

**Rights and choices of women living with HIV: A study of rural women resident in the  
eThekweni district**

By

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As the candidate's supervisor I have/have not approved this short dissertation for submission.

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## ABSTRACT

This study investigates the knowledge women living with HIV in South Africa have of their rights and it analyses the ways in which stigma prevents these same women from accessing their rights. Rights are defined as legal, social, or ethical principles of freedom or entitlement; that is, rights are the fundamental normative rules about what is allowed of people or owed to people, according to some legal system, social convention, or ethical theory. The study draws on qualitative data collected using in-depth interviews and focus group discussions with women from eThekweni district, in KwaZulu-Natal. In total, four focus group discussions and 6 in-depth interviews were conducted with women aged between 24- 63 years and in-depth interviews with 2 key informants. In analysing the data the critical feminist paradigm was used and the focus was on social exclusions.

The findings of the study suggest that women living with HIV lack information and are not aware of their rights. This study suggests that stigma hinders women from accessing or enjoying their rights. The findings of the study also suggest that women living with HIV are excluded due to their gender. Furthermore, the socioeconomic status of women living with HIV is further exacerbated by their status. This study found that socioeconomic status hinders women from accessing their rights, particularly around reproductive health issues. Rights of women living with HIV are violated in different contexts by different people including family members and there are certain mechanisms which are used to exclude them. The mechanisms used in violating the rights of women interviewed include not specifically asking for her consent, not adequately informing her, withholding necessary service and coercion.

Furthermore, with the lack of information, campaigns within communities to provide relevant and sufficient information to community members with the aim to fight stigma and discrimination need to be initiated.

*Key words:* eThekweni district, women, stigma, rights, HIV

# COLLEGE OF HUMANITIES

## DECLARATION - PLAGIARISM

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## ACRONYMS AND ABBREVIATIONS

DoH	Department of Health
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
HIV	Human Immune-deficiency Virus
TB	Tuberculosis
BP	Blood Pressure
VCT	Voluntary Counselling and Testing
IPPF	International Planned Parenthood Federation
STIs	Sexually Transmitted Infections
MTCT	Mother-to-child transmission
PMTCT	Prevention of mother-to-child transmission
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organisation
PAHO	Pan American Health Organization
OHCHR	Office of the High Commissioner on Human Rights
ICCPR	International Covenant on Civil and Political Rights
TAC	Treatment Action Campaign
UDHR	Universal Declaration of Human Rights
SAA	South African Airways
SASSA	South African Social Security Agency
MDGs	Millennium Development Goals
UNFPA	United Nations Population Fund
VAW	Violence Against Women
ICASO	International Council of AIDS Service Organization
KZN	KwaZulu-Natal
ICW	International Community of Women Living with HIV/AIDS
PLHIV	People Living with HIV
IDP	Integrated Development Plan
SRHR	Sexual and Reproductive Health Rights

HRI	Her Rights Initiative
FGD	Focus Group Discussion
IDI	In-depth Interviews
KI	Key Informants

## **DEFINITION OF ZULU TERMS**

*Irherheba* can be defined as an enormous paper.

*Ngihambangizengitshikize* meaning that one walks with pride.

*Siqoma njalo* means that one (women in this case) dates different men all the time.

*IsiZulu asitolikwa* means that zulu is so clear, it needs no interpretation.

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# CHAPTER ONE

## INTRODUCTION

### 1.1 Background

Rights are a sensitive issue in South Africa, largely as a result of the history of the country when the apartheid system allocated certain rights to groups, based on their racial categorisation. In 1994, South Africa had its first democratic election which led to the drafting of a new constitution. The new constitution was drafted and was adopted in 1996; this constitution embraced the principle of an inclusive vision of rights for all (The Republic of South Africa, Act 108 of 1996).

In the International arena, 1994 was the year of the International Conference on Population and Development held in Cairo, Egypt. The conference was concerned with issues of women's reproductive health and rights. This was being driven by the fact that women cannot fully access some rights if they are deprived reproductive freedom. Included in these rights were employment and education rights. The key to full access of health and reproductive rights is health services of better quality. This can start by improvement of family planning methods accompanied by relevant information, education and counselling. The right to information and education stated in the International Planned Parenthood Federation (IPPF: 1) of 1996, "relates to sexual and reproductive health and includes access to full information on the benefits, risks and effectiveness of all methods of fertility regulation, in order that all decisions taken are made on the basis of full, free and informed consent".

The Charter on sexual and reproductive rights of the (IPPF) of 1996, states that women have a right to life. This means that no woman should have her life put at risk because of pregnancy. The charter also highlights the right to privacy by referring to the fact that, "all sexual and reproductive health- care services should be confidential, and all women have the right to autonomous reproductive choice". In addition, women have a right to choose whether or not to marry and to found and plan a family; they also have a right to decide whether or when to have children.

The State of South Africa's Population Report 2000, reports that in South Africa sexual and reproductive rights together with access to sexual and reproductive health care are founded

by strong policy framework. Like any another country, South Africa is also guided by the constitution. This constitution states that “everyone has the right to access to health care services, including reproductive health care” (Constitution of the Republic of South Africa, Act 108 of 1996: 1255).

The Office of the Premier (2007) drafted a strategic plan on Human Immune-deficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS) and Sexually Transmitted Infections (STI's) for a five year period from 2007 to 2011, for KwaZulu-Natal. The strategic plan outlined interventions that government and its partners commit themselves in the fight against HIV and AIDS. One of the goals that DOH highlighted in the plan is to ascertain public knowledge of and adherence to the existing legal and policy framework by ensuring the following: adherence to human rights by service providers, and a supportive legal environment for the provision of HIV and AIDS services to marginalized groups (in this case the marginalised will be women). Women experience marginalisation in terms of gender, class and age. Women qualify as a marginalised group because they are likely to face discrimination or other human rights violations in communities.

The strategic plan (2007) has a goal to reduce vulnerability to HIV infection. To achieve that goal the plan will accelerate programmes empowering women and also educating men and women on general human rights as well as women's rights in particular. This includes the boy and girl child. The mother-to-child transmission (MTCT) of HIV reduction is one of the goals in this plan. The reduction will be done by widening MTCT services and take into account other related services and target groups. Furthermore, the DOH intends scaling up coverage and improving quality of prevention of mother-to-child transmission (PMTCT) services to reduce MTCT to less than 5%. This can be helpful to HIV positive women who chose to become pregnant since not all positive women will be interested or thinking about having children.

However, it is important to note that it is not clear that the rights and strategies contained in these documents are actually accessed by HIV positive women, as it has been noted that as a result of their status, their sexuality is neglected (IPPF, 1996). HIV positive women lack access to information and counselling on options that will help them make fully informed decisions about whether or not to have children (ibid).

## **1.2 Outline of research problem**

The 1996 South African Constitution stipulates different rights that South African citizens have. These include, but are not limited to the following rights: equality, human dignity, life, privacy, health care, social security and information. At times, due to marginalisation of different kinds, these rights are usually taken away from citizens. In South Africa, HIV is frequently high and women are the ones leading in this frequency. “The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO) estimated the number of people living with HIV at the end of 2006 to be 39.5 million worldwide. While approximately 10% of the world's population live in sub-Saharan Africa, an enormous 64% of all people living with HIV live in this region - including 77% of all women living with HIV” (HIV & AIDS and STI Strategic plan for South Africa, 2007-2011:17).

“Women bear the brunt of the epidemic of HIV and AIDS. Women account for 55% of people living with HIV and AIDS in South Africa” (HIV & AIDS and STI Strategic plan for South Africa, 2007-2011: 28). HIV continues to affect women in South Africa but not much is done to ensure that there is adequate awareness of rights to these women.

## **1.3 Motivation and purpose of the study**

In the struggle against HIV, it has become clear that human rights are essential to effective national responses to HIV. Where human rights are not protected, people are more vulnerable to HIV infection, they experience stigma and discrimination, become ill, become unable to support themselves and their families, and if not provided treatment, they die (UNAIDS and OHCHR, 2007). With the gender norms in societies related to masculinity leading to gender inequality has made women become more vulnerable to HIV/ AIDS.

As the number of women infected with HIV in SA is increasing daily, there is growing demand for education on rights. However, the extent to which women are aware of and access their rights is not clear. Also, there is lack of data documented about the influence of knowledge of rights on the choices that women living with HIV make. In South Africa, there is lack of studies that investigate the impact of stigma on women's access to rights and their ability to make choices. Therefore, this study aims to document knowledge of and access to rights and also how issues such as stigma prohibit the way women living with HIV can access their rights. For the purpose of this study, focus was given to sexual and reproductive rights as well as basic human rights; such as the right to health care, right to education, right to shelter, and others.

## **1.4 Why focus on women in particular?**

Prior to looking at the intended objectives and how they were achieved, it is important to highlight why the study focused on women instead of looking at the accessing of rights by HIV positive individuals in general. “Young women (15-24 years) are three times more likely to be HIV-infected than are young men and in 2008, HIV prevalence among young women aged 20-24 years was 21% compared to 5% among young men” Rispel and Popay (2009:90).

The most vulnerable groups are those of young women as they stand double the chance of getting infected when compared to young men. “In Africa, sex and sexuality are still shrouded in mystery, resulting in inadequate information or services, especially for those most vulnerable” (Revell: p2, Trust Africa Conference Report).

## **1.5 Objectives of the study**

- To explore awareness and knowledge of rights of HIV positive women.
- To explore rights that HIV positive women have access to and take advantage of.
- To explore the experiences of HIV positive women when their rights are violated.
- To explore if and how stigma hinders women from accessing or enjoying their rights.
- To explore whether women perceive a connection between rights and choices, and how choice is informed by the knowledge of rights.
- To explore how knowledge of rights, impacts on the health seeking behaviour of HIV positive women.
- To explore how social exclusions are perpetuated in the lives of HIV positive women.

The study wants to answer the following key research questions:

- Do HIV positive women have knowledge and awareness of their rights?
- How do HIV positive women describe their rights?
- How do HIV positive women access these rights?
- Does stigma hinder women from accessing or enjoying their rights?

