FORCED STERILIZATION OF WOMEN LIVING WITH HIV/AIDS IN AFRICA

A dissertation submitted in partial fulfillment of the requirements for the degree LLM (Human Rights and Democratization in Africa)

By

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30 October 2009

Declaration

I, **Farida Aligy Ussen Mamad**, hereby declare that this dissertation my original work and has never been presented in any other institution for any other degree. I also declare that any secondary information used has been duly acknowledged in this dissertation.

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Dedication

This dissertation is dedicated to my parents, Aligy Ussen Mamad and Milema Chalse my role – models for hard work, persistence and personal sacrifices. They instilled in me the inspiration to set high goals and the confidence to achieve them.

To my sisters, Madina Mamad, Rachida Mamad, Abiba Mamad, Naima Mamad, and my brother Adam Mamad for being proud and supportive of my work and for sharing my uncertainties and challenges, I say thank you.

I also dedicate this to all women living with HIV/AIDS.

Acknowledgement

I would not have completed this dissertation alone without the help of some good people. I, therefore, would like to express my sincere gratitude to all those who assisted me.

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I would like also to thank the Centre for Human Rights, Faculty of law of University of Eduardo Mondlane and the Tribunal Supreme of Mozambique for giving me the opportunity to be part of this programme.

Thank you to all my friends.

List of abbreviations

ACHPR	African Charter on Human and Peoples' Rights
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
CEDAW	Convention on the Elimination of all forms of Discrimination against Women
FIGO	International Federation of Gynaecology and Obstetrics
HIV	Human Immunodeficiency Virus
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICW	International Community of Women Living with HIV
PLWH	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
UNICEF	United Nations International Children Emergency Fund
UDHR	Universal Declaration of Human Rights
UNAIDS	Joint United Nations Program on HIV/AIDS
UN	United Nations
WHO	World Health Organization

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Chapter 1: Introduction

1. Forced sterilization on women living with HIV/ADIS in Africa

Research question:
Is forced sterilization a justifiable limitation of reproductive rights of women living with HIV/AIDS?

1.1. Background of the study

From about March 1941 to about January 1945, sterilization was developed by the Nazi regime in the concentration camps.[1] Sterilizing was found by Nazi regime to be the suitable method to preclude reproduction of millions of women with minimum time and effort.[2] The purpose of the sterilization in the concentration camps was to "eliminate present and future Jews"[3]. This happened in Europe during the Second World War.

In the war against HIV, forced sterilization is being used to stop mother-to-child HIV transmission, considering that this is one of the primary causes of the rapid spread of HIV in Africa. From 2007 onwards, several cases of forced sterilization of women living with HIV/AIDS are being reported in Africa, especially in Namibia, Uganda, Zambia and South Africa.[4]

In 2007, for instance, the National Community of Women Living with HIV/AIDS (NACOWLA) reported a case involving sterilization of HIV/ AIDS positive women; one of these women was a Sudanese Refugee and the other two Internal Displaced People (IDPs) affected by the war in Northern Uganda.[5] Another fourteen cases of sterilization of women living with HIV/AIDS were reported in Namibia. Although almost all these women gave signed consent, they claim they were either forced to sign in order to access other health services or signed under duress during labour pains.[6]

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[1] KD Askin *War Crimes Against Women: Prosecution in International War Crime* (1997) 476
[2] As above
[3] As above
[4] In Mail & Guardian. - guardian.co.uk © Guardian News and Media 2009 available at: http://www.mg.co.za/page/contact-us (accessed 07July 2009)
[5] Annual report of the Uganda Legal Aid Clinic (November 2008)
[6] 'Forced sterilization of women living with HIV/AIDS in Namibia' In *New Era* Namibia newspaper of 7 April 2008 available at: http://www.namforum.com/blog/index.php?/categories/6-New-Era-articles (accessed on 07 Jun 2009)

Nevertheless, in Africa on average an HIV positive mother has a one in four risk of transmitting the virus to her child. With the latest antiretroviral drugs, however, the probability can be cut to less than one in 50. But such medical interventions are underfunded and inaccessible to millions of women across the continent.

Considering the reported cases, it is important to understand why in the relevant countries this is happening. It is also imperative to explore the legal and extra legal reasons as well as consequences of this medical action.

1.2. Objectives of the study

The general objectives of this study are:

- To examine the actual reasons for sterilization of women living with HIV/AIDS;
- To debate on reproductive rights of women living with HIV/ AIDS in light of the existing legislation ;
- To give an overview of how the problem has been dealt with in other jurisdictions;

And the specific objectives are:

- To add knowledge on existing research;
- To show the current situation of the sexual and reproductive rights of women living with HIV/AIDS.
- To remedy the gap regarding information on sterilization on women living with HIV/ AIDS

1.3. Research questions

Questions that need to be explored are:

- Why is sterilization performed in Africa?
- Does forced sterilization violate reproductive rights of women living with HIV/AIDS or other human rights?
- What are the available human rights instruments and mechanisms to address such violation?

1.4. Literature review

The scarce literature that exists concerning forced sterilization of women living with HIV/AIDS does not discuss the social consequences of forced sterilization on women. 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 right to dignity, personal securities, right to liberty[7].

Considering that gender violence is a major under-recognized obstacle to reproductive choice, this is where the policies interfere with women's right to control her body[8]. In the case of women living with HIV/ AIDS, the right to autonomy is much more undermined because of the stigma and discrimination which lessens their rights.

Namibia, Uganda, Zambia and South Africa are parties to the African Charter on Human and Peoples' Rights which sets out a range of human right such as the right to be free from discrimination, the right to personal security and the right to liberty[9]. Also the Protocol to the African Charter on the Rights of Women in Africa provides for the right to physical and emotional security, the right to decide whether to have children, how to space pregnancies, and care for prevention and treatment of sexually transmitted diseases[10]. In addition to regional instruments which provide protection for women's rights, at the international level, equality and reproductive rights of women are also guaranteed under the International Convention on Civil and Political Rights and Convention on the Elimination of all forms Discrimination against Women[11]. All these provisions ensure the protection of women's rights as mentioned. The question persists, whether they can be limited.

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[7] *A.S. v. Hungary (2006)* Committee of Elimination of Discrimination against Women, Communication No 4/ 2004, August 2006. Available at:
http://www.un.org/womenwatch/daw/cedaw/protocol/decisions-views/Decision%204-2004%20-%20English.pdf
(accessed 12 Jun 2009)

[8] Petes , J and Woloper, Women's Rights International Feminist Perspective of Human Rights (1995) Rutledge, Great Britain 224

[9] See article 6 , 9 and 18 of the ACHPR

[10] See article 14 of the Protocol to the African Charter on the Rights of Women in Africa

[11] see article 12, CEDEW, States are required to eliminate discrimination against women in their access to health-care services, General recommendation 14

1.5. Methodology

Most of the literatures utilized in this study refer to sterilization in general not specifically on women living with HIV/AIDS, and as such, very little legal literature has tackled the issue. A literature review of primary sources (legislation and cases) and secondary sources (books and journal articles) constitutes a major part of this dissertation. Online internet sources (online legal data bases Hein online, sabinet, Juta) are also utilized.

1.6. Overview of chapters

The study is divided into five chapters. The first chapter provides the introduction. Chapter two looks at the process of sterilization within the context of the right to informed consent in Africa. Chapter three discusses the social consequences of sterilization. Chapter four analyses how forced sterilization infringes upon reproductive health rights of HIV positive women as well as other rights such as right to liberty, security, and freedom from discrimination. It, moreover, access forced sterilization against the principles of reasonability and justifiability of limitation of rights. It also aims at understanding the arguments in favour and against forcefully sterilizing women living with HIV/AIDS and looks at how foreign jurisdictions have dealt with the human rights implications of forced sterilization. Chapter five presents the conclusion and recommendations.

1.7. Limitation of the study

This study only deals specifically with the reproductive rights of women living with HIV/AIDS. Although the right to equality, informed consent and medical responsibilities are equally relevant and related to the study, the main focus is on the reproductive rights of women and the right to informed consent in order to achieve the objectives the study proposes to address.

The study focuses on Namibia as a case study for reasons of accessibility of information compared to Uganda, Zambia, and South Africa where cases have not yet been filed in a court of law and were less publicized compare to the cases in Namibia.

Chapter 2: Consent in the African context

2.1. Introduction

In this chapter, we look at the process of forced sterilization against the right to informed consent in the African context. It is particularly important to analyse, at this stage, the concept of forced sterilization considering the context in which forced sterilization is being undertaken, where motherhood in Africa faces challenges in terms of high illiteracy rate among women, limited influence on decision-making particularly of rural women, poorly managed and unskilled staff, and insufficient primary health care services.

2.2. HIV/AIDS mother-to-child transmission and sterilization

Before discussing the process of sterilization, it is important to flesh out the connection between HIV/AIDS and sterilization. The most common mode of HIV/AIDS transmission is sexual intercourse, followed by mother-to-child transmission, sharing drug-injecting equipments, and contaminated blood or instruments in health care settings.[12]

Mother-to-child transmission of HIV/AIDS, also known as vertical transmission of HIV, occurs when the virus is transmitted from an infected mother to a child, during pregnancy, labour and delivery or breastfeeding. [13] Vertical transmission is the primary cause of HIV/AIDS infection in children under 10 years, and as a result, more than 600,000 infants become infected with HIV every year. Consequently, since the beginning of the pandemic, an estimated 51 million children worldwide have been infected.[14] Of this number, the overwhelming majority have been born in Africa, due to high fertility rate in the general population and the high HIV prevalence among pregnant women in particular.[15]

Considering the number of infections and the rapid rise in the level of infection of children, a number of measures were taken, including primarily the prevention of infection in women of childbearing age by promoting safe sex, and the prevention of unwanted pregnancies of HIV positive women through family planning, safe termination of pregnancy and sterilization.[16]

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[12] A Whiteside *HIV/AIDS: Very Short Introduction (* 2008) 4
[13] As above
[14]" Interagency Coalition on AIDS and Development" available at http:// www.icad-cisd.com (accessed 07July 2009
[15] As above
[16] As above

Among all the measures implemented to limit HIV infection on children, sterilization is one of more restrictive and adversely affects women's physical and mental health,[17] as sterilized women are permanently incapable of childbearing. Therefore, the consent of the concerned woman becomes very important for such an intrusive intervention to be legitimately executed.

2.3 Reproductive health decision making in the African context

2.3.1 Brief overview of reproductive health rights, HIV and opportunities

Drug regimens and procedures that inhibit parents from transmitting HIV to their infants now exist. Prevention of Mother-to-Child Transmission (PMTCT) and availability of medication that can block the transmission of HIV during pregnancy, childbearing and the postnatal period have created new opportunities to reduce the transmission of HIV.[18]

The PMTCT Program was adhered to promptly by governments around the world as a solution to limit mother-to-child transmission and many countries in Africa are currently implementing the program. However, several countries are still facing difficulties to increase access to PMTCT program services.[19] For instance, in SADC up to 2007, in nine countries, women were offered routine testing in PMTCT set-up.[20] In PMTCT set-up, HIV testing is a precondition to access the treatment. The ethical and legal obligation to promote and protect the reproductive rights of those living with HIV becomes very important taking into consideration the challenges that HIV/AIDS is associated with.

2.3.2 The right to informed consent in Africa

Independent informed consent based on complete, accurate and appropriately conveyed and understood information should be obtained from the patient.[21] Voluntary and informed consent is crucial in the context of biomedical and clinical practice. The ethical underpinning for the idea of consent itself lies in empowering women in decision-making spheres; for instance, it is

[17] CEDAW General Recommendation No19 Para 22
[18] "Pregnant women living with HIV/AIDS" Centre for Reproductive Rights, (August 2005), available at: http://reproductiverights.org/sites/default/files/documents/pub_bp_HIV.pdf [(Accessed 14 June 2009)
[19] As above
[20] F Viljoen and S Precious (eds) *Human Rights Under Treat: For Perspectives on HIV,AIDS and the Law in Southern Africa* (2007) 65
[21] G Lindeggerl and L Richter 'HIV Vaccine Trails: Critical Issues in Informed Consent' 96 (June 2000) *South African Journal of Science* 317

assumed that in the African context, decision-making is highly influenced by culture which often works against women.

