) 4. Doing casual work or part time 5. Unemployed (not working at all)	
7	Sexual Activity	
7.1	Are you sexually active?	
	1. Yes 2. No	
7.2	If NO, Why not?	
	_____ _____ _____	
8	Physical Disability	
8.1	Do you have a physical disability of any kind?	
	1. Yes 2. No (Go to 9)	
8.2	What kind of disability?	
9	Number of People Living in Household	
9.1	How many people live in your household?	
	1. None 2. 1-2 3. 3-4 4. 5+	
10.	HIV Testing Experiences	
10.1	When did you first learn of your HIV-positive status?	

	<ol style="list-style-type: none"> 1. Less than 6 months ago 2. About a year ago 3. About two years ago 4. About three years ago 5. About four years ago 6. About Five years ago 7. More than Five years ago 	
10.2	Why did you go for an HIV test?	
	<ol style="list-style-type: none"> 1. Employment 2. Pregnant 3. To prepare for marriage 4. Referred to a clinic for STIs 5. Partner tested HIV positive 6. Referred due to HIV-related symptoms 7. I just wanted to know my sero status 8. Lost my spouse/partner 9. Spouse was sick 10. Child was sick 11. Other (specify) 	
10.3	Where were you tested from?	
	<ol style="list-style-type: none"> 1. Private Clinic 2. Government Hospital 3. Private health facility 4. Outreach program 5. Other (Specify)..... 	
10.4	Why did you go to that specific healthcare facility where you were tested?	
	<ol style="list-style-type: none"> 1. To get tested for HIV 2. For antenatal care 3. Father/mother took me there 4. Other (Specify)..... 	
10.5	How did you feel about the service you received from the healthcare professionals when you were tested?	
	<ol style="list-style-type: none"> 1. Friendly 2. Good 3. Bad 4. Terrible 5. Other (specify) 	
10.6	Can you give reasons for your answer ----- ----- ----- -----	
10.7	Did they provide you with sufficient information about being tested?	
	<ol style="list-style-type: none"> 1. Yes 2. No 	
10.8	Did they maintain confidentiality about your test results?	
	<ol style="list-style-type: none"> 1. Yes 2. No 	
10.9	Did you receive support after receiving your HIV test results? (support from the health facility)	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 11) 	
10.10	What kind of support did you receive? (Respondents can give more than one answer)	
	<ol style="list-style-type: none"> 1. None 2. Psychosocial, e.g. counseling 3. Medical, e.g., condoms, ART, etc. 4. Financial 5. Material, e.g., food, mosquito nets, etc. 6. Referral 7. Spiritual 8. All the above 9. Other (Specify) 	
11	Are you a member of any support group?	
11.1	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 11.4) 	
11.2	If yes which one? _____	
11.3	What kind of support have you obtained from the group?	
11.4	If not, Why not?	
12.	Disclosure	
12.1	Did you disclose your results to anyone? (Respondents can give more than one answer)	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 12.5) 	
12.2	Who did you disclose to?	