- Which rights are HIV positive women taking advantage of and which are the ones they are not taking advantage of?
- Is there any information or awareness raised concerning reproductive rights?
- Is there a connection between their rights and choices and how does the knowledge of their rights inform their choice?
- How does knowledge of rights impact on the health seeking behaviour of HIV positive women?
- How are social exclusions perpetuated in the lives of HIV positive women?

## **1.6 Theoretical framework**

This study uses a critical feminist paradigm, focusing specifically on social exclusions as the theoretical framework. “Feminist research is an established type of research, which has the specific purpose of studying women and their status in the community. Feminist research is an emancipatory inquiry focusing on enlightenment and on social change. This means that it does not only document aspects of reality; it also takes a personal, political and engaging stance to the world” (Foundations of social research, n.d.:54).

### **1.6.1 Definition of Social Exclusion**

Silver (2007) defines social exclusions as a phenomenon which its interest is in social relations, focussing on the sharing, governing and distribution of social resources. Chen (2000) comments that these exclusions provide socially reproduced inabilities in certain groups of people to play a role in their communities and participate in politics. This is caused by their social and poverty status. Chen (2000) further comments that being in a disadvantaged position, and the inability to attract social cohesion in order for one to escape that disadvantageous state defines social exclusion.

Khosla (2009: 588) offers yet another definition, she sees exclusion as “an accumulation of confluent processes with successive ruptures arising from the heart of the economy, politics and society, which gradually distances and place persons and groups in a relationship of inferiority in relation to centres of power, resources and prevailing values”.

### **1.6.2 Implications of Social Exclusion**

Silver (2007) sums exclusion’s definition into three expressions and those are; loss of social status, lack of recognition and humiliation. Cultural boundaries and social institutions can be

used to express social exclusions in a manner that those found to have gone beyond these boundaries may consider themselves excluded (ibid). Hickey and Du Toit (2007) support this in their article when they speak of cultural appropriateness and inappropriateness being intertwined with allocation and deprivation of resources. It is therefore difficult or rather challenging for those who have lost their social entitlement to claim for what is theirs in the society.

In Silver's article (2007), he says that these exclusions deprive victims from partaking in society activities and may also prevent them in access of information, resources and social recognition. These people end up in locked situations when it comes to political and community participation as they have neither power nor influence (Adato et al., 2006). They therefore have no say in social capital (ibid). When they are unable to participate in social capital, they are in a position where they are unable to access their rights fully.

### **1.6.3 How Exclusion is created**

Adato et al (2006) view the exclusion acts as acts based on discrimination, rejection, eviction and ineligibility. People who suffer from social exclusions share the same feelings as those who suffer from the above-mentioned terms. Bhalla and Lapeyre (1997) analyse the operation of social exclusion as one that is not only individual based but also policies and institutions based. Gore (cited in Hickey and Du Toit, 2007) puts exclusion from political spaces and organisations as the major indicator of social exclusions and he says this is mostly found in sub-Saharan Africa.

According to Bhalla and Lapeyre (1997) political exclusion is defined as a deprivation of rights, participation and organization of social transformation. Wood (2003) highlights the importance of exploring nature and terms with which the poor participate in political spaces, discourses and structures. This is due to lack of ability, in general, of the poor to express themselves and their interest in political spaces. When, by people's disadvantage, one is unable to partake in public spaces' activities and social intercourses, it is said that s/he is suffering from social exclusion. This does not only affect them externally but also from the inside, which leads them to their voluntary and involuntary withdrawal from being part of the community (Hickey and Du Toit, 2007).

De Haan (1999) argues that Social exclusions have nature of multidimensional deprivation and Silver (2007) says, in support of De Haan, forces of exclusion can exist as playing out differently at different times backing up and sustaining each other. Exclusion is a process of

social isolation that strips away dimensions of social involvement. Social exclusions may mean the lack of social ties to social structures, including state services and institutions (Bhalla and Lapeyre, 2007). Exclusion may also mean denial of rights of citizenship and to communities. Exclusions are also about power relations in a society, in terms of who has power to decide on how resources are shared, who has access to such resources, and who should be in and out of the access brackets (Adato et al. 2006).

According to Adato, et. al (2006) social exclusions exist because of enforcement of rights that is lacking and also because of discriminatory practices. Discriminatory issues are connected with being a woman as well as the women's HIV positive status in this research's context.

#### **1.6.4 Stigma and Social Exclusions**

Stigma and social exclusions may co-exist. It is said that stigma associated with HIV may exacerbate exclusions.

For example, vulnerable women who are poor may face exclusion from the economy, political systems and general community life (Khosla, 2009). This particular exclusion might increase these women's vulnerability to HIV infection. Their exclusion will increase if their HIV status becomes known (Ibid.). Thus, exclusions are fuelling and sustaining each other. This point is largely becoming prominent in the South African context where the level of poverty and marginalisation is high, such that it becomes an issue to theorise about social exclusions, because the majority of people are excluded anyway (Adato, et. al. 2006). As a result, this indicated that HIV positive women may actually be excluded because they are poor and that they will be excluded further because they are HIV-infected which can be seen to reflect deviant behaviour, a fact that depreciates their social value.

#### **1.7 Organisation of the dissertation**

This dissertation consists of five chapters. Chapter one is the introduction that comprises; the background of the research, the objectives and aims of the study, outlines the research problem and motivation for the study, and the theories informing the study. Chapter two reviews the literature and looks at various rights that women living with HIV are entitled to, a description of how gender rights are a particular issue for women living with HIV, and the barriers to those rights. Chapter three outlines the methods used for data collection and data analysis. Chapter four presents key findings of the study. Chapter five presents the discussion of the results, the recommendation and the final conclusion.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 Defining human rights

The concept of human rights is one of the few moral visions ascribed to internationally (Bunch, 1990: 486). Generally, rights are defined as legal, social, or ethical principles of freedom or entitlement; that is, rights are the fundamental normative rules about what is allowed of people or owed to people, according to some legal system, social convention, or ethical theory (Baase, 2013). On the other hand, human rights are defined as “a set of moral and legal guidelines that promote and protect recognition of our values, our identity and ability to ensure an adequate standard of living” (Australian Human Rights Commission, 2009:1). Furthermore, human rights are those rights that people have simply because they are humans regardless of their gender, age, and race. Other simple definitions of human rights include the recognition and respect of people’s dignity as well as the basic standards by which we can identify and measure inequality and fairness. Promotion of human rights is a widely accepted goal and thus provides a useful framework for seeking redress of gender abuse (Bunch, 1990).

The Commission on Human Rights highlighted the necessity and the vitality to provide assistance to countries on how to take strong steps to protect human rights in the context of HIV. For years in South Africa, there has been much discussion regarding human rights but not much has been seen that directly speaks to women. “Article 2 of the 1966 International Covenant on Civil and Political Rights together with the Universal Declaration of Human Rights, requires states to protect the rights and freedoms of all persons regardless of race, colour, sex, language, religion, political or other opinion, national or social origin, economic status, birth or any other social condition” (PAHO, 2008:3). This article excludes and does not say much about women. Eleanor Roosevelt and the Latin American women fought for the inclusion of sex in the Declaration of Human Rights with an intention for it to address the problem of women’s subordination (Bunch, 1990).

At the end of 2010, people living with HIV globally were estimated to be 34 million as opposed to an estimation of 22.9 million in Sub-Saharan Africa. Furthermore, women are said to be more affected in Sub-Saharan Africa and they account for 59% of all people living with HIV. Women appear to be more vulnerable to HIV infection. UNAIDS and OHCHR

(2006) confirms that vulnerability to HIV infection and to impacts of HIV are exacerbated by the violation of human rights including discrimination against women. One's HIV status is recognised by the international human rights system as a prohibited ground for discrimination. The human rights perspective contends that the rights and dignity of individuals must be promoted and protected, focusing more on those that are discriminated against or those whose rights are interfered with (UNAIDS and OHCHR, 2006).

Mbonu et al (2009:10) states that, "many cultures consider ignorance of sexual matters as a sign of purity, making women reluctant to seek reproductive health information and services". In the international human rights framework it is highlighted that national governments must put into place laws, policies and practices that give access to HIV positive women and men to fulfilling their sexual and reproductive health needs and aspirations. "States have a legal obligation to promote and protect the human rights of people living with HIV, including their rights related to sexual and reproductive health" (Gruskin et al, 2007:5). If much attention is paid to human rights in shaping the response to HIV and sexual and reproductive health opportunities can be created.

Sexual and reproductive health services are not only family planning clinics with some treatment of sexually transmitted infections. "The five core components of sexual and reproductive health care are: improvement of antenatal, perinatal, postpartum, and newborn care; provision of high-quality services for family planning, including infertility services; elimination of unsafe abortions; prevention and treatment of sexually transmitted infections, including HIV, reproductive tract infections cervical cancer, and other gynaecological morbidities; and promotion of healthy sexuality" (Glassier et al, 2006:1596).

## **2.2 Description of why human rights may be a particular issue for HIV positive people**

In the struggle against HIV, it has become clear that human rights are essential to effective national responses to HIV. Where human rights are not protected, people are more vulnerable to HIV infection. Where the human rights of HIV-positive people are not protected, they experience stigma and discrimination, become ill, become unable to support themselves and their families, and if not provided treatment, they die (UNAIDS and OHCHR, 2007). People living with HIV/AIDS are the stigmatised in the world. The human rights of people living with cancer or other life threatening illnesses are not such an issue because they are not stigmatised when compared to those living with HIV/ AIDS. The community is more

understanding and supportive towards people suffering from cancer and other life threatening illnesses. Simbayi et al (2007: 1823) writes “AIDS stigmatising beliefs are the product of multiple social influences including attributions of responsibility for HIV infection and beliefs that individuals with HIV/ AIDS are contaminated and tainted”. Furthermore, because sex is one of the ways in which HIV is transmitted through, there is that perception that those who acquire it acquire it because they are promiscuous, therefore being stigmatised even more.

### **2.3 Right to confidentiality**

Article 17 of the International Covenant on Civil and Political Rights (ICCPR) sets out the right to privacy. According to this article this right covers legal responsibilities to respect physical privacy (eg, the legal responsibility to look for informed consent to HIV testing) and the need to respect the privacy of personal information e.g, information that has got to do with person’s status (UNAIDS and OHCHR, 2007). It goes without saying that the right to confidentiality has to a certain extent been infringed. Confidentiality is very important and once it is breached it contributes to enhanced stigma and discrimination towards people living with HIV but mostly it places people at risk of other human rights violation.