Culturally, "African societies are male-oriented; consequently decision making is commonly delegated to the most powerful figure in the society, such as father, husband or male adult". [22] The question remains, does this type of decision making arrangement save autonomy to women in making voluntary and informed consent on health issues?

The term voluntary and informed consent refers to respect for autonomy - showing regard to the choice of the individual person. As far as health care is concerned, it requires admitting that people possess the freedom to accept or refuse intervention that affect their life and well-being, after being fully informed of its implications.[23]

Research in Africa has shown that community beliefs and norms relating to health behaviours strongly influence the health care decisions individuals make.[24] But this is not to suggest that in Africa the individual is not counted as important or that the individual liberty is not valued; on the contrary, it is a common parlance that the individual finds the true freedom and fulfilment within such values.[25] It has to be recalled that society is dynamic and susceptible to a range of factors; therefore, the community's level of socio-economic development, educational level, and female autonomy can influence greater individual value and autonomy within the community.[26]

The community's influence on the individual's life such as decision-making as part of traditional norms and cultural values is a violation of human rights, if we consider consent as voluntary and individually made. Therefore, the cultural decision making set-up is in contradiction with all the legal definitions which are implied in different human rights instruments.

For instance, there is an international consensus that "reproductive rights imply that people are able to have a satisfying and safe sex life, and that they have capability to reproduce and the freedom to decide if, when and how often to do so".[27] Also it is considered that implicit in these

[22] C Agulana 'Informed Consent in Sub-Saharan Africa Communal Culture: "The Multi- Step" Approach' (2008) 40 unpublished LL.M Thesis, University of Linköpings universitet

[23] As above

[24] R Stephenson Contextual Influence on the Use of Health Facilities for Childbirth in Africa, 2006 .V. 96 NO 1 PP8

[25] Agulana (n 22 above) 57

[26] Stephenson(n 24above) 8

[27] 'Continental Police Framework on Sexual and Reproductive Health and Rights' African Union Commission, Addis Ababa, July 2006.

rights is the right to be informed about, among others, methods of their choice for regulating their fertility, and the best chances of having a healthy infant.[28]

Although Article 17 (2) and (3) of the African Charter on Human and Peoples' Rights (ACHPR), which entitles every individual to freely take part in their cultural and traditional life, has been interpreted as protecting customary and religious laws that violate women's rights, such as their right to equality and liberty, the Protocol on the Rights of Women recognizes women as individual human beings with all its accompanying entitlements including protection against harmful traditional practices.[29] Law has two major functions: to regulate human behaviour and to transform society. The Protocol has a major role to achieve in transforming society and cultural practices.

Decision-making in the health-care sector has an emphasis on information. In order to voluntarily give consent, one should have proper knowledge of the content and implications of what she/he is going to *accept* or *refuse.*

The right to be informed may be broken in to two components: first, the delivery of the information and second the reception of the information. Delivery of the information is considered here to refer to the knowledge and capacity of the one giving information and the condition under which the information is provided.

In the context of delivering information, it is of concern that the power imbalance between the health care provider and the one to be treated may influence the decision making by the latter. It has to born in mind that the subjects of this study are women, who "make up two thirds of the worlds illiterate people"[30] which often results in the deprivation of adequate health services, [31] especially in Africa where usually the poor and uneducated are more likely to use public health care facilities,[32] where "almost half of the births take place without skilled birth attendant".[33]

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[28] As above

[29] R Musa 'Women, Equality and the African Human Right System' in H Abbas (ed) *Africa Long Road to Justice* (2007) 29-30.

[30]Kelly D. Askin *et al* (eds) Women and International Human Right Law, Vol 2; 1998

[31] International Centre for Research on Women 'Women's property and inheritance Rights the context of HIV/AIDS in sub-Saharan Africa' – working paper (June 2004) available at *http://www.icrw.org/docs/2004_info_haveandhold.pdf* (accessed 27Jun 2009)

[32]F Viljoen and S Precious (eds) *Human Rights Under Treat: For Perspectives on HIV,AIDS and the Law in Southern Africa (* 2007) 62

[33] UNICEF, 'Millennium Goals: Poverty, Education, Gender equality, Child Mortality, Maternal Health, Diseases Environments Development' http//: www.unicef.org (accessed 19 August 2009)

Inability to speak and understand the language the health providers use is also another obstacle to informed consent. For instance, if the health care provider does not speak and understand the language which the patient uses or vice-versa, and if there is no translation provided, it can lead to lack of proper communication.[34] Consequently, in these conditions, there is a risk of the information not being adequately provided or explained. As such, the risk that a decision may not be informed or made with full and sustainable consent is high. Moreover, international guides on HIV deem mere verbal communication inadequate for the purpose of obtaining informed consent.[35]

Taking into consideration the underlying principle recognized by the World Health Organization (WTO) "informed consent of the patient is a pre-requisite for any medical intervention."[36] In addition, mutual understanding between the medical provider and the patient is important for facilitating decision-making. In other words, the more the patient has information and understands it, the more autonomy he/she will have to make appropriate decisions.

Stigma and discrimination also can negatively influence decision-making. Fear of violence shapes women's choice. Also it came out from the result of a research done in Brazil that "[h]ealth professionals were not considered by most participants to be supportive enough or even impartial about HIV positive people having children".[37]

Furthermore, most of the time health workers just take a decision without founded knowledge to support their position of discouraging or preventing an HIV/AIDS positive woman from having a child[38]. As mentioned above, the power imbalance between the health care provider and the one receiving care may lead to patient's choice being determined by the health worker's perceptions, preferences and values, consciously or unconsciously.[39] This sustains the point about cohesive paternalistic health systems especially in cultural settings, where the medical

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[34] 'The International Community of Women Living With HIV/AIDS' ICW Report of March 2009
[35] WHO/ UNAIDS Guidance on providers – initiated HIV testing and Counselling in the facilities (2007) http://whqlibdc.who.publications/2007/ 9789241595568_eng.pdf(accessed 25 August 2009)
[36] Regional Office for Europe, World Health Organization (WHO) available at: http://www.euro.who.int/ (accessed 25 August 2009)
[37] V Paiva *et al* 'The Right to Love: The Desire for Parenthood among Men Living with HIV' (2003) 11 (22)*Reproductive Health Matters*, 91-100
[38] International Community of Women Living with HIV 'Overview of ICW's work to end the forced and coerced???' available at http://www.icw.org/node/381
[39]L London *et al* 'Even if you're Positive ,You Still have the Right to Because you are a Person : Human Rights and the Reproductive Choice of HIV-Person'8 (1) (2008) *Developing World Bioethics* 13

professional has unequal power relationships with most patients and where the authority of the professional is not easily questionable.[40]

For example, telling HIV/AIDS positive women that they should not be pregnant because they are positive directly during the consultation without counselling and keeping them in waiting areas specifically designated for HIV positive patients is stigmatizing. In this case, the health care provider is being explicitly discriminating against HIV/AIDS patients.

In some cases, the health facilities are not available, and in cases where there are, they may not provide PMTCT services. Even when maternal health facilities are available, expectant mothers in Africa do not always get timely care. A study by the Africa regional office of the WHO noted that sometimes women or birth attendants "fail to recognize danger signals and are not prepared to deal with them,"[41] mostly because the public health services are generally unavailable, inaccessible as well as in poor quality.[42]Therefore, voluntary and informed consent in the African context faces particularly acute challenges.

Voluntary and informed consent in HIV/AIDS context is the most important right, a pillar supporting the rest of the rights which can be violated consequently. Despite this fact, in Africa the right is submersed on challenges, as if women do not have rights. HIV/AIDS positive women are human beings, and as such they have the guarantee to exercise their rights without any interference like everybody else. It is important that States fulfil their duties to protecting and promoting women's rights and to implement regional action plans which provide for methodologies that will address most of the challenges pinpointed.

For instance, in the Maputo Plan of Action, it was required that each country in Africa should rapidly increase access to an essential package for integrated reproductive health services that will reduce the current gap on the universal access, and the adjustments include doubling of medical and pharmaceutical salaries required to increase commitment of the staff.[43] Hence, the right to voluntary and informed consent is centred on the health care provider as the active person, because he/she should make sure that the women understand the importance of their reproductive right. Considering the fact that violation of reproductive rights of women endangers

[40] See comment of Christine 'Straggling on Botswana Network of Law and Ethics (BONELA) in Botswana 'Routine HIV testing not as straightforward as it sounds' IRIN news , Cited in N Chingore, 'Routine testing of individuals attending public health facilities: Are SADC countries reedy? Viljoen and Precious (n 30 above) *87*

[41] M Kimanil 'Social Hurdles to Better Maternal Health in Africa, United Nations' *Africa Renewal*, www.un.org/AR (Accessed 28 August 2009)

[42] As above

[43] 'Maputo plan of action for the operationalization of the continental policy framework for sexual and reproductive and rights' 2007-2009, SP/MIN/CAMH 5(1) Maputo 10-22 September 2006

dignity and life, empowering them with enough information and values which can significantly improve the protection of the reproductive health rights and life of women in Africa is essential.

2.3.3 Accurate information regarding mother-to-child infection

Until recently, there was no means of preventing MTCT for those HIV positive women who wished to give birth. The promising intervention used separately or in combination with providing antiretroviral drug and modification of infant feeding practices has proved to be highly effective.[44] In conjunction with these methods for prevention and treatment, the reduction of women's vulnerability should also be considered. They should be provided with information and education as well as proper tools for communication.[45]

Furthermore, women living with HIV should be informed not only about the forms of transmission and treatment but also about methods to improve their safety of conception and childbirth. Safety measures including sperm washing, artificial insemination and in-vitro fertilization as methods of assisted conception, antiretroviral therapy and caesarean section for child birth should be promoted. [46]

For example, women should be informed that, an HIV positive woman can become pregnant with an HIV negative partner without endangering her partner by using artificial insemination (the process by which sperm is placed into a female's genital tract using artificial means rather than by natural sexual intercourse). This simple technique provides total protection for the man, but does nothing to reduce the risk of HIV transmission to the baby and other mechanisms must be employed to secure the health of the child, and in case they want to use one of the methods, it is important to know about the consequences, risks and benefits.[47]

In Africa, few HIV infected women receive information about treatment options that will protect infants from HIV infection. However, those how have greater knowledge about the prevention of prenatal HIV transmission have fewer sexual relationships. Also, fewer desire to have children, because they face disapproval of having children from health professionals.[48] Therefore, the rights of those with HIV to found a family depend as much on curing the ills of prejudice and discrimination, including among health professionals.

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[44] World Health Organization Report, October 2000

[45] Interagency Coalition on AIDS and Development, available at, http://www.icad-cisd.com (Accessed 7 July 2009)

[46] M Bryn 'Fulfilling rights for women affected by HIV/AIDS. A tool for monitoring progress toward Millennium development Goal' (2006) available at http:// www.ipas.org (accessed 30June 2009)

[47] 'Interagency Coalition on AIDS and Development' available at http://www.icad-cisd.com, (accessed 07June 2009)

[48] As above

2.3.4 Accurate information about sterilization

Sterilization is defined as the process of rendering someone barren. This is accomplished by surgical removal of ovaries or inactivation by irradiation or by trying of or removing a portion of reproductive organs or uterine tubes.[49]

Sterilization is included in the list of measures to reduce mother-to-child transmission of HIV. From the list of options, sterilization is permanent and with adverse effect on women. Therefore, it should be based on voluntary and informed consent and should not be made under stress or duress. [50]

As mentioned above, voluntary and informed consent is a cornerstone of the reproductive health rights of women. In order to secure the protection of this right during the sterilization process, some countries passed legislation towards its regulation. For example, Brazil has legislation on voluntary sterilization according to which sterilization can only be performed in institutions which can offer all options and methods of reversible contraceptives, according to article 14 of the law 9.263 (Brasi1997) "***só podem ser autorizadas a realizar esterilização cirúrgica as instituições que ofereçam todas as opções de meios e métodos de contracepção reversíveis*". [51] *All the institutions which perform sterilization should be able to inform the patient about the options available on contraceptives which are reversible and consciously decide for sterilization as voluntary and informed consent* (emphases mine). Therefore, voluntary and informed consent in sterilization implies that the individual understands the sterilization itself, the process, why it is necessary, the benefits, risks, alternatives and possible social implications of the outcome.