	<ol style="list-style-type: none"> 1. Spouse 2. Parent 3. Adult family member 4. Religious leaders 5. Friends 6. Other(specify) 	
12.3	Did you feel pressured/forced to disclose you HIV status?	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 12.5) 	
12.4	From who? (respondents can give more than one answer)	
	<ol style="list-style-type: none"> 1. Yes, I felt pressure from people living with HIV 2. Yes I got pressure from people not living with HIV 3. Family members 4. From spouse/partner 5. Others (specify)----- 	
12.5	For those who have not disclosed, how often do you feel pressured/forced to disclose?	
	<ol style="list-style-type: none"> 1. Often 2. A few times 3. Once 4. Never 	
13	Reproductive Health Counseling & services	
13.1	Have you received any reproductive health counseling since your HIV diagnosis?	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 14) 	
13.2	Where did you receive the counseling from? (respondents can give more than one answer)	
	<ol style="list-style-type: none"> 1. Health worker 2. Social worker 3. Friend 4. Family member 5. Other (specify)..... 	
13.3	If you received counseling from a health worker, what did she/he advise you?	
	<ol style="list-style-type: none"> 1. No advise was given (Go to 14) 2. To stop having any more children 3. To have more children 4. To use family planning 5. Other (specify) 	
13.4	If you were advised on family planning, which type of family planning were you advised on?	
	<ol style="list-style-type: none"> 1. Pills 2. Injectables 3. Intra-uterine device (IUD) 4. Condoms 5. Sterilization (tubal ligation) 6. Others (specify) _____ 	
14	Pregnancy and access to eMTCT/PMTCT services	
14.1	Have you been pregnant since your HIV diagnosis?	
	<ol style="list-style-type: none"> 1. Yes 2. No 	
14.2	What is the sero status of your children? (insert number of children)	
	<ol style="list-style-type: none"> 1. No child 2. HIV positive ----- 3. HIV negative ----- 4. Others (specify) ----- 	
14.3	Have you heard about eMTCT/PMTCT?	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 15) 	
14.4	Have you had access to eMTCT/PMTCT services since you became pregnant?	
	<ol style="list-style-type: none"> 1. Yes, I have received treatment. 2. I did not have access to such treatment. 3. I was denied such treatment. 4. No I was denied access to eMTCT/PMTCT. 5. No, I was not HIV positive when pregnant. 	
15	Participation in anti- retroviral/Clinical trials	
15.1	Have you ever participated in anti – retroviral/ARV drug trials?	
	<ol style="list-style-type: none"> 1. Yes 2. No 	
15.2	If YES, was your participation voluntary?	
	<ol style="list-style-type: none"> 1. Yes 2. No (Go to 15.3) 	
15.3	If NO, why?	
15.4	Have you had any challenges with anti-retroviral/ARV drug trials?	
	<ol style="list-style-type: none"> 1. Yes 2. No 	
15.5	If Yes, what challenges have you encountered?	

16	Antiretroviral (ARVs) Treatment	
16.1	Have you received any form of antiretroviral (ARVs) treatment?	
	1. Yes 2. No (Go to 16.3)	
16.2	What challenges have you experienced with antiretroviral (ARVs) treatment?	
16.3	Why have you not received any antiretroviral (ARVs) treatment? _____ _____	
17.	Self-Description of Health	
	How would you describe your health?	
	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor	

THANK YOU

Annex 1c

IN-DEPTH INTERVIEW GUIDE

RESPONDENTS:

- Women living with HIV who have experienced either coerced or forced sterilization or any other SRHR violations
- Currently married, widowed/separated/divorced
- Disclosure status (disclosed or not disclosed)

INFORMED CONSENT

My name is I am part of a team from the International Community of Women living with HIV Eastern Africa (ICWEA).

The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS NOW (SAN), a partner of the Link Up Project is conducting a study to understand the experiences of women living with HIV in Uganda who have been coerced into sterilization.

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership based organization founded in 2005 that exists to give visibility to women living with HIV. ICWEA believes that gender inequalities and the limited access to sexual and reproductive health and rights for women are at the heart of the HIV epidemic. Our advocacy is based on evidence of our daily lived experiences complemented by research through participatory processes to address the priorities of women living with HIV including young women.

ICWEA's vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels; local, national, regional, and international, where decisions that affect our lives are being made;
- Have full access to care and treatment services; and
- Enjoy full rights, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders. Your participation in this study is important in improving service delivery for women living with HIV and for protection of their Sexual and Reproductive Health and rights. We request you to participate in responding to the questions in this questionnaire. Your name will not be recorded and no one will penalize you for your opinions. Please feel free to ask me anything about this study before we proceed.

Do you agree to participate in the interview? Yes/No If NO, discontinue interview.

BACKGROUND INFORMATION TO COLLECT

- Date _____ Location _____
- Time start: _____ Time end: _____
- Interviewer(s): _____
- Note taker: _____
- Language in which the interview was conducted: _____
- Individual information as follows:

Name	
Age	
Place of residence	
Education status/level	
Work or occupation	
Marital status	
Number of children	
Ethnicity/tribe	
Religion	

Question Guide

1. HIV testing experiences

- Please describe your experiences of getting tested for HIV.
- Why did you decide to get tested?
- When did you get tested?
- Where did you get tested?
- Why did you go to the healthcare facility where you were tested? (Did you go specifically to test for HIV or for some other reason, e.g. pregnancy?)
- How did you feel about the service you received from the healthcare professionals when you were tested?
- Did they provide you with sufficient information about being tested?
- Did they maintain confidentiality about your test result?
- What kind of support did you receive after you received the HIV positive result, e.g. psychosocial, medical, spiritual, financial, and material, etc.?
- What support groups/associations are you a member or affiliated to?
- What kind of support have you obtained from such groups?