In South Africa there have been cases where people living with HIV have had their status disclosed without their consent especially by health workers, be it nurses, doctors or councillors. The Common Law of Confidence established the need for confidentiality in healthcare. For NAT report “..... a medical professional is obliged to keep personal information about a patient confidential, and is only entitled to share that information in two situations: with the patient’s consent or if the disclosure is in the ‘public interest’” (NAT, 2009:4). Furthermore, a patient may give consent for their information to be shared with another healthcare professional for purposes of treatment or care. One of the cases where a patient had their status being disclosed without their consent is that of McGeary, he “was a patient infected with HIV, which was then seriously stigmatised and widely misunderstood disease. He lived in Brakpan. His right to confidentiality was violated by his doctor, who in 1991, told two other people of his HIV status without his consent” (Mbali, 2005:15).

Another example is that of Mumbai in India where it was reported that healthcare workers often disclosed a woman’s HIV diagnosis to her husband in the belief that the woman herself will not understand (Esplen, 2007). Breach of confidentiality has serious implications on women as they may be discouraged to test for HIV, to seek treatment or even be open about

their status knowing there is a possibility of their status being made public without their consent. In a Swaziland workshop participants pointed to confidentiality and disclosure concerns and noted that it is difficult for a woman to maintain an ARV (antiretroviral) treatment regimen without disclosing her status (USAIDS, 2006).

## **2.4 Right to treatment**

“In the HIV/AIDS epidemic, both a person’s sex and gender determine the extent to which he or she will be vulnerable to infection and his or her ability to access available treatments” (Nangia, 2006:174). UNAIDS (2000) cited in Maharaj and Roberts (2006), reported that, “the disease has a strong gendered dimension, with an estimated twelve to thirteen women infected for every ten men, and an average rate of infection that is five times higher for young girls than young boys in some countries in the region”. The above statement does not imply that it is only women who get infected by HIV, but mainly it is because of inequalities that exist in societies that women find themselves in vulnerable situations. Therefore, more women than men require access to treatment.

According to Maharaj and Roberts (2006: 213), “the right to health implies that the government is responsible for prevention, treatment and control of diseases and the creation of conditions to ensure access to health facilities, goods and services required to be healthy”. “The South African Medicines and Related Substances Control Amendment Act (No. 90 of 1997) aimed to provide a legal framework for national drugs policy and contained measures to make medicines more affordable and accessible” (Grown et al, 2006:221). The Prevention of Mother-to-child Transmission programme was seen as the first step towards state-sponsored anti-retroviral treatment plan. Treatment Action Campaign (TAC) played a significant role in demanding government to be involved in the HIV/AIDS struggle so that it can realise the need for roll out of treatment. A recent longitudinal study conducted in South Africa found that, as rates of diagnosis rose, an increased proportion of newly diagnosed HIV infected people were successfully followed up over time and started on ART once eligible (Cáceres et al, 2008). In Peru a year after ART inception, the National ART programme had achieved coverage for 50% of those who needed treatment but were not receiving it. Two and a half years later, coverage reached 90%. Congress modified the AIDS legislation in 2004, making ART a right (Cáceres et al, 2008).

According to Leclerc-Madlala (2005:850) “A total of 23,000 people (as opposed to 53,000) were receiving anti-retro viral treatment in the public sector, with Gauteng province leading

in the treatment of 9,691 patients, Western Cape treating 6,188, KwaZulu-Natal 4,964, North West 2,797, Eastern Cape 2,749, Free State 945, Limpopo 729, Northern Cape 515 and Mpumalanga 754". Furthermore, "some 6.6 million people in low and middle-income countries were receiving treatment at the end of 2010" (UNAIDS, 2011:2). Amongst participants who participated in workshops with different countries, "some South African participants reported in the validation workshop that at times their access to treatment programs is contingent on other factors, such as agreeing to use certain contraceptives" (USAIDS, 2006:).

## **2.5 Right to employment**

Article 23 of the UDHR and articles 6 and 7 of the International Covenant on Economic, Social and Cultural Rights, entails the right of every person to access employment without any precondition except the necessary occupational conditions. The right to employment is a very important right as it allows people to earn and sustain their livelihoods. However, this right has been violated in different incidences where people especially those living with HIV are likely to be mistreated or even lose their jobs once their sero-positive status is known. Discrimination and stigma surrounding HIV/AIDS does to a certain extent affect the ability of HIV positive women to find and keep work especially in cases where one needs to present their HIV results before being considered or offered a position.

Esplen (2006) points out that women may be fired by their employers after receiving an HIV diagnosis but sometimes that may happen after compulsory testing. In addition to this, when an applicant or employee is required to undergo mandatory testing for HIV and as a result dismissal or refusal of employment based on positive results is a violation of this right to employment (UNAIDS and OHCHR,2007). Despite employers dismissing or denying HIV positive people employment, in some cases you may find other employers not being keen on having an HIV positive colleague. For example, in a survey of Canadians' attitudes about HIV/AIDS, almost one-third of participants indicated they would not be comfortable working in an office with someone who is HIV-positive or shopping in a store whose owner is HIV positive.

Furthermore, half of the participants said that people living with HIV/AIDS should not be allowed to serve the public in positions such as dentists or cooks (Elliot and Gold, 2005). Another case from South Africa is the one that took place in 2000 between Mr Hoffman and the South African Airways (SAA). Mr Hoffman applied for a job as a cabin attendant with

SAA and was required to get tested for HIV of which his results came back positive. That resulted in SAA denying giving Mr Hoffman the job claiming that part of his job involved travelling to different countries and he would need to have a yellow fever vaccination. His case was referred to Constitutional court where the court was requested to make a decision whether SAA had gone against Mr Hoffman's right to equality, dignity and labour practices. The court in its decision, decided that SAA had discriminated against Hoffman; that the discrimination was unfair and infringed his dignity and lastly being HIV negative was not an inherent requirement of the job being a cabin attendant; SAA should have taken greater steps to investigate how Hoffman's immune system could have dealt with travelling and the possibility of getting a strange disease.

## **2.6 Right to social security**

The enjoyment of this right is found in article 25 of the UDHR and in article 9 and 11 of the International Covenant on Economic, Social and Cultural rights, is essential to reducing the impact of AIDS on people living with HIV, families impoverished by AIDS and children orphaned or otherwise made vulnerable by HIV. "States should ensure that people living with HIV are not discriminately denied an adequate standard of living and/or social security services" (NAT report, 2007:9). South Africa is well known for its laws and regulations, however it has been vague which laws and regulations are applicable in the right to social security. The scope of coverage of the South African social security system is limited. There is no clear procedure or mechanism for enforcing social security rights. The South African Social Security Agency (SASSA) which has its fraudulent and corrupt reputation.

Furthermore, SA social security system has to a large extent been constructed around social assistance and social insurance meaning that mandatory contributory system of one kind or another or regulated private sector provision, concerned with the spreading of income over the life cycle or the pooling of risks whereas the latter refers to a state provided basic minimum protection to relieve poverty, essentially subject to qualifying criteria on a non-contributory basis (Mpedi, 2008). In South Africa people have to meet certain requirements to benefit from the social security system. However, for those living with HIV it has been a challenge for them to access a disability grant as they need the doctor to fill the form for them and them getting this grant depends on professional doctors assessment whether a person is fit to work or not. In most cases doctors refuse to fill the forms. "Those who have applied for social grants reported that they were still waiting for a response or that the doctor at the

hospital had refused to sign their application forms to declare them incapable of working due to their HIV status” (LAC, n.d:22).

## **2.7 Description of how gender rights are a particular issue for women living with HIV**

“In sub Saharan Africa women constitute 60% of people living with HIV. Gender norms related to masculinity encourage men to have multiple sexual partners and older men have sexual relations with much younger women” (WHO, 2013). Williamson (2009: 4) confirms that “The severity of the epidemic among women is related to the degree of gender inequality and their low social status”. While society may approve of men having multiple sexual partners, there is an expectation that women must have one partner otherwise they might be called names if they decide to have more than one partner. Society expects girls to maintain their virginity until marriage while the expectation differs for boys. It is through these norms that women become more vulnerable to HIV/AIDS. “Once infected, women and girls have limited means and power to access the care and support they need. HIV/AIDS vulnerability is gender-biased and mediated by factors that are largely out of women’s control. These factors include gender-based violence, imbalance in sexual power relations, unequal access to rights, discriminatory laws and policies, traditional norms and practices, poverty, and poor access to services” Williamson (2009: 3).

However, specific gender barriers when named, are more frequently articulated in relation to HIV-negative women than HIV-positive women. In addition, when documents do support the rights of people living with HIV/AIDS, they either articulate poorly or fail to address the barriers faced by women living with HIV (USAIDS, 2006). Williams (2009: 4) attests that “the South African situation starkly captures the particularly disproportionate vulnerability of young women and their limited power to protect themselves. National surveys of 15- to 24-year-olds showed that young women make up 77% of the 10% of people living with HIV nationally; and 16% of 15- to 24-year-old females were HIV-positive, compared with 4.8% of males in the same age group”. In order for women living with HIV to enjoy their rights there needs to be some kind of balance in the gender. Furthermore, social change is required to create the atmosphere of women’s rights to be embedded in the fabric of society as well as for these rights to be enforced.

### **2.7.1 Right to sexual health**

One of the important issues in sexual and reproductive health is access to contraceptives and use thereafter of those contraceptives. Literature suggests that overall accessibility of contraceptives and prevalence of condom use are likely to shape patterns of use among women living with HIV. According to Delvaux and Nostlinger (2007:47), “in countries with high HIV prevalence and relatively high contraceptive prevalence rates, such as Zimbabwe or South Africa, higher contraceptive use among women living with HIV is also more likely though greater condom promotion and use will be needed”. In most cases, the same contraceptive options are available to couples irrespective of their HIV status. Delvaux and Nostlinger (2007) postulate that, although women living with HIV make up 59% of all adults living with HIV in sub-Saharan Africa, there is still limited evidence of the extent or type of contraceptive used by them.