The Committee on the Elimination of All forms of Discrimination against Women, in its General Recommendation 21, stresses the importance of access to information, specifically in the context of sterilization, by stating that “in order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services, as provided in article 10 (h) of the Convention.” [52] Also, the Millennium Development Goals[53]

[49] Medicare plus Blue ‘A*dvantages private free-for- services, sterilization’* (Report, 2009) available at: http://www.bcbsm.com/pdf/systema-prof-837-835 pdf. (Accessed 23August 2009)
[50] FIGO Committee for the study of Ethical Aspects of Human Reproduction and Women ‘(2006) 74 Health Ethical Issues in obstetrics and gynaecology’
[51] See, article 14, BRASIL, 1997b. Portaria 144, de 20 novembro, 1997. *Diário Oficial da Uniã*o, 24 Nov.
[52] The Committee on the Elimination of All Forms of Discrimination against Women, General Recommendation No 21

provide that policy and programs must ensure that sterilization of any HIV positive woman only occurs when she gives her full, informed and unpressured consent.[54]

FIGO as well, lays out information that must be conveyed during counseling, including that sterilization is intended to be permanent; that life circumstances may change as a result of the procedure; and that the patient may later regret her state of sterility[55]. Similarly, the World Health Organization, in its "Medical Eligibility Criteria for Contraceptive Use" explains that "[56]all clients should be carefully counseled about the intended permanency of sterilization and the availability of alternative, long-term, highly effective methods."[57]

Contrary to this, in Africa, some cases were reported; for instance, the ICW has documented cases in Namibia where minutes from giving birth, HIV positive women were encouraged and pressurized to sign consent forms for sterilization to prevent them from having more children. Jennifer Gatsi-Mallet, its coordinator in the country, said: "They were in pain, they were told to sign, and they didn't know what it was. They thought that it was part of their HIV treatment. None of them knew what sterilisation was, including those from urban areas, because it was never explained to them." After six weeks, they went to the family planning centre for birth control pills and were told that it's not necessary, they're sterile. Most of them were very upset. When they went back to the hospital and asked, 'Why did you do this to us?' the answer was: 'You've got HIV'."[58]

In the abovementioned cases, women were forced or coerced to sterilization. Bearing in mind what was discussed above, before any intervention which limits, infringes or controls women's reproductive health rights is made, voluntary and informed consent should be obtained. In the absence of consent, the sterilization will be forced or coerced. Of course, all rules have exceptions. For instance, South African National policy[59] on testing for HIV provides for some exceptions on voluntary and informed consent:

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[53] Millennium Development Goals (2000) Available at http://www.un.org/millenniumgoals/ (Accessed 19 August 2009)
[54] Bryn(n 46 above)
[55] FIGO (n 50 above) Para 6.
[56] World Health Organization 'Medical Eligibility Criteria for Contraceptive Use' (3rd ed) (2004) 1 Available at http://www.who.int/reproductive-health/publications/mec/mec.pdf (Accessed 10 August 2009)
[57] Committee on the Elimination of all Forms of Discrimination Against Women Center for Reproductive Rights, Supplementary Information Re: *A.S. v. Hungary* Communication No: 4/2004 Amicus brief, available at: http://www.un.org/womenwatch/daw/cedaw/protocol/decisions-views/Decision%204-2004%20-%20English.pdf (accessed 20 September 2009)
[58] International Community of Women Living with HIV 'Overview of ICW's work to end the forced and coerced???' available at http://www.icw.org/node/381 also published in, Mail & Guardian (n 4 above)
[59] See article 5 (4) National Policy for Health Act, 1990 (Act No. 116 of 1990) South Africa Department of Health available at: http://www.doh.gov.za/aids/docs/policy.html

"Health care workers do not have to seek consent in the following circumstances: If the patient needs emergency medical treatment. If, considered the same principles on sterilization, in case of diseases which affect the uterus and for the survival of the patient the only solution is to remove the uterus. And if the patient is mentally ill, consent must be obtained from a next of kin" here we have the case of incapacity to give informed consent.[60](Emphases mine)

Moreover, in most African countries abortion is forbidden or the law is very restrictive. In Malawi, abortion is permitted only to save the woman's life; while in Botswana it is allowed in exceptional circumstances, for instance, when the health of the mother or the baby is at risk.[61] Taking into account those exceptions, they can also apply for sterilization to say that if during the delivery process the Doctor found out that the life of the woman will be in danger or for other scientific reasons, he may not need the consent of the patient.

Bearing in mind those HIV positive women at such difficult time were encouraged to sign consent forms to prevent them from having more children, the aforementioned cases from Namibia represent forceful sterilization cases. It is safe to say that any consent, if granted at all, was improperly secured.

Firstly, the sterilization was done in the absence of proper information about the process, risk, consequences, and benefits. The medical personnel failed to provide full and accurate information regarding sterilization procedures, in order to sign the consent form with proper knowledge of what was going to happen. Secondly, the patients were under pain and duress, which puts them under vulnerable situations.

The process of obtaining informed consent with all its regulations and conditions is more than an elaborated ritual. Furthermore, declaration of understanding does not always guarantee the true understanding by the patient. Because there is a danger that formal requirement can be manipulated in a simple way to conform to a minimum set of criteria, meeting the ethical requirement to respect autonomy of individuals must be given equal emphasis.[62] Otherwise, the concept of voluntary and informed consent will be violated.

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[60]A Moweg Agenda (1992) (12) A Journal About Women and Gender, 41-3. available at: F:\botswana.htm,
[61] As above
[62] Lindegger and Richter(n 21 above)17

Therefore, it is important to find out, if the absence of voluntary and informed consent is within the exceptions discussed previously. For instance, it needs to be certified that the health of the mother or the baby was at risk. It is also important to look at the negative influences of HIV on pregnancy, in which case forced sterilization may be justified.

It is scientifically proved that pregnancy does not make a woman's own health worse in respect of HIV. However, being pregnant may cause her CD4 count (see below) to drop slightly, but it should return to its pre-pregnancy level soon after delivery.[63]

The question remains, in case of Africa, HIV is attached with a number of challenges. Mythical rather than scientific implications are accorded significant consideration. Moreover, mother-to-child transmission of HIV in low-resource settings, especially in those countries where infection in adults is continuing to grow or has stabilised at very high levels, continues to be a major problem. [64]

Modern drugs are highly effective in preventing HIV transmission during pregnancy, labour and delivery. When combined with other interventions, including formula feeding, a complete course of treatment can cut the risk of transmission to below 2%. Even where resources are limited, a single dose of medicine given to mother and baby can cut the risk by half.[65]

Due consideration needs to be given to the risk run by mothers. If all the measures are taken in a timely and appropriately manner, such as avoidance of routine artificial rupture of membranes, vaginal cleansing with chorhexidine 0.25%, the use of partogram and anti-natal follow up programs, mother-to-child transmission rates will fall significantly.[66] Elective caesarean section can reduce up to 50% HIV mother-to-child transmission compared to vaginal delivery.

Definitely, scholars will say it is not as simple as one single dose of medicine because it involves costs. This and other arguments compose the argument of public health supporters. This work will attempt to bring the relevant arguments to support the public health argument. Counter-arguments are outlined in chapter four of the paper.

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[63]R Bessinger et al 'Pregnancy with the progress of HIV disease attending an HIV auto patient program' (1998) 147(5)*American Journal of Epidemiology*. 434-440 also spouted by M Weisseer *et al* 'The Swiss HIV cohort study (SHCS), and the Swiss collaborative HIV and pregnancy study (SCHP)'. 'Does the pregnancy influence the curse of HIV infection? Evidence from two large Swiss cohort studies'1998, 17(5) *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 404-410

[64] UNICEF 'Millennium Goals: Poverty, Education, Gender equality, Child Mortality, Maternal Health, Diseases Environments Development' .http//: www.unicef.org last visited 19/08/09

[65]As above

[66] 'Preventing Prolong Labor : a practical guide' Geneva, World Health Organization , 1994 WHO/ FHE/MSM/ 93.9

2.4 Conclusions

Voluntary and informed consent is an important right on the fulfilment of the reproductive health rights of HIV positive women. Therefore, sterilization on HIV positive women without voluntary and informed consent is a limitation of their reproductive health rights. In Africa, this right is submerged in several protracted challenges. Thus, the respect of voluntary and informed consent within PMTCT and sterilization of HIV positive women should be considered a pre-condition to any further treatment. For this, curving the societal belief and way of action is imperative.

In any case, sterilization should be performed only with consent of the patient. In other word, the patient should know and understand all the substantive and technical information such as: the process, benefits, and risks, other options of treatment available as well as other possible physical and social consequences. All this information will help the patient to make voluntary and informed decision thereby justifying the sterilization.

Chapter 3: Social consequences of forced sterilization

3.1 Introduction

From the days it was initially discovered, in addition to being a medical and epidemiological issue, HIV/AIDS has been a phenomenon that has had deep cultural implications. It can only be placed in the correct context if we take into account the social and cultural heterogeneity, institutionalized behavior and norms within each society.[67] Therefore, this chapter puts forward the social consequences of sterilization by analyzing the social issues related to HIV and conceptualizing the accompanying stigma and discrimination against sterilized women.

3.2 Social Issues related to HIV

One of the major factors that play a role in the dynamics of HIV infection is the level of empowerment of society including HIV positive persons.[68] The patriarchal system as well as the low level of education among women, puts women in a subservient position.

For instance, in many Sub-Sahara African countries, sexuality is a man's right. Women take only a passive role - if they have a role at all - in deciding over how many children the couple will have, when, how and whether to have sex, among other things. Thus, the relationship between a dominant man and submissive female attitude towards sexuality and reproduction, coupled with woman's subsequent role as nurturer, in contrast to the men's authority figure, places the women in a much vulnerable position.[69]

This situation is fuelled by unequal access to resources, illiteracy, economic dependence, and the views of the community and the society at large. These reinforce women's subordination consequently reduce the possibility of equal participation in issues having a huge impact on their lives.[70]

Furthermore, the social conception about the disease is that the man is always a victim of the woman's promiscuity. Sexually Transmitted Infections (STIs) are often attributed to taboos such

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[67] 'Situational Analyses of the National Strategically Plan on HIV/ AIDS 2005-2009' National AIDS Council of Mozambique (2008) 32

[68] N Nawar *et a*l 'The Third Phase of HIV Pandemic consequences of HIV/AIDS Stigma and Discrimination &Future Needs'122 (2005) *India Journal of Medicine* 472.

[69] Mozambique Report (n 67 above)

[70] Mozambique Report (n 67 above)

as birth, pregnancy, marriage and death which pose women as the vectors. As a result, in some African communities, STDs are perceived as "women diseases" transmitted to men by their sexual partner[71].

A study in Zambia confirmed that fewer than 25% of the women could refuse to have sex with their husband, even if he had been demonstrably unfaithful and was infected. Only 11% thought that women could ask their husbands to use condom in their sexual relations.[72]

Furthermore, violence against women often is socially tolerated and, in some cases, forced sex with a spouse and wife beating are accepted or even expected and considered as expressions of masculinity.[73] This shows that the social power imbalance between men and women increases the risk of HIV infection of the latter.