2. Experiences of sterilization

- When were you sterilized (year)?
- How old were you at the time?
- What is the name of the facility where you were sterilized?
- Why had you gone to the healthcare facility?
- When you were offered the sterilization? (birth of a child, termination of pregnancy, etc.)
- How did you first hear about sterilization?
- Did you request the sterilization yourself or was it recommended to you?
- If recommended, by who?
- Were there other family planning services that were offered? (list the services)
- What was the reason for the sterilization?
- Did you understand these reasons?
- Did you agree with these reasons?
- What were you told about sterilization by the healthcare workers before you underwent the procedure?
- Were you informed of other alternatives to sterilization, e.g., contraception, etc?
- What type of sterilization did you get (tying of tubes, cutting of tubes, burning of tubes)?
- What information were you given about this sterilization?
- What were you told about the risks of the procedure?
- What were you told about the reversibility of the procedure?
- What information were you given about other family planning options?
- Were you able to ask questions about the sterilization and how it would affect you?
- Were these questions answered to your satisfaction?
- What did you understand having sterilization would mean for you?
- Who did you discuss being sterilized with before you underwent the procedure, e.g., healthcare worker, partner, friend or parent?
- How did you feel about being sterilized?
- Did you feel pressured or coerced?
- Did you feel that you were able to say 'NO' to sterilization?
- Can you explain why? (Or why not?)
- Did you provide consent for the sterilization to happen?
- If not, who did?
- Why did someone else provide consent on your behalf?
- Did you, or the person consenting for you, give consent in writing?
- Were you given a copy of the consent form?
- Can you describe the circumstances at the time when consent was provided, e.g., in the doctor's office, during labor, while unconscious?
- What information were you given after sterilization?
- Do you feel that you were given enough information to make the decision to be sterilized?
- Why? (Why not?)

3. Impact of sterilization

- How has being sterilized impacted on you?
- How do you feel about being sterilized?

- How do you feel about your body and your fertility now?
- How do you feel about not being able to have children?
- What has been your experience of using the healthcare services after your sterilization?
- Have you experienced any medical complications as a result of being sterilized? If so, please describe.
- What kind of support have you received after your sterilization, e.g., psychological support; medication, etc.?
- What kinds of support would have helped you cope better after the sterilization?
- How has being sterilized impacted on your financial or economic opportunities?
- Have you endured any financial consequences as a result of being sterilized?
- How has being sterilized affected your sexual relationships, e.g., talking with your partner, pleasurable sex, being abused, etc.?
- How has being sterilized affected your partner, family, or community relationships?
- Have you considered or enquired about possible ways to reverse your sterilization?

4. Redress

- Do you think it was wrong for the clinic to sterilize you? If so, why?
- Who have you told about the procedure/process?
- What was their response?
- Have you heard of other women who went through similar experiences?
- Can you tell us more about this?
- Where did you hear about this, e.g., support groups etc?
- Why do you think it is (or could be) difficult for women to talk about being sterilized?
- What do you know about reproductive health rights, e.g., laws that protect women from being sterilized without their consent?
- Why do you think that women get sterilized without their consent given that it is against the law?
- What would have made your experiences of being sterilized better?

5 Experiences of forced and coerced termination of pregnancy

- When were you forced to terminate your pregnancy (year)?
- How old were you at the time?
- What is the name of the facility where your pregnancy was terminated?
- Why had you gone to the healthcare facility, when you were forced to terminate of pregnancy?
- How did you first hear about the termination of pregnancy as an option for women living with HIV?
- What was the reason for the termination of the pregnancy?
- Did you understand these reasons?
- Did you agree with these reasons?
- What were you told about the termination of the pregnancy by the healthcare workers before you underwent the procedure? Probe for risks about the procedure.
- Were you informed of other alternatives to the termination of the pregnancy, e.g., contraception, etc?
- What were you told about the reversibility of the procedure?
- Were you able to ask questions about the termination of your pregnancy and how it would affect you?
- Were these questions answered to your satisfaction?
- Did you understand what termination of your pregnancy would mean for you?
- Who did you discuss being forced to terminate your pregnancy before you underwent the procedure, e.g., healthcare worker, partner, friend or parent?
- How did you feel about being forced to terminate your pregnancy?