Directive counselling on contraceptive methods is also common, and positive women often face pressure to have an abortion or sterilisation (Esplen, 2007). Often, when women are given information about the type of contraceptive method to use, focus has mainly been on use of those contraceptives to limit fertility. In case of a discordant couple (only one partner is positive), the possibility of infection is a concern whereas when the couple is concordant (both partners are positive), the possibilities of re-infection are a concern, these have to be taken into consideration. Relevant information and counselling is more than necessary in situations as above. Dual protection is the most recommended method of contraceptive, which means one is not only protected from pregnancy but also from any sexual transmitted infections. “Understanding of dual protection and dual method use for HIV discordant couples who wish to prevent pregnancy and HIV transmission is also limited among providers” (Bharat and Mahendra, 2007: 96).

As stated by Delvaux and Nostlinger (2007: 50), “data suggest that dual use is more likely to occur if partners are concerned about unfavourable consequences of sexual activity (i.e. unwanted pregnancy and/or HIV/STI infection)”. Improving reproductive health is central to achieving the Millennium Development Goals (MDGs) on improving maternal health, reducing child mortality and eradicating extreme poverty (Williamson et al, 2009). This requires that women have access to safe and effective methods of fertility control. The promotion of family planning, so that women can avoid unwanted pregnancy, is central to the

World Health Organisation (WHO) work on improving maternal health and is core to achieving the MDG on this (Williamson et al, 2009).

In developing countries, maternal mortality is high, with 440 deaths per 100,000 live births (in sub-Saharan Africa, this figure reaches 920). One in three women give birth before age 20 and pregnancy-related morbidity and mortality rates are particularly high in this group. One quarter of the estimated 20 million unsafe abortions and 70,000 abortion related deaths each year occur among women aged 15-19 years, and this age group is twice as likely to die in childbirth as women aged 20 or over (Williamson et al, 2009). It is estimated that 90% of abortion-related and 20% pregnancy-related morbidity and mortality, along with 32% of maternal deaths, could be prevented by use of effective contraception (Williamson et al, 2009). In sub-Saharan Africa, it is estimated that 14 million unintended pregnancies occur every year, with almost half occurring among women aged 15-24 years (Williamson et al, 2009).

Studies have shown that in developing countries there is less use of modern contraceptives by sexually active adolescents when compared to developed countries. Williamson et al, (2009:2), writes that, “for example, 69% of adolescent women in a UK study reported a use of modern contraceptive method at most recent sex, compared with 12% in Mali, and in the US 54% of 15-19 year old females reported condom use at most recent sex, compared with 21% in Tanzania” (Williamson et al, 2009).

According to Mantell et al, (2009:369), “contraception, in particular, has been highlighted as a means to prevent HIV transmission from mother to child. Condoms are promoted to prevent both pregnancy and HIV transmission between sexual partners”. Consequently, coerced abortion and sterilization, plus pressure to use long-acting contraceptive methods, are not uncommon (Mantell et al, 2009). The International Community of Women Living with HIV/AIDS reported that some HIV infected women in the Democratic Republic of Congo, Namibia, South Africa and Zambia are sterilized without their consent or being pressured to consent (Mantell et al, 2009).

Due to the rapid spread of the HIV epidemic and STI's especially in South Africa, use of contraceptives on their own has called for a concern. It started to become a problem because those who used other methods of protection did not see the need to use condoms. According to Berer (2006: 162), “in places where barrier methods had been the only means of contraception, condom use fell off steeply and diaphragm production and use all but

disappeared”. This concern of rapid spread of HIV/AIDS epidemic calls for the education of both men and women as to which methods they can use to protect themselves from both the epidemic and unwanted pregnancy, which is known as dual protection. Berer (2006: 162) defines dual protection as the, “protection from unwanted pregnancy, HIV and other sexually transmitted infections”.

It is important to inform people about various dual protection methods that are available to them. As much as there are other methods made available, condoms still do remain the mainstay of dual protection. Both female and male condoms are the only single method that offers dual protection from both unwanted pregnancy as well as STIs including HIV/AIDS. The problem that would arise with condoms as a method of protection is that people fail to use them consistently. Most women still fear negotiating condom use with their partners and they leave this responsibility to men. When it comes to female condoms they have been well accepted and used. “Early studies of female condom acceptability reported high rates, ranging from 37% to 96%” (Hoffman et al, 2004: 140).

In South Africa, there is high HIV prevalence amongst the youth. The contradiction is that as much as there is high contraceptive prevalence there is also high teenage pregnancy prevalence. This can be attributed to inconsistency use of protective methods and also lack of access to reliable programmes. In South Africa, there are still communities who consider talking about sex to teenagers and youth as taboo and where health providers still question or judge youth who show an attitude of wanting to know about options that are available to them. This then means that the only time teenagers get to use any type of reliable protective and contraceptive method is after they have given birth to their first child.

Dual protection should be a priority to those who are still uninfected by HIV/AIDS. They should be able to choose any method of contraceptive they want to use in preventing unwanted pregnancy but they should also be encouraged to use condoms consistently. Any method they choose to prevent pregnancy should be used in conjunction with condoms. On the other hand those who are already infected with HIV, it is good to allow them to choose efficient, safe methods but most importantly methods that are going to prevent transmission of HIV. With HIV positive persons it would be better to encourage them to use methods that can stabilise the virus and condom use at all times. When they are at a stage where an HIV positive women wants to fall pregnant they can be counselled on proper reliable methods that can prevent transmission and reinfections of the virus after the virus has been stabilised.

### **2.7.2 Right to abortion**

In South Africa, the right to abortion or termination of pregnancy are among the rights accorded to women. A woman who has been pregnant for 12 weeks does not have to give reasons as to why she wants to terminate pregnancy whereas a woman who is 13-20 weeks can terminate after consultation with medical doctor who thinks that continued pregnancy would affect social and economic circumstances. This is not only specific to HIV negative but it's inclusive of women living with HIV. Like other women, women with HIV/AIDS may have unwanted pregnancies due to rape, contraceptive failure, lack of access to or partner refusal to allow use of contraception (de Bruyn, 2003). Even among women who are able to access contraceptives and negotiate their use, many women with HIV may seek to end an unplanned pregnancy.

When performed by qualified professionals in sanitary conditions, abortion is considered safe for HIV positive women (Esplen, 2007). However, issues surrounding unwanted pregnancy and induced abortion for HIV-positive women have received little attention (Esplen, 2007)). When information and access to legal pregnancy termination are lacking, HIV-positive women may be prevented from terminating unwanted pregnancies safely or at all. Researchers in Zimbabwe found that HIV-positive women may be ready to end childbearing, but often cannot put that decision into practice because they lack control over contraception and access to abortion, among other reasons due to the cost. However in Peru, abortion is only legal when the life of the woman is in danger (Cáceres et al, 2008).

deBruyn (2003) reports that, in Sweden, HIV testing is offered at almost all antenatal clinics but not all abortion clinics. Women found to be HIV-positive at abortion clinics are given the chance to reconsider their abortion applications but the HIV test results have not always been available at the time of the procedure (deBruyn, 2003). This may limit the choice that women have to terminate their pregnancy. In many countries information on the procedure of termination, as well as side-effects that those living with HIV might be confronted with has not been made available. Therefore, particular attention needs to be given to ensuring that HIV positive women know where safe, legal abortion is available, understand the abortion procedures being provided and their expected side effects, and are aware of the risks of undergoing unsafe abortions (UNFPA/WHO 2006). A study that was conducted in Nigeria found no difference between HIV-positive and HIV-negative women regarding a history of prior abortions and the decision to terminate a pregnancy (deBruyn, 2003).

### **2.7.3 Right to legal protection from violence**

The United Nations Declaration on the Elimination of Violence Against Women defines violence against women (VAW) as: "any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women– including threats of such acts, coercion or arbitrary deprivation of liberty, whether in public or in private life" (Soul City, 1999:5). Violence significantly adds to the vulnerability of women and marginalized groups to HIV. Violence has many facets, within the household this can include battering by an intimate partner, marital rape, dowry-related violence, and sexual abuse. Violence outside the home can include rape, sexual abuse, sexual harassment and assault.

For millions of women, the experience or fear of violence is a daily reality and, increasingly, so is HIV/AIDS. Studies from various countries have shown up to three fold increases in risk of HIV among women who have experienced violence as compared to those who have not (ICASO, 2007). Violence against women constitutes a violation of human rights and fundamental freedoms of the women. A study done on experiences of domestic violence with pregnant women in KZN found that domestic violence among rural pregnant women was high (31%) which was consistent with other studies. Studies in other African countries reported higher levels of violence, for example 57.1% in Uganda during pregnancy while 43% women in Zimbabwe reported experiencing physical violence in adulthood (Hoque et al, 2009).

### **2.7.4 Right to protection from sexual abuse and violence**

In South Africa, violence against women contravenes numerous constitutionally guaranteed rights, most significantly, the right to equality, which provides for equality before the law and the right to equal benefit and protection of the law. The criminal justice system in South Africa fails to respond adequately to incidents of violence against women. The system is structured in such a way that does not consider the rights of survivors. A woman who has been raped has to go through a tedious process before opening a case. They first have to go for medical examination and only after the doctor has confirmed the rape then a case can be opened. This process is in itself tedious and traumatic to rape survivors. Rape survivors in their attempt to get justice for themselves are faced with secondary victimization from police officers and other civil servants.

However, rape survivors have the right to be treated with respect and dignity at all times by doctors, nurses and police officers. Most importantly survivors have the right to be given full and accurate information about their health. They must be provided with the necessary medical treatment including anti-retroviral medicines that could reduce the risk of getting HIV. In terms of violence against women, Swaziland has enacted no policies or legislation concerning the administration of ARVs to rape victims (USAIDS, 2006). A study conducted in South Africa, found that women who experienced coercive sex were nearly six times more likely to use condoms inconsistently than those who did not experience coercion and, in turn, women with inconsistent condom use were 1.6 times more likely to be HIV infected than those who used condoms consistently.

### **2.7.5 Right to children**

Most women believe that experiencing parenthood is very crucial to understanding what it means to be human and is fundamental to their social identity. Having children is also an important source of security in old age, and may help women fight the dehumanising effects of living with HIV (Gutmacher Institute in Esplen, 2007). HIV positive women often have limited reproductive choices however, as decisions may be made for them by their husband, in-laws or health care staff. HIV positive women often get caught between pressures from health workers not to have children, and pressures from family members to have children (Gutmacher Institute in Esplen, 2007).