It may be considered that, the social power imbalance is also accentuated by the fact that sex and sexual behavior in Africa are hitherto tabooed subjects for discussion between parents and children and youth. Hence children and youth are likely to have more misconceptions and be misinformed, and in the long run, pose higher risk for HIV/AIDS infection and transmission.[74]

It is equally recognized that the evolution of the epidemic is closely associated with individual sexuality as well as sexual behavior. But the way individuals develop and express their sexuality is influenced not only by individual traits, but also by a number of social, cultural, economic and political factors.[75] For instance, the components of sexuality cut across phenomena such as initiation rites, polygamous and traditional marriages, rites of passage, taboos, and traditional medicines.[76]

It may be argued that, all that is described as social issues do not take into consideration the dynamic nature of society and the difference between the urban and the rural areas. In fact, before acknowledging that the urban or urbanized population has the same attitude thawed HIV/AIDS , there is a need to "describe the rural culture or ethno-cultural features that influence

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[71] [71] Mozambique Report (n 67 above) 33

[72] A Carbert, *et al Advancing Reproductive Rights and Sexual Health: A Handbook For Advocacy in the African Human Right System* (2002) 11

[73] Department of Reproductive Health and Research Family and Community Health World Health Organization, 'HIV-infected Women and their Families: Psychosocial Support and Related Issues' (2003) WHO/RHR/03.07,WHO/HIV/2003

[74]AR Moore and DA Williamson 'Problems with HIV/AIDS Prevention, care and Treatment in Togo, West Africa: Professional Care giver AIDS care' (2003) 15,615

[75]As above

[76] Moore & Williamson (n 74 above)

the urban population, given the fact that urbanization in African societies not only is very precarious, but also very recent".[77]

Therefore, the mere fact that there are people living in urban areas and others living in rural areas does not as such conclusively describe their actual behavior and actions. This means that the representation about sexuality and other social roles does not change drastically simply because there has been a shift from one societal space to the other. This is further strengthened by the fact that most African societies urbanization are from the past 35 years.[78]

Having said that, it should in any case be noted that social construction has a very high influence in the way individuals respond in terms of perception as well as behavior towards the pandemic itself. This, in sum, leads to stigma against people living with HIV, and consequently, it has severe social consequences related to their rights such as health care services, freedom, self-identity and social interaction.

3.3 HIV and its social consequences

Right from the beginning, the HIV/AIDS epidemic has been accompanied by fear, ignorance and denial, leading to stigmatization of and discrimination against PLWA and their family members, which intensifies the pain and suffering of both the PLWA and their family. [79]

This situation has been exacerbated by the fact that HIV has been associated with severe reactions, ranging from the banning of entry of HIV-infected persons to isolation of an individual in the family or deserting a pregnant wife on knowing her HIV status, among others.[80]

Therefore, talking about HIV/AIDS is never easy and very few people, even those who know themselves to be at risk, find the courage to discuss the issue surrounding HIV or to face the possibility that they might be infected.[81] Consequently, people who feel they might experience frequent discrimination may be reluctant to disclose information that will attract further prejudice against themselves or their family.

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[77] As above
[78] Mozambique (n 67 above) 32
[79] International Centre for Research on Women 'Addressing HIV- related stigma resulting discrimination in Africa: a three countries study in Ethiopia, Tanzania and Zambia', Washington, DC: ICRW. 2000
[80]N Nawar *et al* 'The Third Phase of HIV Pandemic consequences of HIV/AIDS Stigma and Discrimination &Future Needs'(2005) 122*Indian Journal of Medicine* 472.
[81] J Scott & A Henley 'Culture, Religion and Childbearing in Multiracial Society: A handbook for Health professionals' (1996) Elsevier Science available at www.elseverheath.com (Accessed 10 September 2009)

HIV has also led to increased gender based violence. HIV positive women are assaulted, prevented from having children, dismissed from employment, disowned by their families and communities out of sense of shame sometimes, and are even killed.[82] Studies show a strong link between violence against women and HIV, and demonstrate that HIV- infected women are more likely to have experienced violence, and women who have experienced violence are at higher risk of getting infected with HIV.[83] The UN Committee on Elimination of Discrimination against Women (CEDAW) described "family violence as one of the most insidious forms of violence against women."[84]

These negative reactions towards HIV and HIV positive persons have shaped the behavior of HIV infected persons and have limited the effectiveness of prevention efforts. For instance, "the level of disclosure of HIV status by women in the PMTCT programmers is generally low in Southern Africa."[85] Due to fear of violence, stigma and ostracisms, many women avoid taking HIV test, consequently denying themselves an opportunity to benefit from programmers to prevent HIV transmission to their newborn.[86]

3.4 Stigma, discrimination and sterilization

Social science research on stigma has grown dramatically over the past two decades, particularly in social psychology, where researchers have elucidated the ways in which people construct cognitive categories and link those categories to stereotyped beliefs.

In order to conceptualize stigma on sterilization and sterilized women, it is important to put forward the means of sterilization itself and why it is subject to stigma. Although it is very

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[82] United Nations Development for Women (UNFEM) 'Turning the TIDE: CEDAW and the Gender, Dimension of HIV/ AIDS Pandemic' 9(2001), available at http:// www.unife.org/resoursesitem-details.php?ProductID=13;INTERNATIONAL (accessed 25 August 2009)

[83] UN Secretary General (2006).'UN Secretary-Generals study on violence against women, background documentation for 61st session of the general assembly' Item 60(a) on advancement of women UN Document A/61/122/Add.1. available at: http://www.unicef.org/doc/UNDOC/GEN/N06/419/74/PDF/N0641974.pdf (Accessed 10 August 2009)

[84]Committee on the Elimination of all forms of Discrimination against Women. General Recommendation No 15 (1990) avoidance of discrimination against women in national strategies for the prevention and control of acquired immunodeficiency syndrome (AIDS). Avalable at: http://www.un.org/womenwach/daw/recommendation/recomm.htm. (Accessed 15 September 2009)

[85] A Medley *et al* 'Rates, barriers and outcomes of HIV sero-status disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes' (2004) 82 *Bulletin of the world Health Organization 300,* Cited in N Chingore 'Routine testing of individuals attending public health facilities: Are SADC countries reedy? [85] in F Viljoen and S Precious (eds) *Human Rights Under Threat: four perspectives on HIV,AIDS and the law in Southern Africa (2007) 87.*

[86] 'Pregnant women living with HIV' Centre for Reproductive Rights, Brief Paper (2005) available at www.reprodactiverights.org (Accessed 30 September 2009)

common, in this type of discussion, to link stigma and HIV, this work discusses the presence of stigma on sterilization itself, and the possible link between stigmas, in the context of HIV, sterilization and the social implications of sterilization on women living with HIV is unveiled.

Medicare Plus has adopted a similar definition as it conceptualizes sterilization as a process of rendering someone barren.[87]A sterilized individual is incapable of childbearing.

From the social science perspective, it is argued that as childbearing is a significant human experience, it has special social meaning. It is shaped by the culture in which women live. Birth is socially rewarding everywhere (excluding, of course, childbearing out of marriage and other instances), and its management occurs within the social and cultural context of the event.[88]

Childbearing is usually 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.[89] 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.[90]

In this view, if "stigma represents a construction of deviation from some ideal or expectation"[91], inability to bear children has implications for women, as they are unable to fulfill cultural and personal expectations, resulting in stigma and discrimination.

The concept of stigma has been criticized as being too vaguely defined and individually focused. In response to these criticisms, Springen defined stigma as the "co-occurrence of its components–labelling, stereotyping, separation, status loss, and discrimination and further indicates that for stigmatization to occur, power must be exercised finally".[92]

All those components of stigma have their provenance from how the society views and values issues. In Africa, 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

[87] 'Medicare Plus Blue *advantages private free-for- service, sterilization'*, Report, 2009 available at http://www.bcbsm.com /pdf/systema-prof-837-835pdf
[88] B Jordan *Birth in for Culture: A cross-cultural Investigation of childbearing in Yacutan, Holland , Sweden, and the United of States (1993)* 385
[89]B Hartman *Reproductive Rights and wrongs* : *The global politics of population control and contraceptive control (*1995) Harper& Rom, New York 388
[90] As above 389
[91] AA Alonzo and NR Reynolds 'Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory' (1995) 41*Social Science and Medicine* 303-315.
[92] K Springen 'what it mean to be a woman' *Newsweek health* Sep.14 to15.2008, available at Newsweek-com.mht (Accessed 25 September 2009)

human race, sources of hope for the survival of the family name and history and the key links between the present and the future.[93]

Therefore, women who desire to control their reproduction or are incapable of childbearing are negatively viewed, through the influence of pervasive cultural discussions, which suggest that in so doing she will also be upsetting the state of cosmological equilibrium that must be maintained through her, or husband's, lineage.[94] Hence, in a culture that immensely values having children, sterilization will not be easily accepted, as it upsets the cosmological balance of the society. Furthermore, sterilization represents a risk because it puts women's sexuality and fertility under patriarchal control and a system of beliefs which condemns rejection of maternity as being "unnatural".[95] In addition, male sterilization is considered impossible and the inability to conceive is attributed to the woman who is believed to interfere with conception through birth control, abortion, adultery or sorcery. [96]

Often the female takes the blame even when the problem lies with the man. Women often keep their husband's secret and bear the pain and insults. For example, in Chad, a proverb goes, "A woman without children is like a tree without leaves."[97] As a consequence, if a woman does not bear children, her husband may leave her or take new wives with society's blessings.[98] In some Muslim based societies, women cannot go on the street on their own[99]. "If they have a child with them, they can do their errands".[100]

As a result, the woman will be stigmatized by the husband and the community. For example, family or social norms consider that childbearing gives a woman high social status, whereas inability to have children entails loss of same. Nevertheless, the stigma that infertile women face can infiltrate every aspect of life. They may not even be invited to weddings or other important gatherings. "People see them as having a "bad eye" that will make you infertile.[101]

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[93] P Limputtom *(ed) Reproductive Childbearing and Motherhood: A cross- cultural perspective* (2007) Nova science, New York 284.
[94] As above
[95] As above
[96] As above
[97] 'Infertility and social ostracism: Global Public health Thought a Feminist lens' Available at: http://stanford.edu/class/humbio129s/cgi-bin/blogs/feministlens/2009/04/24/infertility-and-social-ostracism/ (Accessed on 13 September 2009).
[98] Mozambique (n 67 above) 32.
[99] Infertility (n 97 above).
[100] Springen (n 92 above).
[101] D Castaldo 'Divorce without children: solution focused therapy with women at Midlife', *Contemporary Family Therapy* Taylor and Francis, New York, 2008, 254.

It is hurtful that, "to this day, women without children have no common activities, no common language".[102] Fisher observed that those women share common stigma, but the meaning and level of stigma often varies depending on how women perceive the situation and their level of empowerment, autonomy and independence.[103] Still, the exclusion of childless women is obvious from the perception of the society which leads to stigmatization. The only difference is the level of internal self stigma which is generally low in educated and empowered women.

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 children.[104]

It is in this context that the number of children that a family has becomes an issue for the couple and the community at large. It is generally understood that the more children a couple have the more secured they are. As such, sterilization is viewed as jeopardy to the survival, development and perpetuity of the family. Couples without children are considered "poorer" and the women as losers.[105]

Women's internalization of stigma related to sterilization can also have grave social consequences on the sterilized woman herself. 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.[106]

Religion is also an element which influences the culture of most societies. It shapes individual's attitude: for example, the bible states that "People are supposed to go out and populate the earth"[107]. In the Hindu religion, it is believed that a woman without a child, particularly a son, can't go to heaven. Sons perform death rituals. Infertile couples worry that without a child, there will no one to mourn for them and bury them. In China and Vietnam, the traditional belief is that the souls of childless people cannot easily rest. In India, the eldest son traditionally lights the funeral

[102]L Lisle *without child: challenge the stigma of childless* (1999) Routledge, New York 8
[103] As above
[104] R Hallgren *West Africa Childbirth Tradition* (1983) 96(11) *Jordemodern*, 96
[105]As above 97
[106] C Pamela *Church ladies, good girls, and local stigma and the intersection of gender, ethnicity, mental illness, and sexual in relation to HIV risk* (2008) *social science & Medicine* vol/is 67/3 398-408
[107] See Genesis chapter 22 verse 15- 18 The Holy Bible, New century version 2003

pyre. In Muslim cultures, the stigma follows childless women even after death: women without children aren't always allowed to be buried in graveyards or sacred grounds."[108]

All these are religious perceptions which can and do influence and perpetuate stigma on childless women, sterilized ones and those who are mothers to daughters only. The solution to stigma relating to childless women is not only to have a child but, to produce an offspring who must be male. Consequently, interrupting women's reproductive health right through sterilization interferes with their social life.