6 Feelings of pressure or coercion

- Did you feel that you were able to say 'no' to the abortion?
- Can you explain why? (Or why not?)
- Did you provide consent for the termination your pregnancy?
- If not, who did?
- Why did someone else provide consent on your behalf?
- Did you or the person consenting for you give consent in writing?
- Were you given a copy of the consent form?
- Can you describe the circumstances at the time when consent was provided, e.g., in the doctor's office, during labor, while unconscious?
- What information were you given after the abortion?
- Do you feel that you were given enough information to make the decision to terminate your pregnancy?
- Why? (Why not?)

7 Impact of termination of pregnancy

- How has being forced to terminate your pregnancy affected you?
- How do you feel about your body and your fertility now?
- How do you feel about the possibility of not being able to have children?
- What has been your experience of using the healthcare services after your termination of pregnancy?
- Have you experienced any medical complications as a result of termination of pregnancy? If so, please describe.
- What kind of support have you received after termination of pregnancy, e.g., psychosocial support, medication?
- What kinds of support would have helped you cope better after the termination of pregnancy?
- How has the termination of pregnancy impacted on your financial or economic opportunities?
- Have you endured any financial consequences as a result of termination of pregnancy?
- How has termination of pregnancy affected your sexual relationships, e.g., talking with your partner, having pleasurable sex, being abused?
- How has termination of pregnancy affected your partner, family, or community relationships?

8 Redress

- Do you think it was wrong for the clinic to force you to terminate the pregnancy? If so, why?
- Who have you told about the procedure/process?
- What was their response?

- Have you heard of other women who went through similar experiences?
- Can you tell us more about this?
- Where did you hear about this, e.g. support groups etc?
- Why do you think it is (or could be) difficult for women to talk about termination of pregnancy?
- What do you know about reproductive health rights, e.g., laws that protect women from being forced to terminate pregnancy without their consent?
- Why do you think that women are forced to terminate pregnancy without their consent given that it is against the law?

Annex 1d

KEY INFORMANT INTERVIEW GUIDE

Introduction

The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS Now (SAN), a Link Up partner is conducting a study that aims to explore the experiences of women living with HIV in this area who have been coerced into sterilization or have experienced other sexual and reproductive health rights violations.

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership based organization founded in 2005 that exists to give visibility to women living with HIV. ICWEA believes that gender inequalities and the limited access to sexual and reproductive health and rights for women are at the heart of the HIV epidemic. Our advocacy is based on evidence of our daily lived experiences complemented by research through participatory processes to address the priorities of women living with HIV, including young women.

ICWEA's vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels; local, national, regional, and international, where decisions that affect our lives are being made;
- Have full access to care and treatment services; and
- Enjoy full rights, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders, your participation in this study is important in improving service delivery for women living with HIV. We request you to participate in responding to the questions in this questionnaire. Your name will not be recorded and no one will penalize you for your opinions. Please feel free to ask me anything about this study before we proceed.

Name: _____ Gender _____
 Ministry/Department /Agency/Institution: _____
 Designation/position held: _____

Category of Respondents:

- Health workers
- Local district leaders
- Representatives of non-governmental organizations working on HIV&AIDS

Question Guide

Role of the institutions/agency in advancing sexual and reproductive health rights for HIV positive women in Uganda, areas of focus, etc.