In some instances, there are women who are positive who face discrimination from health care workers only because they do not believe that they should have children. The health care workers discriminate against these positive women because of the risk that HIV will be passed on to the baby during childbirth or breastfeeding or out of concern for the child if its parents die prematurely from AIDS. Young HIV-positive women experience particular hostility from health workers with regards to having children, encountering dual criticism on account of being young and pregnant, and HIV positive (ICW in Esplen, 2007). However like any other women, women living with HIV have a right to have children regardless of their status so long they desire to.

### **2.7.6 Right to consultation in the development of policies and programmes**

To fully address the needs of women and girls living with HIV/AIDS, it is vital that policymakers and health practitioners prioritise these needs and be on familiar terms with the expertise of positive women themselves (Esplen, 2007). The South African government developed 8 principles known as Batho Pele principles. One of the principles is consultation, where users must be consulted to ensure representativeness. Consultation is a powerful tool that enriches and shapes government policies. However, in South Africa people at the lower ground are not consulted when policies are developed, only those who are in power have a say in policy and programme development.

Furthermore, the vulnerable groups for example the poor, women, and people living with HIV (PLHIV) who are mainly affected by these policies are not consulted in the process of these policies being formulated. These groups are made inferior at all times. In a study conducted with Swazi participants, many felt that they lacked a strong voice to enter the policymaking arena, noting that society largely ignores women's voices (USAID, 2006). They remarked that capacity building needs to be a two-way process so that governments, businesses, and organizations can learn how to shape meaningful involvement. Furthermore, participants felt that they lacked the skills, knowledge, or confidence to participate in policy formulation (USAID, 2006).

Consultation can be done through research in a form of questionnaires and interviews. However, participants in the Swazi workshop noted that they seldom, if ever, have the opportunity to be involved in developing prevention much less treatment materials; to monitor and evaluate HIV/AIDS related activities; to engage in research; to implement government programs; and to attend conferences and conventions. The involvement of HIV positive women in workplace policy development and implementation to ensure the retention and employment of HIV positive staff, including women, is essential (ICW in Esplen, 2007). To enable genuine involvement, Esplen (2007:21) suggests that, "governments and funders need to invest in the capacity of networks and organisations run by and for positive women to participate meaningfully in the policy-making process, through better funding, as well as by providing training in fund management, strategic planning, and administration, and giving emotional and moral support".

## **2.8 Barriers to rights**

### **2.8.1 Knowledge**

Amongst other things that women living with HIV are faced with is that when they go for antenatal care not many options are given to them about opting in or opting out of being tested. It is still not clear as to whether these women have a choice to opt out of being tested, in many cases services mostly in the form of counsellors have made it mandatory that women living with HIV get tested. “The opt-in model offers all women the option of choosing whether to be tested while the opt-out model informs women that they will be tested for HIV unless they specifically state that they wish to opt out” (Bharat and Mahendra, 2007: 96). The challenge is that opting-out does not necessarily mean they will not be tested, instead women are not told that they have a right to refuse being tested, which might result in coercion.

Findings from a study in Canada (Elliot and Gold, 2005) reported that even with the policy to use the opt-out model with women in one centre, some of the women did not know that they could opt out or even that they were being tested for HIV. In sub-Saharan Africa, justification for opt-out testing must rely on the expected medical benefits for those individuals being tested and treated. “These medical benefits hinge upon the ability of opt-out programmes to provide treatment to those HIV-infected people who would have otherwise remained undiagnosed” (April, 2010). In Africa, studies that have investigated the association to care rates when antenatal clinics introduced opt-out consent suggest that gap patients are linked to care as often as other patients.

Literature suggests that in settings where health care providers lack ample awareness and information about essential concepts to help HIV positive people with their sexual and reproductive health needs, women can be deprived of relevant information that will help them make informed decisions about what to do. HIV positive women lack access to information and counselling on options that will help them make fully informed decisions about whether or not to have children. “Women living with HIV/AIDS may also be deterred from returning to health clinics by the judgemental attitudes of health workers, who sometimes deny women the opportunity to give informed consent to HIV testing and treatment, violate their confidentiality, treat them with disrespect, deny them services, or push them to access services without providing comprehensive information about alternatives” (Esplen, 2007: 10).

Mantell et al, (2009:370) writes, “the International Community of Women Living with HIV/AIDS recently reported that some HIV-infected women in the Democratic Republic of Congo, Namibia, South Africa, and Zambia are being sterilized without their consent or being pressured to consent”. Information given by counsellors to women about breastfeeding in antenatal care is very crucial because it will affect a child’s life. A study conducted in rural Tanzania found that counsellors doing breastfeeding counselling were lacking clarity on, “operational terms and the meaning of exclusive breastfeeding, the increasing risk of HIV transmission to the infant the longer a women breastfeeds and the recommended method of weaning for infants born to HIV positive women, and they had difficulty conveying breastfeeding advice meant for HIV positive mothers” (Bharat and Mahendra, 2007: 96).

### **2.8.2 Attitude-HIV stigma**

Gender refers to the commonly shared expectations and norms within a society about appropriate male and female behaviour, characteristics and roles (Gupta, 2000). Gender determines to a greater extent how people think, how they feel, and what they believe they can and cannot do as women and men. Gender roles, norms and expectations vary over the life cycle of women and men, and vary within and between cultures. The norms result in unequal balance of power between women and men that is deeply rooted in the socio-cultural context of each society. This unequal balance is also enforced by society’s institutions such as schools, workplaces, families, and health systems. These institutions tend to treat male children better and assign them tasks that dominate them over female children. Gender norms do not only result in unequal balance but affect women’s and men’s access to information and services, and how they cope with illness once infected or affected.

Gender structures are culture specific and they work in relation to class, race, age, ethnicity, sexual orientation, and international status to expose men and women to various degrees of oppression (Dube, 2004). These gender constructions almost always dis-empower women in the area of decision-making. Due to their ascribed gender roles, women are highly vulnerable to infection; they bear the burden of caring for the infected; they carry the HIV/AIDS epidemic (prevention, care, stigma and confronting social injustice). This results in significant differences in what women and men can or cannot do in one culture as compared to another. But across cultures, what seems to be fairly consistent is that there is always a distinct difference between women’s and men’s gender roles, access to reproductive resources, and decision-making powers. When men have decision-making authority, women’s rights are neglected.

It has become apparent that HIV/AIDS thrives through all forms of social injustice that often leaves people powerless to implement decisions that empower them against the epidemic (World Council of Churches cited by Dube, 2004: 5). According to Kanyoro (2004: ix), many women are vulnerable or made vulnerable by external issues, laws and cultures, which regulate low status for women. Research has found that gender inequalities are the foremost driving force behind the AIDS epidemic (ibid, 7). However it is important to note that the dilemmas of women are not homogenous to all women of today. Women's lives are lived in very different contexts (economics, race, culture, caste, geography, generation, sexuality, education, health and physical challenges). Fairly consistent across cultures is that there is always a distinct difference between women's and men's roles influenced by the gender gap – literacy, school enrolment, labour force participation, land ownership, and access to credit.

Wingood et al (2008: 237) attest that, “since the beginning of the epidemic people living with HIV and the social groups to which they belong have been stigmatized worldwide”. It is worth mentioning that stigma is not merely an attribute but it represents a language of relationships, as labelling one person as deviant reaffirms the normalcy of the person doing the labelling (Goffman cited in Deacon et al, 2005). The main focus here is not just stigma faced by any person living with HIV but rather the stigma faced by women living with HIV. According to Herek and Glunt cited in Sandelowskietal (2004) explain that HIV/AIDS does not only signify a disease epidemic but also an epidemic of stigma and of significations of cultural meanings. Furthermore, because women are believed to be all-purpose deviants in society they are presumed to have a distinctive experience of the HIV-related stigma (Bunting and Schur cited in Sandelowskietal, 2004).

Mbonu et al (2009: 3) writes, “stigmatization is part of a conservative reassertion of power relations, poverty, or moral authority resting on the ability to control sexuality”. In many societies women living with HIV are cast out from their communities and they are deemed not able to contribute to the development of their societies. For example, some studies have shown that women chose not to reveal their HIV status in attempt to avoid being secluded from participating in the sociocultural aspect of food preparation within their homes and communities, since food is regarded as an expression of support and acceptance (Mbonu et al, 2009). Society is mostly intolerant of those females living with HIV/AIDS rather than their male counterparts. A study carried in Kenya showed that 56% of women are commonly viewed to be targets of stigma compared with 12% of men (Mbonu et al, 2009). Also, because of the female gender roles in societies, she may not have the power to insist on the

use of a condom in cases when a partner refuses, which is a very important factor in prevention and spread of HIV infection. Studies have shown that women who share their HIV test results with their partners may experience a range of reactions from support and understanding to accusations, discrimination, physical violence and abandonment. Issues of stigma also function to limit and complicate access to care. Stigma and discrimination are widely documented and evidenced as main barriers to effective responses to HIV, in that stigma and discrimination manifest especially women's risks and susceptibilities to HIV. It also limits women's *'ability'* to access, participate in, and benefit from available HIV prevention, testing, treatment, care and support services (Kehler, 2012). In South Africa there is lack of studies that state that stigma prohibits access to women's rights and choices.

### **2.8.3 Lack of policy**

The stigma and discrimination that women living with HIV are confronted with in all facets of their lives, is exacerbated by the fact that sexual and reproductive health policies, programmes and services often fail to take into account their unique needs. South Africa has made some positive strides in some HIV related policies relating to children for example PMTCT however, specific gaps and weaknesses still exist in policies. There is a need for comprehensible policies for people living with HIV, but mostly they have to be consulted and have a say as these policies will affect and impact their lives. When looking at reproductive policies women need to be key actors in their development.

### **2.8.4 Lack of services**

Sexual and reproductive expectations of people living with HIV have been influenced by advances in HIV prevention and treatment that have shown to offer better health. Nevertheless, there is still an expectation that the health system would urgently respond to the needs of people living with HIV. Bharat and Mahendra (2007: 93) add that, "this has led to calls to expand the role of the health care system to provide sexual and reproductive health services for HIV positive people". The quality and pace at which these services can be rendered is affected by restrictions within and outside the health sector that serve to weaken the expanded role for health care providers. Linking of Programs and integration between sexual and reproductive health and HIV services are being recommended, but many unexplored opportunities have been documented.