In many communities, reproductive and sexual health issues are not comfortably discussed. They present a formidable challenge due mainly to the lack of openness. Combining reproductive and sexual health issues with an analysis of women's place in society and respect for human rights may require a shift in social expectations that will certainly face strong resistance.

As there are so 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. [109]

It needs to be kept in mind that in this work, sterilization is being viewed in the context of HIV/AIDS. Therefore, it becomes imperative to look at this pandemic in the context of sterilization as it continues to carry enormous social stigma despite the fact that the face of AIDS has become more subtle, and has changed the population most affected today. AIDS-related stigma tends to be high on low-income minorities and especially on HIV positive women who become pregnant".[110]An analysis of the public panic response to AIDS and the infected person shows the influence of pre-existing attitude toward contagious diseases.[111] The threat of being infected with an incurable and potentially terminal disease inevitably means that people with HIV/ AIDS present a real material threat or 'risk' to those who are not infected.[112]

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[108] Springen(n 92 above)
[109] As above
[110]D Rochon *HIV- Positive women and health care* , Bylor College of Medicine PP32 available at : https://tspace.library.utoronto.ca/bitstream/1807/16688/1/Rochon.pdf (acessed 10 august 2009)
[111] As above 34
[112] J Stein 'HIV/ AIDS stigma: The Latest Dirty Secret' *(*2003) Centre for Social Science Research, University of Cape Town

Furthermore, "[t]hroughout history, the medicalisation of women's body has gone so far as to turn into a disease".[113] This action may be attributed to the social set-up; for instance, if we look at the African social context, the male-dominant medical profession, the patriarchal nature of social life and the pro-natal consciousness imposed on women a need to fulfill societal expectations.[114] Bearing in mind that health care providers form part to the society, which is build on stigmatizing norms and values, it is unwise to expect them to act completely differently from the general society.

Hunter substantiates this fact by pointing out that, becoming a health-care provider does not eliminate a person's values and beliefs, nor does it mean that the provider will be non-judgmental and considerate of diverse viewpoints and lifestyles once he or she enters the health-care setting.[115] The social reality of this issue is revealed in the following case: when a social worker in South Africa was asked about HIV risk and sexuality among women diagnosed with severe mental illnesses, she stated that "mental health and sexuality are two things that you don't talk about. We have come from a society where those are taboos".[116]

Therefore, HIV positive women face enormous social challenges from the time they learn about their sero-status to the consequences which follow as a direct result of this diagnosis. Sterilization as a consequence of HIV/ADIS, therefore, becomes the main factor that perpetuates and reinforces this pervasive stigma and discrimination. Hence, to be HIV-AIDS positive also means to assume all prejudices regarding the incapacity of childbearing and social consequences which maintains and strengthens it.

Consequently, it should be noted that sterilized women face double stigma. However, it must be considered that HIV positive women come from the same society with HIV negative women and they undergo the same socialization process which emphasizes childbearing as a supreme value. Therefore, it should not be surprising to be diagnosed with HIV does not cause an infected woman to abandon all notions about motherhood that she has been developing since

[113] R Diamond 'Coerced Sterilization under Federally Funded Family Planning Program' (1997) 11(2) *New England Law Review* 589-614.
[114] L Caron and L Wynn 'The intent to parent among young, unmarried college guardians: family in society' (1992) 73(8) *The Journal of Contemporary Human Services* 483
[115] E Hunter and W Rose 'Determinant of health-care work's attitude toward people with AIDS'(1991) 21(11) *Journal of Applied Social Psychology* 947-956
[116] Colombia University Department of Psychiatry, New York, cited in Collins P Dual 'Taboos: Sexuality and women with severe mental illness in South Africa: Perceptions of Mental health care providers' (2001) 5 (2)*AIDS and Behaviour* 151

adolescence. "It may actually increase the desire to bear children".[117] A survey conducted in Brazzaville on attitude prevailing among pregnant women has shown that women would not mind an HIV test but the result would not influence their decision on childbearing.[118]

As a result, the serious effects of stigmatization have created an environment in which silence about HIV threatens everyone's health. Furthermore, it may lead to childbearing and delivery through unhygienic and dangerous means which poses substantial health risk to HIV positive women and their children. However, it should be understood that that the most far-reaching social development of modern times is free motherhood and the achievement and the enjoyment of women's human rights.[119]Therefore, such avoidance and stigmatization processes are uncalled for.

Stigma, as discussed above, has been identified as one of the barriers to proper health care, suggesting that HIV-infected and pregnant women may be disinclined to seek health care if health care professionals exhibit negative attitudes. Mostly influenced by social norms and values, this gives rise to discrimination in regard to access to proper heath care. Hence, it is common for stigmatized people to repress their anger at being discriminated against. This manifests itself as self-hatred and shame which can result in auto-isolation or suicide in the worst cases.[120] It also compromises care because HIV positive women may fear to be blamed for contagion. Victim blaming, lack of confidentiality, misinformation and negative attitudes towards HIV significantly limits a caregiver's ability to provide effective, respectful and dignified care to PLWH and their family.[121]

3.5 Conclusion

It is clear that ensuring sexual and reproductive rights cannot be viewed only as a technical issue of access and availability of services but touches profoundly on issues of socio-cultural and gender inequalities. Societal norms and values which stigmatize HIV positive women can influence access to health care, attitude of the health care provider, the patient and the response

[117]W Ross, A Wodak, Miller and J Gold 'Attitude toward termination of pregnancy and associated risk behaviour in drug-injecting women' in F.Melica (ed) *AIDS and Human Reproduction* 1st International symposium on AIDS and Reproduction, Genoa (December 1992) 12-15, 55-60. Basel, Switzerland: Karger.

[118] K Tomasviski *Women and Human Rights* (1999) London, Atlantic Highlands 67

[119] Eve Cary & Kathleen Willert Peratis '*Woman and the Law' (1977*) 193.

[120] A Alonzo & R Eynolds 'Stigma, HIV and AIDS: An explanation and elaboration of stigma trajectory'(1995) 48 (50) *Social Science and Medicine* 303-315

[121] World Health Organization, Department of Reproductive Health and Research Family and Community Health , 'HIV-infected Women and their Families: Psychosocial Support and Related Issues' WHO/RHR/03.07,WHO/ HIV/ (2003) 9

of the society towards the disease. This can cause stigma and discrimination against HIV positive women.

Sterilization of HIV positive women has enormous social consequences at the level of exposure to stigma and discrimination is double; firstly because the woman is HIV positive and secondly because she cannot bear children. HIV and infertility are the two carriers of stigma as they are considered as threats to the patriarchal society which considerers childbearing as a supreme value and the most prominent, if not the sole, role of women.

It should also be noted that society is more concerned with thinking about social values like issues of death, sex, misbehavior, blame, shame, rejection, than technical factors about HIV/AIDS. The human rights of HIV positive women will continue to be subjected to violation if the current situation is not improved from a human rights perspective.

Chapter 4: Forced sterilization as limitation of reproductive health rights of women living with HIV/AIDS

4.1 Introduction

Ever since the surfacing of the HIV/AIDS pandemic, women have often been targeted by HIV/AIDS prevention measures designed to avoid infection of their future children. In few countries, compulsory HIV screening of all pregnant women has been required by law, or made part of the national AIDS prevention control programme. In others, forced sterilization and abortion have also been included in the list of such measures. In Namibia, for example, instances of sterilisation without consent of HIV positive women have been documented, while in other countries, women living with HIV have been coerced by health care providers to abort.[122]

This chapter shows how forced sterilization infringes upon the rights of HIV positive women. It puts forward the arguments against and in favour of forced sterilization of women living with HIV/AIDS and explores the principle of reasonability and justifiability of such measures. It also looks at the position of foreign jurisdictions on how they have dealt with the human rights implications of forced sterilization of women living with HIV/AIDS.

4.2 Forced sterilization as a limitation of HIV positive women's right

Encouraging HIV positive pregnant women to abort or to subject them to sterilization without their consent is a violation of their right to equality and the prohibition against discrimination. For instance, the birth of children with genetic disorders reveals a striking difference between the medical treatments received by HIV positive women compared with the negative women.[123] If we look at the actual difference, the overall risk of women having a child with major defect is 2% to 3%[124] compared to1% for women with HIV infection[125].

Actually, HIV positive women with intervention of the treatment minimise the risk of mother–to-child HIV transmission in contrast to pregnant HIV negative women who suffer from genetic defects, such as *tay sachs*, chronic diseases, as a result of late pregnancy. For example, today due to several factors, women are choosing to bear children at later stage of their lives. In such

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[122] ICW (n 58 above)

[123] D Rochon *HIV- Positive women and health care*, Bylor College of Medicine PP.42 Available at https://tspace.library.utoronto.ca/bitstream/1807/16688/1/Rochon.pdf(accessed August 2009)

[124] R Cooper *et al* 'Combination antiretroviral strategies for the treatment of pregnant HIV-1- infected women and prevention of prenatal HIV-1-Trasmission' (2002) 29 (5) *Journal of acquired immune deficiency syndrome* 484-494.

[125]R Bessinger *et al* 'Pregnancy with the progress of HIV disease attending an HIV auto patient program(1998) 147(5) *American Journal of Epidemiology* 434-440 also supported by Weisseer (n 61 above) 404-410

cases, advancing maternal age heightens the inherent risk of the child to suffer from diseases such as Down syndrome.[126] Those women continue their pregnancy and are supported and assisted in their quest for motherhood.

However, HIV positive women are neither supported nor assisted during their pregnancy. National and international policies are giving emphasis on the prevention of pregnancy amongst HIV-positive women.[127] As a result, professionals mainly in the medical sphere insist on discouraging HIV positive women from becoming pregnant. Such negative attitude propagates and reinforces the belief that these women are irresponsible for having babies who may face early death and whose future care may be a burden to society.[128] Furthermore, some of the egregious examples of discrimination against PLWH, including those suspected to have AIDS, which often violate the right to non-discrimination, include cases such as the denial of care, neglectful treatment and insult from health staff.[129] This violates the right to non- discrimination which stems from the concept of equality requires that people in similar situations, under similar circumstances be treated alike and people unalike be treated unalike.[130] The South African Constitutional Court interpreted the right to equality as implying the right not to be discriminated against and as being closely related to the right to human dignity.[131]

Therefore, HIV positive women face discrimination on the basis of their sero-status in accessing health care and benefiting from reproductive health rights. Unfortunately, as mentioned earlier, HIV positive women are being encouraged to sign consent forms to prevent them from having more children. The same treatment is not applied to HIV-negative women who are at risk of giving birth to a child with other types of diseases or defects.

[126] C Livinel and N Dubler 'HIV and Childbearing : Uncertain risk and bitter realities: The reproductive choice of HIV-infected women' (1990) 68(3) *Millbank Quarterly* 323

[127] London(n 37 above) *22*

[128] International Community (n 36 above)

[129] PANOS and UNICEF 'HIV/AIDS and Prevention of Mother-to-Child Transmission: A Pilot Study in Zambia, India , Ukraine and Burkina Faso' 29 (2001) available at: http:// www.unicefe.org/evaldatabase/index14350.html. (Accessed 13 September 2009)

[130] A Fagan 'Dignity and unfair discrimination: a value misplaced and a right misunderstood' *(*1998) 14 *South African Journal on Human Rights* 239.

[131] See for instance *Brink v Kitsoff NO* 1996 (4) SA 197 (CC); *Prinsloo v van der Linde* 1997 (4) SA 1 (CC);*President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC); *Harksen v Lane NO* 1998 (1) SA 300(CC); *National Coalition for Gay and Lesbian Equality v Minister of Justice* 1999 (1) SA 6 (CC); *National Coalition for Gay and Lesbian Equality v Minister of Home Affairs* 2000 (2) SA 1 (CC); and *Hoffmann v SouthAfrica Airways* 2000 (1) SA 1 (CC).