Attitudes and Values towards Women living with HIV's Reproductive Choices

1. What are the main reproductive health and rights problems affecting women living with HIV in this community?
2. What are your views about reproductive health rights for women living with HIV &AIDS?
3. Is it okay for women living with women living with HIV o get pregnant? If so why if not why not?
4. What is your opinion about women living with HIV using family planning methods?
5. What do you think is the best family planning method that women living with HIV should use? Why?
6. What is your opinion about sterilization of women living with HIV? Under what circumstances should women living with HIV get sterilized?
7. Under what circumstances are women living with HIV forced to terminate a pregnancy?
8. What are the legal implications for forcing women living with HIV into sterilization and terminating their pregnancy? What options do women have to seek legal redress?
9. How does sterilization affect them and their sexual relationships with partners?
10. How does sterilization affect these women's financial/economic opportunities? Should HIV positive women who are widowed get married or have sexual partners? If yes, why and if no, why not?
11. How does abortion affect them and their sexual relationships with partners?
12. How does abortion affect these women's financial/economic opportunities? Should HIV positive women who are widowed get married or have sexual partners? If yes, why and if no, why not?
13. What forms of redress and support should HIV positive women who have been coerced or forced to sterilize or terminate a pregnancy be given or prided ?
14. What programs or services exist in this community to support HIV positive women who have been forced or coerced into sterilization or termination of pregnancy?
15. What should be done to protect HIV positive women's reproductive health rights?

Annex 1e

FOCUS GROUP DISCUSSION FOR WOMEN

INTRODUCTION AND INFORMED CONSENT

My name is I am part of a team from the International Community of Women living with HIV Eastern Africa (ICWEA). The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS NOW (SAN), a partner of the Link Up Project is conducting a study to understand the experiences of women living with HIV in Uganda who have been coerced into sterilization.

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership based organization founded in 2005 that exists to give visibility to women living with HIV. ICWEA believes that gender inequalities and the limited access to sexual and reproductive health and rights for women are at the heart of the HIV epidemic. Our advocacy is based on evidence of our daily lived experiences complemented by research through participatory processes to address the priorities of women living with HIV, including young women.

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- Have full access to care and treatment services; and
- Enjoy full rights, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders. Your participation in this study is important in improving service delivery for women living with HIV and for protection of their Sexual and Reproductive Health and rights. We request you to participate in responding to the questions in this questionnaire. We shall take your name for follow up where necessary but will not record it in the report and no one will penalize you for your opinions. Your views will be treated with utmost confidentiality. Please feel free to ask me anything about this study before we proceed.

Do you agree to participate in the interview? Yes/No If NO, discontinue interview.

INSTRUCTIONS

Category of respondents: Women living with HIV in the reproductive age group of 15 – 30 and 31 – 49

Materials needed: Note book, pen, and recorder

Thematic focus:

- Attitudes and values towards HIV-positive women's reproductive choices
- HIV testing experiences
- Disclosure
- Reproductive health counselling & services
- Coerced or forced sterilization
- Pregnancy and access to eMTCT/PMTCT services

BACKGROUND INFORMATION TO COLLECT

- Date _____ Location _____:
- Numbers of participants (at beginning): ____ (at end): _____
- Kind of participants (men/women, age group) _____
- Ages (average): _____
- Time start: _____ Time end: _____
- Facilitator(s): _____
- Note taker: _____
- Language in which the interview was conducted: _____
- How was the process? Was it participatory? Did everyone take part in the discussion? Did anyone dominate? Did anyone walk out? Why? Was it difficult / easy to manage? Why? Were people comfortable / uncomfortable? Why? etc.

A: Record Participants Bio-data

- Names, age, marital status, education level, occupation, religion, ethnicity/tribe etc.

B: Attitudes and Values towards HIV Positive Women's Reproductive Choices

- What are the general reproductive health problems faced by women living with HIV in this community?
- Are women living with HIV aware of or know about their reproductive health rights?
- What are your views about HIV positive women getting pregnant?
- Should HIV positive women who are widowed get married or have sexual partners? If YES, why and if NO, why not?

C: HIV Testing Experiences

- Do women in this community generally go for HIV test? Under what circumstances do women go for testing?
- Where do women get tested, private clinic, government hospital, private health facility, outreach program, etc?
- What are your views about the services provided by the healthcare professionals? Probe for the specific facility.
- What are your opinions about the information given at the health facility after testing? Probe for whether the information was sufficient, maintaining confidentiality.
- What kind of support does WOMEN LIVING WITH HIV receive? Probe for psychosocial, medical, material, referral, spiritual, etc.
- Are there support groups for women living with HIV? What about those for women living with HIV who have been sterilized?
- What kind of support do women get from the groups?

D: Disclosure

- Is it common for women in this community to disclose their status after testing positive? To whom do they disclose?
- Do women in this community feel pressured/ forced to disclose their HIV status? By who?
- For those who have not disclosed, what do you think is the reason?