## CHAPTER THREE

### RESEARCH METHODOLOGY

#### 3.1 Profile of eThekweni district

eThekweni Municipality is a metropolitan city found in the South African province of KwaZulu-Natal. This municipality largely consists of urban areas but there are areas which are considered rural. “The demarcation of municipalities carried out in 2000 has meant that 67% of eThekweni’s spatial footprint is now rural” (Xaba and Associates, 2007: 03). According to Xaba and Associates these areas in eThekweni are defined as rural due to lack of services, extreme poverty, high disease burden, low incomes with heavy reliance on social transfers, scarcity of economic opportunities, and the erosion of natural environment. In this municipal, you find people from different ethnic backgrounds (Community Survey, 2007:8). The majority of the population comes from the African community (73.8%) followed by the Indian community (16.7%), White community (6.6%), Coloured community (2.5%) and other (0.4%) (Community Survey, 2007:8). Individuals within the 15-34 year age group comprise the majority of the population. According to Census 2011, in terms of gender the municipal population comprises 1,679,040 males and 1,763,321 females. eThekweni had 17.1% of households living in informal dwellings as opposed 8.6% provincial average” (Community Survey, 2007:8).

In 2011 eThekweni comprised 54% of KZN’s unemployment rate and females constituted 47% of eThekweni’s unemployed. Literacy and education have been improving over the last five years in eThekweni and, when compared to the averages of KZN and South Africa, eThekweni performs the best. However, in comparison to the other metro municipality averages, eThekweni ranks fifth in the percentage of the population over the age of 15 with a matriculation level of education by 42% and then also ranks fourth in literacy rates by 87.0% (eThekweni Municipality IDP Review, 2013/2014).

The primary health concern in the eThekweni district Municipality remains HIV / AIDS, and the Municipality and local Health Officials are making progress in terms of their response to the epidemic. Tuberculosis (TB) is a very serious problem in South Africa and the eThekweni Municipality has a lot of reported TB cases.

### **3.2 Details of Phakamisa and HRI**

This study was carried out in two different organizations that are located in EThekweni. The name of organizations are Phakamisa and Her Rights Initiative (HRI).

Phakamisa works out of Pinetown in a radius of 50km serving in the townships, informal settlement and rural communities. The organization serves areas like the Valley of 1000 Hills in the north which is a rural community, East as far as KwaMashu and to Queensburgh in the South. Phakamisa began as a voluntary organization in 1994 and became a full time ministry of the Pinetown Methodist Church in 1996. This organisation was founded by Glenda Howieson, who began by voluntarily running teacher training workshops for illiterate and uneducated women. Phakamisa which translates to “lift up” communities and give local residents the skills to care for their children. Phakamisa exists to serve, uplift and empower impoverished communities through the provision of educational training, resourcing and support. The organization was developed because of a desperate need in the rural areas for early childhood education and support. This organisation serves impoverished communities and no one falls outside the work that this organisation does. Out of the many services Phakamisa provides, they also provide support through an HIV/AIDS support group. Tholuthando is an HIV/AIDS support group which meets once a fortnight to celebrate life and learn how to live positively with their disease. This support group currently is made up of 40 women. The support group is open to everyone who is HIV positive, which means members are not recruited.

Her Rights Initiative (HRI) is an initiative that was formed in 2009 by a group of feminist South African women. The initiative was formed from the knowledge and experiences of its founding members who all identified the gap between HIV/AIDS policies and HIV positive women's experiences. It is also formed on the potential HIV positive women present in refining present policies or recommending new ones to ensure women living with HIV/AIDS are able to access their sexual and reproductive rights in South Africa. This organisation serves HIV positive women who are of reproductive age. HRI is an advocacy organization with a drive of generating a world where women living with HIV have full access to and enjoy their human rights. Conducting policy research, doing policy reviews in different issues like gender based violence and HIV positive women, sterilisations of HIV positive women, cancer and HIV positive women.

The organization's main objectives are to promote the rights of women living with HIV, particularly positive women's sexual rights, reproductive rights, and the right to be free from all forms of violence. A small component of HRI involves capacity building where women are used as case studies, for example; with women that were coercively sterilized workshops where women were educated about specific rights that were violated when they were coerced into sterilisation were conducted. The Initiative currently works in four South African provinces, KwaZulu-Natal, the Eastern Cape, Gauteng, and the Western Cape. The organization is implementing one of its programmes at a regional, SADC region level, and supports and provides technical guidance to other Sexual and Reproductive Health and Rights (SRHR) programmes and initiatives of women living with HIV throughout the region. These organizations were primarily chosen because they work with and cater for HIV positive women. The one thing common with both organizations is that they both advocate for full access of sexual and reproductive rights and access to basic human rights for women living with HIV. In addition, HRI also advocates for the right to be free from all forms of violence.

In HRI, entry to participants was obtained through the founder of the organization who was contacted by the researcher and the research supervisor. The founder then linked the researcher with different women who helped in mobilizing other beneficiaries to participate in the study. In Phakamisa, entry was also obtained through the founder of the organization. The researcher heard about the organization from a lady she met on-campus who goes to the Methodist church in Pinetown, she provided with a telephone to contact the organization. An appointment to meet with the founder was made telephonically; she suggested that the researcher comes to the organization on the day when there was a support group so that she introduces herself and what her study is about. On the day the researcher went to the organization and spoke to the women about the study, all those who were present were interested to participate and that was about twenty seven women and they gave their contact details. Each organization gave the researcher permission to use their facilities to conduct interviews. All participants were re-imbursed for transport, to and from the interviews.

### **3.3 Methodology**

This is an exploratory research based on a qualitative study design. Pilot and Hungler (1997) suggest that exploratory research begins with some phenomenon of interest, intended at discovering the dimensions of the phenomenon, the manner in which it is manifested, and the other factors with which it is related. Exploratory research is appropriate for this study because the study aimed to explore rights and choices of HIV positive women.

According to Pope and Mays (1995: 43), “the goal of qualitative research is the development of concepts which help us to understand social phenomena in natural rather than experimental settings, giving due emphasis to the meanings, experiences, and views of all the participants”. Qualitative methodology is appropriate here because it is effective in identifying intangible factors such as social norms, and so on (Family Health International, n.d.). For this study intangible factors that were explored are the rights and choices of HIV positive women.

#### **3.3.1 In-depth interviews**

In-depth interviews were used in this study as data collection technique. In-depth interviews are also known as unstructured interviewing. deVos (2000: 298) explains that in-depth interviewing, “is a type of interview which researchers uses to elicit information in order to achieve an understanding of the participant’s point of view or situation”. This study incorporated in-depth interviews because they allowed participants to express their views, perceptions and opinions regarding rights and choices based on their own understanding and experiences. “Engagement implies willingness on the part of the researcher to understand the participant’s response to a question in the wider context of the interview as a whole” (de Vos, 2000:299).

The researcher used interviewing skills, including listening skills to get grasp of the information. De Vos (2000:301) reports that “it is essential to listen for implicit and explicit meanings in the explanations and descriptions provided by the participant”. In total, six in-depth interviews were conducted with participants and two more were conducted with key informants. Participants from Phakamisa were interviewed in IsiZulu because that was their preference while all three from HRI were interviewed in English. Probing was done to seek more clarity from participants; however it was easy to probe when the participant is free to talk and gave responses whereas when the participant gave more limiting responses it became difficult to probe. However the researcher used probes where appropriate to gather more information. Both key informants were interviewed in English. The key informant from

Phakamisa was interviewed in Phakamisa while the one from HRI was interviewed on campus. All Phakamisa interviews were conducted in the Methodist Church facility which is where the organization is based while HRI in-depth interviews were conducted at Lifeline offices in Warwick Junction (Durban). The researchers aim in using all these different settings for interviews was to use spaces where participants could feel safe and comfortable to share information and it was in settings which were easily accessible to participants.

According to de Vos (2000:300), “A quiet environment, where no interruptions occur, will facilitate the process. This could be at the participant’s home, or in a more professional environment, or in a setting agreed upon by both parties. Select a setting that provides privacy, is comfortable, is a non-threatening environment and is easily accessible”. Participants were relaxed and were able to seek clarity where they didn’t understand. Before starting with interviews the researcher read and explained the consent form for the participants to accommodate those who could not read. Secondly, the researcher ensured that participants signed informed consent form which stated the aims of the study, assured them of confidentiality and the fact that their participation was voluntary.

Field and Morse (cited in de Vos, 2000:301) writes that, “Consent can be obtained during preliminary interviews when finalizing arrangements, or a verbal consent may be recorded at the beginning of the interview”. Furthermore, consent to use a recorder was requested and obtained from participants and they were all reassured that the information they provided will remain confidential. Williams cited in de Vos (2000: 65) state that “obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which participants may be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives”.

### **3.3.2 Focus group discussions**

Morgan cited in de Vos (2000) describes focus groups as a technique that collects data through group interaction on a topic determined by the researcher. The group members were selected because they had a common characteristic, which is they were all women who are living HIV. For this study, four focus (two focus groups per organisation) group discussions were conducted and three of them comprised of eight members each while only one had seven members. One HRI focus group was conducted in a church at Ntuzuma where the support group meets and it was convenient for participants. The second HRI focus group was

conducted at Cato crest clinic in the backroom where the support group meets. “Groups are typically six to eight people who participate in the interview for one-half to two hours” Patton (in Flick, 2009:195). The researcher played a role of being facilitator during group discussions. Babbie and Mouton (2001) explains that the focus group can be run the same way the basic interview is conducted, however what makes the focus group different is that the researcher needs to facilitate the whole group rather than one or two individuals. Furthermore, de Vos (2000) identified three fundamental strengths of focus groups that are shared by qualitative methods and those are exploration and discovery, context and depth and interpretation. In cases where other group members were shy and reserved to express themselves they were encouraged to speak out but not forced to talk. “The main advantages of group interviews are that they are low cost and rich in data, that they stimulate the participants and support them in remembering events, and that they can lead beyond the answers of the single interviewee” (Flick, 2009:196).