Article 1 of the Universal Declaration of Human Rights (UDHR) stipulates that "all human beings are born free and equal in dignity and rights."[132]Human right law guarantees freedom from discrimination on grounds such as race, colour, sex, language, religion, political or other opinion or social origin, poverty, birth or other status.[133]

The High Commissioner for Human Rights explained that in provisions dealing with non-discrimination, "other status" must be interpreted to include health status, including HIV/AIDS.[134] In addition, article 12 of the Convention on the Elimination of Discrimination against Women (CEDAW) puts forward the right to health care of women. It focuses on equal access to health care facilities for women including pre- and post-natal care.[135] Furthermore, at the African level, the African Charter on Human and Peoples' Rights recognizes and reaffirms women's rights. Article 18(3) requires all State parties to ensure the elimination of all forms of discrimination against women as well as ensure the protection of the rights of women.[136]

Also, the protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa provides that States shall ensure that reproductive health rights are promoted and respected, giving due consideration to the right to choose any method of contraception and self-protection.[137]

Forced or coerced sterilization of HIV positive women not only violates the right to non-discrimination, but also severely limits the reproductive health rights of infected women. According to the Cairo Program, reproductive rights include the right to a "safe sex life with the capability to reproduce and the freedom to decide if, when and how to do so". The right to reproduce safely and freely includes the right to access appropriate health care services that will enable women to go safely through pregnancy and childbearing and to provide couples with the best chance of having a healthy infant.[138]

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[132] See Universal Declaration of Human Right, adopted Dec.10. 1948, article1 G.A, Res 217 (III) at 71.UN. Doc. A/810 (1948).

[133] See article 2of the ICCPR and ACHPR.

[134] Office of the United Nations High Commissioner for Human Rights 'The protection of Human Rights in the context of Human Immune Deficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)' (2003) Para16 available at: hpp://ap.ohehr.org/documents/E/CHR/resolution/E-CN_4RES-2003-47.doc. (Accessed 22 September 2009)

[135] CEDAW, article 12

[136] ACHPR, article 18(3)

[137] See Article 14 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2003).

[138]See United Nations *Report of the International Conference on Population and Development* Document A/Conf, 171/13(1994) at Para.72.

The Beijing Platform also states that the human rights of women include the right to sexual and reproductive health free of coercion, discrimination and violence, and that full respect for the integrity of the person requires mutual respect and consent.[139]However, women, when seeking treatment from healthcare providers, are often subjected to stigma and discrimination. Perceived as being vectors of diseases, they are judged for having not only unprotected sex and exposing their partners to infections, but also for taking the risk of giving birth to an infected child.[140]

The right to health as protected under the ICESCR imposes an immediate obligation on State Parties to ensure access to healthcare without discrimination of any kind.[141] It should also be understood that this does not imply identical medical treatment. Instead, the principle of equality and non-discrimination recognize important differences between women and men as well as among women themselves depending on their circumstances. But in the HIV context, women with some risk of transmitting diseases to their children are often treated differently.

In the context of forced or coerced sterilization, women are not requested to give voluntary and informed consent based on the respect for their inherent dignity as human beings[142] as discussed in chapter 2 of this work. Human dignity requires that each woman is treated as an end in herself, rather than a means to achieve other goals.[143] Voluntary and informed consent is also implies a recognition of and respect for women's autonomy and requires that health care professionals remain non-judgemental and non-discriminatory in their provision of health service.

All these provisions provide for the protection of the reproductive rights of all women, including those living with HIV. Consequently, forced or coerced sterilization limits all the rights provided in the instruments which guarantee reproductive rights through permanently precluding HIV positive women from childbearing.

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[139] Beijing Declaration and Platform for Action (1995) Fourth World Conference on Women.15 September 1995 UN Documents A/CONF.177/20 (1995) and A/CONF.177/20/Add.1 (1995) available at http:// www.un.org/ess/gospher-data/conf/off/a--20.en. (Accessed 20 September 2009)

[140]K Stefiszyn *et al* 'Realizing the Right to Health in the Universal Declaration of Human Rights After 60 Years: Addressing the reproductive health rights of women living with HIV in Southern Africa' Centre for Human Rights, University of Pretoria for the Swiss initiative to commemorate the 60th Anniversary of the UDHR- Protecting Dignity : An Agenda for human right (2009) 35

[141] General Comment No 14, The right to the Highest attainable standard of health, UN CESC, 22nd Session .UN Doc. E/C.12/2002/4 (2000), U.N.Doc. HRI/GEN/1/Rev.6 at 85 (2003) Para 30

[142] J Vollamann & R Winau 'Informed consent in human experimentation before the Nuremberg Code' BMJ No 7070 volume 313 available at: http://www.bmj.com/archive/7070nd1.htm (Accessed 23 August 2009)

[143]FIGO (n 50 above) 13

4.3 Reasonability and justifiability analyses

Forced or coerced sterilization of HIV Positive women limits a number of rights which are linked to their reproductive autonomy and rights. The question, therefore, remains, is this limitation reasonable and justifiable based rules on limitation of rights?

According to article 4 of the ICESCR, limitations, as are determined by law, may be executed only in so far as this may be compatible with the nature of the relevant rights and solely for the purpose of promoting general welfare in a democratic society. Also the ACHPR provides for possible limitation of rights for reasons and conditions previously laid down by the law. Hence, these two instruments expressly require that limitation of the rights must be legally provided. However, in the reported countries, sterilization is not provided or authorized by law but, it is a practice in the health care institutions in the name of protecting public health.[144]

Considering that HIV is a health issue, and assuming that it constitutes a public emergency[145] which threatens life, the ICCPR provides for exceptions. Article 4 of the ICCPR provide for derogation: "in time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the State Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, colour, sex, language, religion or social origin."[146]

In this regard, Sub-Saharan Africa has the worst indicators of women's health particularly in the case of reproductive health. These indicators include the highest number of HIV positive women and the highest infant, maternal, and HIV-related death rates worldwide.[147] In response to this shocking reality, different aggressive measures have been taken, including for instance, HIV screening of pregnant women voluntary or compulsory. Abortion and sterilization are also frequently resorted to.

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[144] International Community (n 38 above)

[145] K Mehoboob Assistant Director, Geral Administration and Finance Department in his welcoming remarks to the Symposium available at: http://www.fao.org/sd/2003/PE0101a_en.htm (Accessed 19 September 2009)

[146] Article 4 of the ICCPR

[147] Centre for Reproductive Rights 'The Protocol on the Rights of Women in Africa: an instrument for advancing reproductive and sexual rights. Briefing paper' (2006) 1 available at: ww.reproductiverghts.org (Accessed 13 August 2009)

Does the derogation clause provided in article 4 of the ICCPR apply in the context of HIV/AIDS? In the event that States may take measures derogating from their obligations under the Covenant to the extent strictly required by the exigencies of the situation, women are "encouraged" to be sterilized due to their positive status in order to prevent infection of their future children.[148] Furthermore, "pregnancy is discouraged based on a number of reasons including to avoid exposure to re-infection for herself and her partner, exposure to infection for the baby, weakened immune system, risk of death and child abandonment"[149].

Therefore, in the context of policy making, national and international emphasis is placed on the prevention of pregnancy amongst HIV positive women in order to avoid mother-to-child infection. In light of the above, health care providers tend to often discourage the reproduction of HIV positive women.[150]

However, HIV infection can occur during sexual intercourse, sharing drug-injecting equipment, and contaminated blood or instruments in health care settings.[151]If we look at the forms of transmission of HIV/AIDS, it is difficult to understand how sterilization will stop the spread of HIV/AIDS as the pregnancy is post-exposure to infection. This means, pregnant women are already infected and in the case of re-infection, it already occurs at the moment of conception.[152] Therefore, the prevention must take place before the conception or the measure will not be helpful to avoid transmission.

Today, with scientific developments, it may be possible to reduce the risk of HIV transmission through sexual contact by optimising the health of HIV positive individuals before they attempt to conceive. This includes the use of antiretroviral therapy by infected individuals and the treatment of sexually transmitted infections other than HIV.[153] However, the avoidance of pregnancy itself will not stop the spread of HIV/AIDS; neither will the interruption of pregnancy or sterilization secure the protection from re-infection because, as discussed above, it is not the only or the predominant mode of infection.

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[148] International Community (n 38 above)
[149]Stefiszyn (n 140 above) 39
[150]AC Segurado and V Paiva 'Rights of HIV Positive people to sexual and reproductive health: parenthood. *reproductive health matters (*2007) 15 (29suppl) :27-45; Shelton and EA Peterson 'The imperative for family planning in ART program' *Lacent* 2005; 365:655-656 cited in London(n 39 above) 12.
[151] A Whiterside *HIV/AIDS: Very Short Introduction* (2008) 4
[152] As above
[153] London(n 39above) 14.

In more specific terms, the transmission of the virus from mother-to-child can occur during pregnancy, labour and delivery or breastfeeding. The moment of transmission of HIV/AIDS virus from mother-to-child cannot be estimated with precision, what is known is that the virus can be transmitted during pregnancy[154]. Furthermore, it is scientifically proved that pregnancy does not make a woman's own health worse in respect of HIV. However, being pregnant may cause her CD4 count (see below) to drop slightly which should normally return to its pre-pregnancy level soon after delivery.[155] Therefore, it becomes difficult to accept the reasonableness of the interference with gestation or the radical removal of the capacity to reproduce as preventive measure to control the transmission of the virus.

Consequently, this argument undermines the means employed to achieve the purpose of the limitations stated above and hence the necessity of the measure. Also, it cannot be considered as fulfilling the requirements of article 4 of ICCPR which only permits limitations 'to the extent strictly required by the exigencies of the situation'. In other words, any measure resorted to must be reasonable and justifiable in the particular circumstance.

However, it has been found that reducing unintended pregnancies among HIV positive women by 16% could be estimated to have the same impact in averting HIV infection among infants as antiretroviral prophylaxis.[156] This measure, from the point of view of results, clearly reduces the number of potentially HIV positive children.

The question, however, is whether this measure is reasonable and necessary when tested against international norms of limitations of rights. The Canadian Supreme Court considered that limitations must be reasonable and demonstrably justified in a free and democratic society. The Court also ruled that, in order to meet the requirements, a limitation must be directed to the achievement of an important objective to justify the limitation of the rights in question. In addition, the extent of the limitations should also be proportionate with the objectives it purports to achieve.[157]

Discouraging pregnancy means that HIV positive women will not be able to bear children. Considering that sterilization is permanent and radical, HIV positive women will not even benefit

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[154] Whiterside (n 151above) 4

[155] Bessinger (n 63 above) 434-440. Also spouted by Weisseer(n 61 above) 404-410

[156] Government of Botswana Country Report, United Nations General Assembly Special Session on HIV/AIDS, December 2007 available at: http://www.genderhealth.org/pubs/botswana.pdf (Accessed 21 September 2009)

[157] R v Oakes, (1986) 1 S.C.R. 103, File No.: 17550, February 28, 1986 Supreme Court of Canada Available at: http://csc.lexum.umontreal.ca/en/1986/1986rcs1-103/1986rcs1-103.html (Accessed 18 August 2009)

from future scientific developments. First, HIV/AIDS is a disease which is still a subject of a lot of research and scientific development. In case the cure is discovered or developed, those sterilized women will not benefit from it and be able to enjoy their reproductive health rights due to the irreversible consequences of sterilization. For example, consider the case of a 14-year-old girl who was advised to abort only on condition that she agreed to sacrifice her reproductive rights.[158] In this case, the girl is fourteen years old, with expected span of fertile period of approximately 32 years, which was a reasonably long time for science to come up with a solution to the HIV pandemic. There is an encouraging move in this regard as scientists have very recently developed the first successful AIDS vaccine towards which the WHO and UNAIDS have expressed huge significance sparkling new hope in the HIV/AIDS field.[159]

Second, the preventive measure directed towards women solely focus on preventing the transmission of the virus to their future children or their sexual partner. The reproductive rights of the HIV positive women are not considered at all. [160] For instance, they are not given opportunity to decide freely and responsibly on the number and spacing of children; nor are they entitled to enjoy their rights and freedom. This also includes the impossibility to control their body including their sexual and reproductive freedom, and right to be free from interference, such as not to be subjected to non-consensual medical treatment.[161]

This is the human right perspective of forced sterilization which equally emphasises the freedom of women. In other words, women must be informed and be able to decide whether they want to be sterilized or not. They should receive all the information regarding the pandemic itself, the sterilization processes, benefits, risk, as well as consequences before ultimately making a decision.