E: Reproductive Health Counseling & services

- Do women in this community have access to reproductive health counseling after HIV diagnosis? Where do they get it from?
- If health facility, what do health workers advise them on? Probe for content of counseling and the type of family planning.

F: Coerced or forced sterilization

- What is your opinion about sterilization for HIV-positive women? Probe - under what circumstances should HIV positive women get sterilized?
- How does sterilization affect women and their sexual relationships with partners?
- How does sterilization affect these women's financial/economic opportunities?
- What forms of redress and support should HIV positive women who have been coerced or forced to sterilize be given or provided? Where and from who?
- What should be done to protect HIV positive women's reproductive health rights?

G: Pregnancy and access to eMTCT/PMTCT services

- Do women in this community have access to eMTCT/PMTCT services? Where?
- What do you think about the services in general?
- What could be done better?

I: Antiretroviral (ART) Treatment

- Do women in this community have access to antiretroviral treatment (ART) on a regular basis?
- What challenges are associated with antiretroviral treatment (ART)?
- For those who have not receiving any antiretroviral treatment (ART), probe why they have not?

Suggestions

- What suggestion would you propose to improve SRHR for women living with HIV?
- Do you have any questions?

End discussion by thanking the participants

FOCUS GROUP DISCUSSION FOR MEN

INFORMED CONSENT

My name is I am part of a team from the International Community of Women living with HIV Eastern Africa (ICWEA).

The International Community of Women living with HIV Eastern Africa (ICWEA) with support from Stop AIDS NOW (SAN), a partner of the Link Up Project is conducting a study to understand the experiences of women living with HIV in Uganda who have been coerced into sterilization.

The International Community of Women living with HIV Eastern Africa (ICWEA) is a registered regional advocacy network and membership based organization founded in 2005 that exists to give visibility to women living with HIV. ICWEA believes that gender inequalities and the limited access to sexual and reproductive health and rights for women are at the heart of the HIV epidemic. Our advocacy is based on evidence of our daily lived experiences complemented by research through participatory processes to address the priorities of women living with HIV, including young women.

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- Have full access to care and treatment services; and
- Enjoy full rights, particularly sexual, reproductive, legal, financial and general health rights; irrespective of our culture, age, religion, sexuality, social or economic status/class and race.

We will discuss with different stakeholders. Your participation in this study is important in improving service delivery for women living with HIV and for protection of their Sexual and Reproductive Health and rights. We request you to participate in responding to the questions in this questionnaire. We shall take your name for follow up where necessary but will not record it in the report and no one will penalize you for your opinions. Your views will be treated with utmost confidentiality. Please feel free to ask me anything about this study before we proceed.

Do you agree to participate in the interview? YES/NO If NO, discontinue interview

INSTRUCTIONS

Category of respondents

- Men who have had close relationships with HIV positive women, such as being their spouses, fathers, or brothers, and without regard to their own HIV status

Materials needed: Note book, pen, and recorder

Thematic Focus

- Men's norms, values, and attitudes towards women living with HIV 's reproductive choices and health

BACKGROUND INFORMATION

- Date _____ Location _____ :
- Numbers of participants (at beginning): ____ (at end): _____
- Kind of participants (men/women, age group) _____
- Ages (average): _____
- Time start: _____ Time end: _____
- Facilitator(s): _____
- Note taker: _____
- Language in which the interview was conducted: _____
- How was the process? Was it participatory? Did everyone take part in the discussion? Did anyone dominate? Did anyone walk out? Why? Was it difficult / easy to manage? Why? Were people comfortable / uncomfortable? Why?

A: Record Participants Bio-data

- Names, age, marital status, education level, occupation, religion, ethnicity etc.

B: Attitudes and values towards HIV-positive women's reproductive choices

1. What do you know about reproductive health rights for women living with HIV?
2. Should HIV positive women who are widowed get married or have sexual partners? If YES, why? If NO, why not?
3. What is your opinion about HIV positive women getting pregnant?
4. What is your opinion about sterilization for HIV positive women? Probe - under what circumstances should HIV positive women get sterilized?
5. How does sterilization affect them and their sexual relationships with partners?
6. How does sterilization affect these women's financial/economic opportunities?
7. What forms of redress and support should HIV positive women who have been coerced or forced to sterilize be given or provided? Where and from who?
8. What should be done to protect HIV-positive women's reproductive health rights?