The researcher prepared an interviewer schedule/guide which was used in both in-depth interviews and focus group discussions with an aim to guide interviews. Holstein and Gubrium cited in de Vos (2000:302) explains that the interviewer guide “provides the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designate the narrative terrain”. Closed questions were avoided but rather open-ended questions were used. Open-ended questions were used because of their nature to allow participants to express themselves freely. All questions were neutral, non-judgemental and unbiased. The questions included opening questions where women were asked to explain their understanding of rights of HIV positive women, rights in a relationship, breastfeeding and contraceptives. The questions were arranged in a way that was leading and some sequence, from the basic and simple to specific questions. “It could be meaningful to arrange questions from simple to complex, and from broad to more specific, in order to allow the participants to gradually adjust to the pattern of the interview schedule” (Bailey in de Vos, 2000:302). The interviewer guide was not changed but in cases where new information was added by participants the researcher probed further instead of adding new questions.

### **3.4 Sampling procedure**

“Purposive sampling, one of the most common sampling strategies, groups participants according to preselected criteria relevant to a particular research question” (Family Health International, n.d.). In addition, Kumar (1999:162) suggests that, “the primary consideration in purposive sampling is the judgement of the researcher as to who can provide the best information to achieve the objective of the study”. Purposive sampling was chosen because it allows identification of a population that holds characteristics that may produce valuable information for the purpose of the study. Denscombe (1998:15) suggests that one advantage of using purposive or judgemental sampling is that “it allows the researcher to home in on people or events which are good grounds for believing will be critical for the research”. Participants in this study were women living with HIV aged between 24-63 years. The assumption is that they would have been exposed to many issues that have to do with their rights as women and their rights as women living with HIV.

The sample comprised of thirty seven participants and two key informants from both organizations were also interviewed. Employment status, marital status and race were not used as determinants for the participants; however, participants had to be beneficiaries of either Phakamisa or HRI and be living with HIV to participate in the study. Key informants had to be founders or be in leadership of either organisation. Hence both key informants that were interviewed were founders of these organisations.

### **3.5 Research participants**

Participants of the study were women living with HIV aged between 24-63 years. The study was conducted in eThekweni district, KwaZulu-Natal. Majority of the participants were Zulu speaking and a few were Xhosa speaking. Only a few participants were employed during the time of the interview, some were doing home based care which earned them some income and the rest were unemployed. Amongst those who had children they were receiving child support grant which helped them fulfil their basic needs.

### **3.6 Data analysis**

Data was obtained from thirty seven women living with HIV and two key informants. It was broken down into four focus group discussions and six in-depth interviews. All interviews were audio-recorded and transcribed. Translation was done by the researcher in order to allow her to identify patterns and observe emerging themes. The researcher first transcribed recordings as they were without translating; secondly transcripts were transcribed from

IsiZulu and Xhosa to English. After this stage, all 12 transcripts were used for data analysis. The study used thematic analysis to analyse data. “Thematic analysis is about organizing the substantive content of the interview: the content that is of substance”. Researchers quantify and analyse the presence, meanings and the associations of such words and concepts, then they make interpretations about the messages within the texts, the writer(s), the audience, and even the culture and time of which these are a part.

Thematic analysis allows the researcher to create themes based on the information gathered after the study was carried out, this means that the study will develop itself rather than the researcher being driven by hypothesis and not having an open mind. After transcription, the researcher went through a rigorous process of repetitively reading and reviewing the transcripts and audio-recordings. The main purpose of reviewing transcripts was to identify fundamental thematic content in each transcript based on the words of the participant’s accounts. Due to the time frame the researcher was working on, coding was done manually meaning no computer programme was used. Themes with the same meaning were grouped together and sub-themes were developed. Themes with common characteristics were identified, and defined until six principal themes that represented the consequences of gender based violence on women’s reproductive health were retained.

### **3.7 Ethical considerations**

The Webster New Dictionary cited in Babbie and Mouton (2001) defines ‘ethical’ as being in compliance with the standards of conduct of a given profession or group. This study was approved by the University of KwaZulu-Natal Research Committee and the Research Ethics committee. Throughout the study, research ethics were adhered to, this was done by ensuring that, the rights of the participants are protected and respected. “In many cases, ethical choices involve a trade-off or compromise between the interests and rights of different parties” (Babbie and Mouton, 2001: 520). The participants were briefed about the purpose of the study prior to the interview and then each participant was required to sign a consent form. Participants were informed about the time each interview and discussion requires, in-depth interviews lasted from 45 to 60 minutes each while focus group discussions lasted about 90 minutes to 120 minutes each. Participants were informed that their participation was entirely voluntary and that they were free to withdraw any time they wished to do so. The researcher asked for consent from the participants to use an audio recorder during the interviews and

they were assured that all the information provided during interviews would remain confidential.

### **3.8 Reliability**

According to Babbie and Mouton (2001), reliability can be defined as a matter of whether a particular technique if applied repetitively to the same entity would produce the same results each time. The researcher has observed few qualitative publications on this topic. It is intended that the data collected and presented here will increase understanding and address pre-emptively the concerns faced by women living with HIV in South Africa. The researcher drew on empirical qualitative findings and look at the nature of women's rights and choices.

### **3.9 Limitations of the study**

The researcher was interested in women's knowledge of rights. In most group discussions participants wanted to dwell more on the health sector. Participants focused more on how they are treated in the clinics and barely used other examples of how their rights may not always be respected. The interviewer guide was available in IsiZulu though almost all participants could read and write but understanding of questions for others was very minimal. There were times where the researcher had to explain questions which were in their mother tongue which was not easy to do, as they say '*IsiZulu asitolikwa*' meaning Zulu cannot be interpreted. Level of education as well might have led to this problem. Identifying young participants was challenging as majority of them do not join support groups. Focus group discussions were time consuming as other members took their time in explaining issues. Other support group members found it very difficult to open up as much as the researcher tried to involve them so that they spoke but the problem persisted. The other limitation is that the sample was not truly representative of the women living with HIV who are in their reproductive age.

## **CHAPTER 4**

### **FINDINGS**

#### **4.1 Introduction**

This chapter presents outcomes from a qualitative study conducted in eThekweni district, KwaZulu Natal. The study examines rights and choices of women living with HIV. The chapter starts by providing biographical profile of all participants. Furthermore it will describe themes and sub-themes such as barriers to accessing rights, how rights are accessed, reasons why HIV positive women's rights may not be respected, place rights violated, persons involved in violating rights, mechanisms used for violating rights, and rights violated.

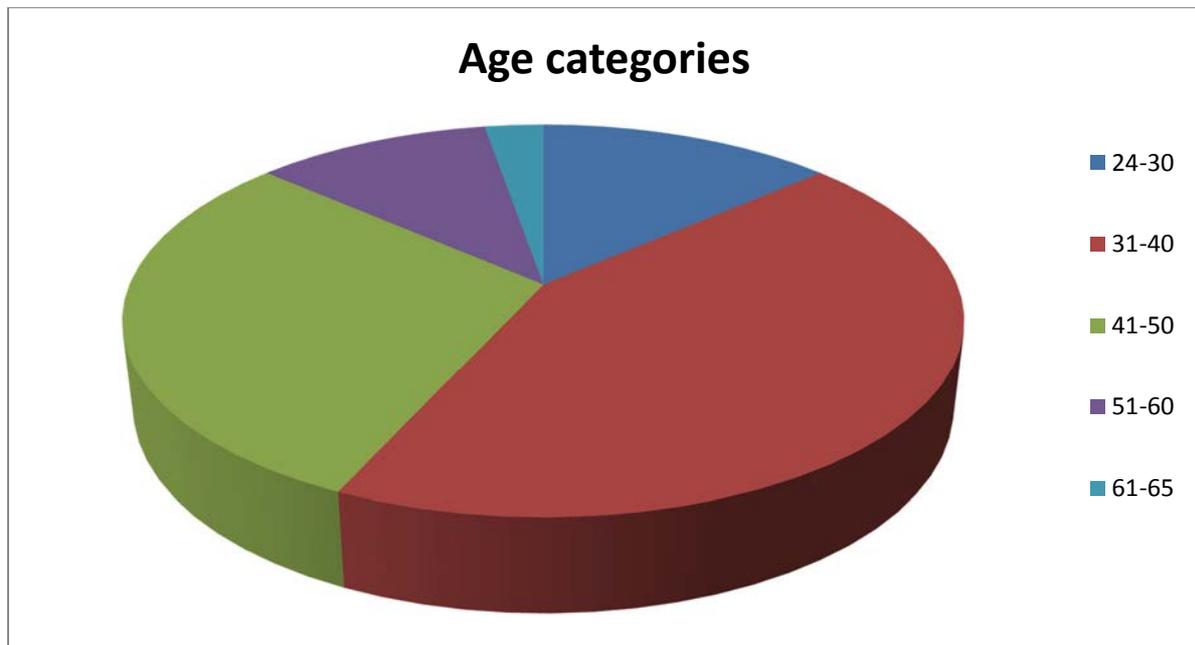
#### **4.2 Characteristics/profile of participants**

This section provides socio-economic and demographic profile of participants. It highlights age of participants, level of education, marital status, and employment status.

##### **4.2.1 Age of participants**

The ages of participants were examined at the time of the study and they are illustrated in figure 4.1. The youngest participant was 24 years while the oldest was 63 years old. The pie chart shows that the largest age category of participants was aged between 31 and 40. Only one participant was in the 61 and 65 category. When looking at these results women in the age group 30-40 seem to be the majority and that may be due to the fact that this age group is most likely to be infected by HIV. Also with issues concerning the rights of women living with HIV the expectation will be to have these women becoming more involved in advocacy.

**Figure 4.1: Age of participants**



#### **4.2.2 Level of education**

The level of education obtained by participants was investigated during the time of the study. The results are presented in Table 4.1.

**Table 4.1 Level of education obtained**

<b>Level of education obtained</b>	<b>No. of participants</b>
Primary school	3
Some secondary school	20
Completed grade 12	11
Some technikon, college or technikon school	2
Some university	1

Three participants had primary school education, twenty had some secondary school education, eleven completed grade 12, and two have some technikon, college, or technical school education, while only one had some university education.

### 4.2.3 Marital status

Marital status of participants was also investigated; results are presented in table 4.2.