Therefore, it is important to know whether the limitation negates the essential content of the right. In other words, it is imperative to ascertain whether the infringement of fundamental rights is against the benefit that the law seeks to achieve through the limitation.[162]

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[158] Mail & Guardian (n 4 above)
[159] M Marchione 'In a first, an AIDS Vaccine shows some Success' *Yahoo News* 24 September 2009. Available at: http://news.yahoo.com/s/ap/20090924/apon he me/med aids vaccine (Accessed 25 September 2009)
[160] S Guskin Negotiating the relationship of HIV/AIDS to Reproductive Health and Reproductive Right. (1994-1995) 44 *The American University Law Review* 1191
[161] Committee on the Economic, Social and cultural Rights (2000). General Comment No 14, Geneva: Office of the High Commissioner on Human Rights. Available at: http://www.unhchr.ch/tbs/doc,nsf/(simbol)/E.C.12.2000.4.En (Accessed 20 August 2009)
[162] I Currie & J Waal *The Bill of Right Handbook* (5ed) (2005) 181

Considering that reproductive health rights are part of the health rights of women, people should be able to have a satisfying and safe sex life and that they should also 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 well informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice.[163]

Also, absence of free consent to a medical or scientific experimentation is a violation of the freedom of a person as it automatically interferes with her/his liberty and security.[164] The Human Rights Committee has specifically stated that protecting individuals from cruel, inhuman and degrading treatment apply also in "medical institutions".[165]

As mentioned above, forced sterilization limits the reproductive rights of women living with HIV. Moreover, "denying women the only skilled care to which they have practical access also constitutes inhuman and degrading treatment, and even denial of their right to life or to the highest attainable standard of health."[166]

Furthermore, forced sterilisation and involuntary abortion have adverse effects on women's physical and mental health. The Human Rights Committee, European Court of Human rights and the Inter-American Human rights institutions have all recognized and condemned mental suffering which can be as distressing as physical pain.[167] Therefore, forced sterilization amounts to inhuman and degrading treatment.

In light of the above, the Namibian case, where HIV positive women minutes to give birth under duress and pain of labour were subjected to sign the 'informed consent' contract, qualifies as inhuman and degrading treatment.[168] Such an act is prohibited in all international instruments including those at the regional level. Moreover, inhuman treatment allows no justifiable limitations or exceptions.[169]Hence, the infringement of this fundamental guarantee through

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[163] See Para 7.2 of Cairo Programme of Action (1994) Available at: http://www.dirittiumani.donne.aidos.it/bibl_2_testi/d_impegni_pol_internaz/a_conf_mondiali_onu/c_conf_cairo_e+5/a_cairo_poa_engl_x_pdf/cairo_dich+pda_engl.pdf (Accessed 23 September 2009)

[164] See articles 7, 9(1) and 17 of the ICCPR

[165] General Comment No 20, Human Right committee, article 7 (44th Session 1992) UN.Doc. HRI/GEN/1/ Rev.1 (1994) Para 30.

[166] RJ Cook & BM Dickens *Reproductive health and human rights: integrating medicine, ethics and law* (2003) 319.

[167] M Sepulveda et al *Universal and regional human rights protection: cases and materials* (2004) 211

[168]See article 4 of the Convention Against Torture, Inhuman and Degrading Treatment or Punishment UN Doc. A/39/51 (1948)1465 U.N.T.S 85

[169] see article 12 of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, article 5 of African ACHPR, article 7 of ICCPR, Article 3 of the European Convention, article 4 of the Charter of the Fundamental Rights of the European Union, Preamble of the Inter-American Convention to Prevent and Punish Torture and the article 16 of the Document of the Copenhagen Meeting of the Conference on

forced sterilization is against the plain entitlements the law entrenches, that of the freedom of women. As such, the limitation is a serious infringement of that right.[170]

But, voluntary and informed consent faces challenges as discussed in chapter two and three of this work. Power imbalance between the health care provider and the patient, the level of understanding, the language used, the lack of skilled personnel in health services as well as the scarcity of institutional capacities are edified challenges on the enjoyment of the freedom of women in exercising their reproductive health rights.

The root cause of all the challenges that voluntary and informed consent faces, however, is stigma and discrimination which has its base in the social construction of HV which brings out the issue of norms and values. Therefore, those norms and values inform decision-making processes from the level of policy making through to health care provision which shape the challenges on the success of the enjoyment of women's freedom in relation to reproductive health rights.

According to the South African Constitution, which reflects internationally agreed upon principles, the criteria prescribed for limitation is that it must be justifiable in an open and democratic society based on freedom and equality. It must be both reasonable and necessary and it must not negate the essential content of the right.[171] Also, though the European Convention on Human Rights has no general limitations clause, it makes certain rights subject to limitation according to specified criteria. The proportionality test of the European Court of Human Rights calls for a balancing of ends and means. The end must be a "pressing social need" and the means used must be proportionate to the attainment of such an end. [172] "[R]easonableness plays a role of a criterion of appropriateness of certain rationales for the use of cohesion by the State towards individuals"[173].

Considering that, stigma and discrimination are the root causes of the challenges which lead to limitation of the reproductive rights of HIV positive women. For example, a woman in Namibia was ignored by health care workers when seeking information on HIV and pregnancy and was

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Human Dimension of the CSCE - http://www.osce.org/documents/odihr/2006/06/19392_en.pdf, (accessed on 12 October 2009)

[170] Currie & Waal (n 162 above) 181

[171] See article 33(1) of the Act 108 of 1996 Constitution of the Republic of South Africa

[172] See article 3 of the European Convention, and *Harksen v Lane NO* 1998 (1) SA 300 (CC).

[173] W Sadurski 'Reasonableness and value pluralism and politics' (2009) 86 (1) *Law and Philosophy* 1572-4395

told "you are HIV positive and you are pregnant. Your baby is already infected".[174] This negative approach reveals the high level of stigma and discrimination which directly contradicts the African concept of "Ubuntu" defined as the respect of a person's dignity and brotherhood.[175] These values are considered essential for an open and democratic society based on freedom and equality because voluntary and informed consent is the indicator of the autonomy, dignity and freedom of women.

In the African regional human rights system, the right to health is guaranteed under article 16 of the ACHPR.[176] It reaffirms that everyone has the right to enjoy the best attainable state of physical and mental health. The African Commission on Human and Peoples' Rights in *Purohit and Another v the Gambia case* [177] has held that the 'Enjoyment of the human right to health as it is widely known is vital to all aspects of a person's life and well-being, and is crucial to the realization of all the other fundamental human rights and freedoms'.

Also, article 14 of the African Women's Protocol[178] contains detailed provisions recognising the right to health. Here, States are required to "ensure that the right to health of women, including sexual and reproductive health of women, is respected and promoted". This important article further provides that States should respect and promote a woman's right to control her fertility, decide on the number and spacing of her children, choose any method of contraception, self-protection from sexually transmitted infections including HIV/AIDS, legal abortion in certain situations and family planning.

Therefore, the ability to attain the highest possible standard of health is not a privilege solely for the elite or HIV-negative people, but a right that comes with being human. As such, "[D]discrimination and stigma amount to a failure to respect human dignity and equality by

[174] ICW (n 34 above)

[175] *Ubuntu ... essence of being human...the fact that my humanity is caught up and is inextricably bound up in yours. A person with ubuntu is welcoming, hospitable, warm and generous, willing to share...open and available to others, affirming of others; do (sic) not feel threatened that others are able and good, for they have a proper self-assurance that comes from knowing that they belong in a greater whole and are diminished when others are humiliated or diminished. "DESMOND TUTU"* Swanson, D.M. (2007). Ubuntu: An African contribution to (re)search for/with a "humble togetherness." The Journal of Contemporary Issues in Education, 2(2), University of Alberta, Special Edition on African Worldviews. [Online] Available: http://ejournals.library.ualberta.ca/index.php/JCIE/issue/view/56

[176] See ACHPR

[177] Communication 241/2001 decided at the 33rd Ordinary Session of the African Commission held from 15th –29th in Niamey, Niger (May 2003).

[178] Adopted by the 2nd Ordinary Session of the African Union General Assembly in 2003 in Maputo CAB/LEG/66.6 (2003) entered into force 25 November 2005.

devaluing those affected, often adding to the inequalities already experienced by vulnerable and marginalized groups."[179]

Furthermore, in the communication *A.S. v. Hungary,* the CEDAW Committee reaffirmed what is stated in its General Recommendation No. 24 on women and health that "[A]cceptable services are those that are delivered in a way that ensure that a woman gives her fully informed consent, and respects her dignity."[180] It found that the government had violated Article 10(h) of CEDAW by failing to provide appropriate family planning information. The Committee also found that the lack of informed consent violated Articles 12 and 16 of the CEDAW, which respectively guarantee the right to non-discriminatory health care service and the right to decide freely and responsibly on the number and spacing of once children and to have access to the information, education and means to enable them to exercise these rights. In both cases, the women faced pernicious and multiple forms of discrimination based on gender, HIV status and ethnicity.[181]

Therefore, it is considered that the right to dignity is a right that evolves with being human. As a result, forced sterilization as a limitation of reproductive health rights is not reasonable as it negates the essential content of the right by radically and irreversibly tarnishing the capacity to reproduce. Father, HIV positive women have the right to a family. The right to found a family is protected by the UDHR and ICCPR by considering that family is a fundamental group unity of the society. General Comment 19 on the ICCPR states that the right to found a family imply the possibility to procreate, and father consider that when State Parties adopt family planning polices, they should be compatible with the provision of the Covenant and should in particularly, not be discriminatory or compulsory.[182]

Another argument which is brought forward by the public health supporters is the lack of institutional capacities, skilled health care providers and insufficient availability of anti-retroviral (ARV) drugs which can reduce the likelihood of risk of transmission to the new born and the male partner as well as increase the longevity and quality of life of infected partner who will be

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[179] Special Rapporteur Paul Hunt 'Report on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' UNDOC E/CN.4/2003/58

[180] *A.S. v. Hungary (2006)* Committee of Elimination of Discrimination Against Women, Communication No 4/ 2004, August 2006. Available at : - http://www.un.org/womenwatch/daw/cedaw/protocol/decisions-views/Decision%204-2004%20-%20English.pdf (Accessed 10 November 2009)

[181] *As above*

[182] Human Rights Committee, General Comment 19, Article 23(Thirty-ninth session,1990), compilation of General Comments and General Recommendations adopted by the Human Rights Treaty Bodies, U.N. Doc. HRIGEN 1Rev.1 at 28(1994).

able to live and care for their children.[183] It is, therefore, argued that public health would be better served by the prevention of infection among newborns and non-infected. Such a public health-oriented policy seeks to limit pregnancy in the context of HIV/AIDS.[184]

Today, anti-retroviral drugs, which have the capacity to reduce the chances of mother-to-child transmission of HIV from 30% to less than 1%, are available. Therefore, in the context of HIV/AIDS, we should not look at prevention as the only solution, but we should also consider treatment as an alternative whenever feasible and effective. However, the question of accessibility of the drug in developing countries is far from conclusively answered. Considering that health systems must provide an uninterrupted supply of antiretroviral drugs to maximize the chances of good treatment outcomes and prevent the emergence of drug-resistance, the shortage constitutes a major hurdle.[185] This can be considered as a big challenge for developing countries considering their low income.