Annex 2

CONSCENT FORM

Title of the study: Violation of Sexual, Reproductive Health and Rights of Women living with HIV in HIV and Sexual Reproductive Health Clinical and Community Settings in Uganda

Telephone: (+256) 772695133... (PI)

Study purpose

The main purpose of the study is to investigate the violations of rights of women living with HIV in their reproductive age within clinical and community settings in Uganda. The main focus among others includes forced and/or coerced sterilization that has been reported to be a common experience for women living with HIV in HIV and sexual and reproductive health clinical and community settings.

Study procedures

On agreeing to participate in the study, I will be asked to complete an interview with a trained interviewer. The answers will be recorded in a confidential manner. I understand what the interview will ask about. I have concern the way I take my drugs.

Benefits

I will benefit from the study by obtaining some information.

Risks

No risks will be posed to my life as a result of this study. No samples will be taken from my body. However, I will be asked to give up 20-30 minutes and may experience some anxiety or discomfort while being interviewed.

Rights to refusal or withdrawal

My participation is entirely voluntary and I am free to take part or withdraw at any time I may choose to answer some or all of the questions posed.

Confidentiality

The results of this study will be kept strictly confidential, and used only for research purposes. My identity will be concealed in as far as the law allows. My name will not appear anywhere on the coded forms with the information. Paper and computer records will be kept under lock and key and with password protection.

The interviewer has discussed this information with me and offered to answer my questions.

STATEMENT OF CONSENT/ASSENT

.....has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not affect me. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Signature of participant Age Date

Signature of Interviewer Date

TEAMS THAT SUPPORTED THE STUDY PROCESS

Members of the National Steering Committee

1. United Nations Joint Programme on HIV and AIDS (UNAIDS)
2. Reproductive Health Department, Ministry of Health
3. Irish AID representing AIDS Development Partners
4. United Nations Population Fund (UNFPA)
5. Marie Stopes Uganda
6. Uganda Network on HIV, Ethics and Law (UGANET)
7. Reproductive Health Uganda
8. Uganda AIDS Commission
9. Mamas Club, representing the Networks of Women Living with HIV
10. Uganda Young Positives, representing the Networks of Young People Living with HIV
11. Uganda National Academy of Science (UNAS)/Research Academia Scientists and Professional Association (RASP)

Technical Working Group members

1. Teresia Njoki, Kenya
2. Gatsi Jennifer, Namibia
3. Sethembiso Mthembu, South Africa

Research Consulting Team (Gender and Social Accountability Consulting Group)

1. Professor Grace Bantebya Kyomuhendo, Uganda
2. Dr Florence Kyoheirwe Muhanguzi, Uganda
3. Dorothy Odhiambo, Kenya

Peer Review by Uganda National Academy of Sciences (UNAS)

1. Mr. Stephen Baguma
2. Professor Frederick I. B. Kayanja
3. Associate Professor Samuel Maling
4. Prof. Edward. K. Kirumira

Research Assistants

1. Florence Aryemo Lagum
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3. Annet Ampaire
4. Betty Muhangi
5. Bako Palma
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7. Doreen Katushabe
8. Leonicia Tumushabe
9. Eseri Muduwa
10. Brenda Acan
11. Florence Masuliya
12. Joy Nekesa
13. Jemima Abello
14. Robinah Tibankanya
15. Annah Mbabazi
16. Jane Opolot
17. Joweria Nakakande
18. Joyce Tibaijuka
19. Judith Mulindwa
20. Robinah Nakabugo
21. Sabrina Nabatanzi
22. Gorreti Asimwe
23. Namungoma Florence,

Others are:

1. Beri Hull
ICW Member USA
2. Nienke Westerhof
Advisor SRHR and Gender, Stop AIDS Now (SAN)
3. Happy Margaret
Former ICWEA staff

ICWEA Staff

1. Lillian Mworeko
Executive Director
2. Dorothy Namutamba
Programmes Manager
3. Elly Mayina
Finance and Administration Manager
4. Rachel Nandelenga
Sexual and Reproductive Health and Rights Officer
5. Giff Maridadi
Business Development Officer
6. Hajjara Nagadya
Project Officer
7. Brenda Banura
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9. Janet Namyalo
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