It should be kept in mind that since the pandemic was considered as an international emergency, a lot of measures have been taken in order to ensure the availability of the drug. For instance, in sub-Saharan Africa, the number of people receiving treatment has increased by more than eight-fold over the two year reporting period (from 100 000 to 810 000) and has more than doubled in recent years. Coverage increased from 2% in 2003 to 17% at the end of 2005.[186]

Furthermore, it was reported that treatment sites providing antiretroviral therapy in low- and middle-income countries grew from about 500 in June 2004 (not including private outlets) to more than 5100 antiretroviral therapy service delivery sites by the end of 2005. It has also been noted that litigation to bring down prices of ARVs drugs in South Africa during the early 2000s led to a substantially reduced cost of paying for drugs and prevented unnecessary expenses by succeeding governments.[187]

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183 London (n 39 above)16

184 As above

185 J Sinowl, Supply Chain Management of Antiretroviral Drugs, *Consideration for initiating and expanding National Supply Chains* Delivery Project, United State Agency for International Development (2006), available at: http://deliver.jsi.com/dlvr_content/resources/allpubs/guidelines/SCManaARVDrug.pdf (Accessed 10 October 2009)

186 Wold health Organization (WHO) and Joint United Nations Programme on HIV/AIDS (UNAIDS) (2006) Progress on Global Access to HIV Antiretroviral Therapy. Report on "3 by 5 and beyond", March 2006 24-26 available at: http://www.who.int/whr/2000/en/index.html (Accessed 10 September 2009)

187 M Heywood 'South Africa's Treatment Action Campaign: Combining Law and Social Mobilisation to Realise the Right to Health' (2009) 1 *Journal of Human Rights Practice* 24.

In addition, it was also considered that the commitment of international donors has grown remarkably in recent years, with global expenditure on HIV/AIDS in low- and middle-income countries increasing from US$ 4.7 billion in 2003 to an estimated US$ 8.3 billion in 2005. A significant proportion of funding is now being provided by the United States President's Emergency Plan for AIDS Relief, the Global Fund to Fight AIDS, the World Bank's Multi-Country HIV/AIDS Program for Africa and Caribbean Multi-Country HIV/AIDS, Prevention and Control Adaptable Lending Program.[188] According to the above mentioned data, all the necessary conditions to reasonably sustain the therapy are available. Above all, it proves without a shadow of doubt that in countries where forced sterilization instances were reported, ARV Therapy is available.

Also the UN Committee has stated that, it is not sufficient that the restrictions serve permissible purposes. Restrictive measures must conform to the principle of proportionality as well: they must be appropriate to achieve their protective function and they must be the least intrusive instruments amongst those which might achieve the desired result. Finally, they must be proportionate to the interest to be protected.[189]

As mentioned above, forced sterilization is a restrictive measure and violates a number of rights of HIV positive women. As a result, the limitation is not proportionate if other means could be employed to achieve the same ends. For instance, in order to reduce and control mother-to-child infection, methods other than forced sterilization can be employed. Voluntary and reversible sterilization, antiretroviral therapy, and family and planning can all achieve similar purposes.

4.4 Redressing violations

As discussed throughout the paper, forced sterilization constitutes a *prima facie* violation of the reproductive rights of women and constitutes discrimination. We also demonstrated that the violation cannot be justified based on rules of limitation of rights as it is not the last resort and also is disproportionately invasive. The next question therefore is on how to help victims of this serious violations of human rights enforce their rights.

One of the main ways to advocate for health and human rights is to lodge complaints or file reports with regional or international human rights mechanisms. These mechanisms were

[188] As above
[189] General Comment 16/32, in ICCPR/C/SR.749, March 23, 1988, para. 4. *Nicholas Toonen v Australia*, Human Rights Committee, 50th Sess., Case No. 488/1992, UN Doc CCPR/C/50/D/488/1992, Para 8.3.

established to enforce governments' compliance with the regional and international human rights treaties they have ratified.[190]

States should take all the necessary precautionary measures to preclude possibilities of forced sterilization particularly through creating awareness within patients as well as service providers including health professionals. But once forced sterilization has been undertaken, the only remedy available to the victim is reparation for the loss she suffered. For this, victims have to have recourse to domestic recourse mechanisms first and then move on to regional or international mechanism, if dissatisfied or the domestic recourse mechanism proves inefficient. In this regard, the African Commission provides a viable alternative particularly as anyone, including NGO, may take action on behalf of victims without a need to show direct interest in the case.

Since all the States have not made a declaration accepting the Competence of the African Court of Human and Peoples' Rights to receive complaints by individuals and NGOs with observer status in the African Commission in accordance with article 34(6) of the Protocol establishing the Court, the Commission may institute action in the Court as authorized under article 5(1)(a) of the Protocol. Before resorting to the Commission, however, victims should first comply with the rules of admissibility of the Commission as prescribed under articles 55 *et seq* of the ACHPR using the domestic legislation on non-discrimination. While the ideal situation is to have an explicit reference to non-discrimination on the grounds of actual or presumed HIV status, most constitutions do not do so as they were written and adopted before HIV and AIDS become a major pandemic. However, most constitutions have a non-discrimination or equality clause that outlines the grounds for non-discrimination. The grounds usually include race, gender, political affiliation and disability, among others. In many countries, HIV and AIDS are considered 'analogous' grounds and are considered as grounds for non-discrimination; As such, looking at the status of domestication of international instruments in some countries, they can be enforced domestically.

The Commission should also raise questions on the measures taken to deal with forced sterilization while analyzing State reports.

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[190] Namibia ratified the African Charter which establishes the African Commission on 30 July 1992; South Africa on 9 July 1996; Uganda on 10 May 1986; Zambia 10 January 1984; and the Democratic Republic of Congo 20 July 1987. Of all these countries, only DRC is not party to the African Women's Protocol.

In addition to reparations, those responsible for the forced sterilization should be held accountable criminally or civilly or both as appropriate. This is a consequence of the rights of victims to access to justice, which requires States to adequately investigate and punish perpetrators of human rights.[191]

4.5 Conclusion

According to the WHO, health is broadly defined as a state of complete physical, social and mental well-being, not merely an absence of disease or infirmity.[192] It is further stated that the enjoyment of the right to health is a fundamental right for all. Stigma and discrimination, barriers to controlling one's fertility, unmet family planning needs and lack of access to contraceptive services, restrictive abortion laws, mandatory HIV testing, unavailability of female controlled prevention methods, and coerced or forced sterilization are all issues confronted by women living with HIV thereby threatening their human rights.

Considering the level of interference regarding the enjoyment of the human rights of people living with HIV, forced sterilization is not a reasonable and justifiable measure to control the spread of HIV/AIDS. The fact remains that sterilization was historically used for discriminatory purposes, for instance 19th Century German Law prohibited women who did not meet State-defined standard of racial purity from having children while at the same time prohibiting women with desired racial purity access to abortion, makes it even more unreasonable and hence unacceptable.[193] Moreover, forced sterilization should not even be a last resort to limit transmission. It is not as such necessary to limit the rights of women as ARV drugs can be equally used to achieve the stated purpose of preventing transmission to the newborn.

Article 14 of African Women's Protocol[194] provides that States should respect and promote women's right to control their fertility, decide the number and spacing of her children, choose any method of contraception, protect themselves from sexually transmitted infections including HIV/AIDS, and legally abort in certain situations and benefit from family planning.

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[191] See for instance, the case of *Velásquez Rodriguez v. Honduras* Inter-American Court of Human Rights Series C. No. 4 (1988) Judgment of 29 July 1988, and *Ipek v. Turkey* European Court of Human Rights Application No. 25760/94 Judgment of 17 February 2004

[192] The Constitution of the WHO was adopted by the International Health Conference, New York, 19-22 June 1945; opened for signature on 22 July 1946 by the representatives of 61 States; 14 UNTS 185.

[193] RJ Cook and S Howard 'Accommodating women's difference under the women's anti-discrimination convention (2007) 56 *Emory Law Journal* 1039, 1072.

[194] Protocol to the ACHPR on the Rights of Women in Africa (2005).

Forced sterilization as public health measure violates this provision. Also, it will have a negative impact on health care access of women because they will be conflicted about availing themselves to neo-natal care services, thus endangering their own health, the health of their unborn child and the community at large.[195] Considering that Namibia, South Africa, Zambia, and the Democratic Republic of Congo are parties to the ACHPR, they have to be held accountable for the violation of the rights of their citizens through initiation of cases in the African Commission and the African Court on Human and Peoples' Rights and other appropriate international judicial bodies.

[195] Viljoen and Precious (n 20 above) 46.

Chapter 5: Conclusion and recommendations

5.2 Recommendations

It is recommended that an investigation team or fact finding mission be sent to these reported countries by the African Commission in order to ensure employment of appropriate measures to protect the reproductive rights of HIV positive women.

The States must take legislative and administrative measures in order to effectively protect the rights of HIV positive women. Also, they must provide human rights education for HIVpositive women, civil society, and health care providers.

Voluntary counselling and testing should be the recommended testing regime. Where provider initiated testing and counselling is adopted, it must not single out pregnant women and must be conducted under rigorous conditions of pre- and post-test counselling and the minimum information as outlined in the WHO Guidelines to ensure informed consent.

Mechanisms for redress should be established if these conditions are not met. The respect for voluntary and informed consent within PMTCT and sterilization of HIV positive women must be considered a precondition to any further treatment.

Considering that Namibia, South Africa, Zambia, the Democratic Republic Congo are parties to the ACHPR and the victims are protected by the Charter, they have to be held accountable for the violation of the rights through the African Commission and the African Court of Human and Peoples' Rights and other international bodies.

Nevertheless, as accessibility of the drugs in developed countries is mainly supported by donor funding, it is also important to conduct a study on the impact of the global financial crises on access to antiretroviral drugs and take measures to alleviate the impacts of the crisis.

5.1 Conclusion

Forced sterilization has its logical base in societal values and norms which perceive HIV positive women as "vectors of the disease", especially when pregnancy reveals their "questionable judgment and morality" given that they had unprotected sex, risking transmission of the virus to

themselves or their unborn children.[196] As a consequence, the inclusion of sterilization as a method of preventing mother-to-child transmission of HIV virus is considered acceptable.

However, forced sterilization of HIV positive women has enormous negative social consequences as the level of exposure to stigma and discrimination is double, first because the woman is HIV positive and second as she cannot bear children. HIV and infertility are two fonts of stigma as they undermine the patriarchal society which views childbearing as a supreme value.

The enjoyment of the right to health is a fundamental right of all.[197] Nevertheless, stigma and discrimination, barriers to controlling one's fertility, dignity and freedom contradict and consequently violate all the provisions which protect those rights.

Therefore, forced sterilization as a measure of preventing mother-to-child transmission is not a reasonable and justifiable measure to control the spread of HIV virus. It starkly contradicts with the reproductive rights of women, the right to liberty and privacy of women guaranteed in countless international and regional institutions. Also, it may have unintended negative consequences on the health care access of women as it might provoke resort to unhygienic traditional health care which might have fatal consequences. In other words, their only option will be to avoid the neo-natal care service which endangers their own health and future, the health of their unborn child and the community at large.[198]

Therefore, it is clear that forced sterilization represents failure of States to protect and respect the individual rights provide in international and regional instruments which they are party to. Consequently, there is a need to use the established mechanisms to enforce governments' compliance with the regional and international human rights treaties they have ratified as mentioned above.

Sterilization can be considered as an acceptable measure to stop the transmission of HIV virus only if it respects the principle of voluntary and informed consent. It must be considered only after the patient has full knowledge and understanding of the process, benefits, risks, and other

[196] Stefiszyn (n 140 above)
[197] The Constitution of the WHO was adopted by the International Health Conference, New York, 19-22 June 1945; opened for signature on 22 July 1946 by the representatives of 61 States; 14 UNTS 185.
[198] Viljoen & Precious (n 20 above) 46.

options of treatment available and the possible physical and social consequences. As such, there is nothing legally wrong with consensual sterilization.

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