**Table 4.2 Marital status**

Categories	No. of participants
In a relationship, living in same household as partner	7
In a relationship, partner lives separately	10
Married, husband lives in same household	3
Married, husband lives separately	0
Widow	5
Separate	2
Not in a relationship	10
Divorced	0

At the time when the study was conducted, three participants were married and living with their husbands in the same household as them, five were widows, 17 were in relationships (seven living in same household as partners as opposed to ten who lived separately with partners), and two were separated while ten were not in a relationship.

### 4.2.4 Employment status

During the time of the study, the employment status of participants was also investigated. Table 4.3 presents results.

**Table 4.3 Employment status**

<b>Status</b>	<b>No of participants</b>
Employed	9
Self-employed	4
Unemployed, looking for work	21
Housewife	1
Unable to work	2

Nine participants were employed, four were self-employed, 21 were unemployed but looking for work and one was a housewife while two were unable to work.

### **4.3 Barriers to accessing rights**

Participants were finding it difficult to access and enjoy their rights. Therefore barriers in accessing rights were discovered. Four barriers were identified: awareness/knowledge; level of education; fear of discrimination and socioeconomic disadvantage.

#### **4.3.1 Awareness/knowledge**

The study found that participants did not know about the rights they have and lacked information about their rights. This is true to women from both Phakamisa and HRI. An expectation would be that women from HRI have knowledge about their rights but surprisingly they were just as ignorant as those from Phakamisa. Only 3 women from HRI had some knowledge of rights and their knowledge was informed by their active involvement in the fight against forced sterilisation since they were also sterilised without their consent. These three women have interacted with other women from Africa in the fight against forced sterilisation. Majority of participants from HRI who were interviewed and proved to lack knowledge of rights have not been so actively involved in any fight against violation of rights. This is part of social exclusions where society or women in this case may be prohibited or cannot access information due to the position they hold in society (Silver, 2007). Participants believed that this lack of knowledge contributed to health care workers doing certain things to women that wouldn't have been done had they been aware about their

rights but mostly their illiteracy makes them believe that doctors know it all therefore agreeing to anything that doctors say. Participants explained:

*“I think most of them don’t know anything about their rights because if women know about their rights like different rights they do have, I mean most of the things that are happening to them right now wouldn’t be happening. Because you have never heard about the government having a workshop to teach women of their rights or something, it’s just not important to them” (IDI#6 p6).*

*“They don’t know that they have a right to say no you know, they’ll just say they are positive some of them are illiterate if the doctor says this they say ok because the doctor said, he knows” (IDI#4 p4).*

*“I think lack of information about rights and information you have contributes because in the end the doctor or nurse makes you do something you wouldn’t have done if you had information”(FGD#2, P5, pg42).*

### **4.3.2 Level of education**

Level of education is an important factor because it can be used to identify how much certain groups of people understand things. The study found that illiteracy contributed to participants being robbed of what belongs to them but mostly illiteracy takes away their right to decide what should be done to them.

*“.....women who have no education almost have no rights” (KI#1 p6)*

### **4.3.3 Socioeconomic disadvantage**

South Africa is known for its high levels of poverty and marginalisation, and women in SA are more likely to be unemployed. The socioeconomic status of women living with HIV is further exacerbated by their status and vice versa. Poverty affects the socioeconomic status of women living with HIV in that due to unemployment women become even more deprived and vulnerable which makes them to continuously rotate in the same deprivation trap. The study found that socioeconomic status hinders participants from accessing their rights.

*“To go to a lawyer you have to pay for consultation, for the case to go to court to high court you have to pay for that you know. It goes with money, the money that we don’t have” (IDI#4 p5).*

*“And they don’t have the right to say no because they are afraid they going to lose the support, food the children won’t go to school, they won’t eat; that’s why they don’t get....it’s a big problem” (IDI#5 p6).*

#### **4.3.4 Gender**

The study found that gender was a barrier preventing participants from accessing their rights. Gender inequality is said to hamper the overall wellbeing of women, as captured in a paper titled, ‘being born a female is dangerous for health’ by Murphy (2003). Due to gender hierarchy which embraces men over women, men have always been superior to women. The study found that participants were cursed, oppressed, not respected, denied certain benefits just because they were women. Participants stated that women still have the mentality that men are superior to them and that they live under men, further participants felt disrespected and in some situations they were cursed. Participants expressed:

*“It is just that women still have the mentality that men are superior; the oppression we grew under still governs us. I sometimes look at us who grew up knowing that we have to go and get married whereas if we knew that you can be independent even as a woman, go to school, things would have been better, but we as women still have that mentality that we live under men. I think it is not easily overcome though, so we have to instil it to our children so they can grow up knowing that they can be independent” (FGD#1, P4, pg15).*

*“It is because they see us as unrespectable disgraceful because there are those words that are used to curse women that you are a bitch” (IDI#1 p4).*

Furthermore, participants raised the issue of condom use in relation to power relations and the women’s inability to negotiate condom use and to refuse sex were highlighted by participants. This is similar to what Ndinda et al (cited in Rispel and Popayi, 2009) found in rural KZN that although there is a sense of urgency on the part of women in contraceptive use, it is particularly difficult for married women to “say no to sex and condom use negotiation does not even arise”.

*“They always say women mustn’t have children meanwhile men who are HIV positive impregnate women who are maybe HIV negative. They have the right but for us just because we are women, we need to stand up and say no” (IDI#5 p2).*

*“They live in this world that women should be using condoms; they know that the powers are not equal men are dominating the power struggle so it’s hard for women to negotiate condom use” (IDI#6 p2).*

*“I mean how many women can just refuse sex to men when men..... if men want it and they much stronger than we are, they can demand it we can you know those of us who are better educated can perhaps talk our way out of it but if a man has been drinking you’ve got no chance” (KI#1 p6).*

One participant shared an experience where after losing her husband she had to do hard labour so she could provide for her children after the project that was giving her a food parcel every month had just stopped without giving her reasons. She expressed:

*“She knew my situation because she is the head of the project, so she knew that I was not well but because I am a woman I have to live I have children and I have to eat. So, when this help came along I just took because theirs just got cut off and I was never told the reason why it got cut off” (IDI#3 p7).*

Participant went further to share how as women they can be oppressed by situations in their lives by sharing her own situation. She shared how the life that some men including her husband lead them to death and how them as women have to deal with the aftermaths of their death having to explain to children what caused their father’s death but over and above the expectation children have on the mother to provide even if they are sick. These are some of the burdens of HIV which many women in Sub Saharan Africa are facing; having to care and provide for their children, deal with death of partner while they are sickly themselves.

*“But many situations oppress us women because he has passed away and you can see that his death was caused by the way he was living his life, because you as a woman has to accept that the man is a player but in the end it is you who suffers. I had to even tell the child what was making me sick, it was not easy to walk the path alone, you see many paths you end up walking them alone, and the children are expecting you to provide and you are sick, it is not easy” (IDI#3 p11).*

One participant expressed that being HIV positive, being a woman and your race (being black) can exacerbate exclusion by being denied certain things just like in her case where she was denied her hospital records and she believes that was because she was a black woman living with HIV.

*“Like for instance, the one I’ve told you about now that is the first one and it’s the major one. Two, I.... ok, it’s not like if you are only HIV positive. If you are a woman and you are HIV positive and they look at your colour because I believe if I went to that private institute and I was white with long hair and say I want my records. I was going to get them straight away” (IDI#4 p4).*

#### **4.3.5 HIV status**

The study found that the rights of women living with HIV may not be respected. Participants stated that their rights may not be respected on basis of their gender and on basis of their HIV status. The way in which HIV is predominantly transmitted in South Africa, i.e. through heterosexual intercourse, creates stigma that the disease infects only those who are promiscuous. HIV positive women are not seen as national pride, instead they are disgraceful and they have nothing to say because they are going to die anyway. Other participants shared that once you are HIV positive there is a belief from the greater community and health workers that there is something wrong with your mind.

*“Ahh! A combination of many things, first the fact that they are women’s rights and second is that they are rights of HIV positive women so these people are not important they are troublemakers, you know they are squeegees of society so yah they are diseased they really bad they don’t necessarily contribute to the national what is it? Nation building project or national pride or anything so it is ok to violate their rights” (KI#2 p10)*

*“Also, they think that you got this virus because you are promiscuous” (FGD#3, P2, pg12).*

##### **4.3.5.1 Lack of empathy for condition**

Empathy is very important because it means one is able to put him/ herself in another person’s position and try to feel or go through what they may be going through. What women living with HIV experience almost daily as long as they live is the lack of empathy for their condition of being HIV positive. Participants felt that being HIV positive had implications on

their lives and those living with HIV are believed to be suffering from a punishment disease because of how they had led their lives maybe. It was clear that those who had other diseases like cancer or heart diseases were more likely to find empathy from others be it community members or health workers as opposed to those who were infected by HIV.

*“You are taken as someone who has a punishment disease and now there is that everywhere because when you go in to the clinic with someone who has cancer; people are going to feel sorry for her after they have heard that it is cancer. She may have stroke, BP, heart disease, etc but when it is you who is sick and you have this disease they do not feel sorry for you, even at the queue when you come already sick they do not have that. That is oppression by disease” (IDI#3 p7)*

*“so one understands because there are implications and ramifications of that one little word ‘positive’ it’s entirely life changing and then I think the problem is it’s the stigma that’s added because if there were no stigma it would be like being told you’ve got cancer, it would be the same life changing, horrible, awful situation” (KI#1 p7)*

#### **4.3.5.2 Association of HIV with promiscuity**

The study found that HIV is associated with promiscuity. Participants said that the fact that HIV is transmitted through sex creates a mentality that it’s a punishment disease and that those who acquire it acquire it because they are careless and promiscuous. Participants explained:

*“The way, by which AIDS entered, it had created a certain stigma because of the type of disease it is. The disease is deemed as a disease that is acquired through promiscuity; it is never considered that out 100 people how many of them got it through promiscuity and how many got it by certain situations. You are taken as someone who has a punishment disease.....” (IDI#3 p7).*

*“Even that what is generally known is that we women are promiscuous ‘siqomanjalo’ that we have sex anyhow, we drink alcohol and sleep around that is why in the end our rights are disregarded” (FGD#2, P1, pg31).*

#### **4.3.5.3 Fear of discrimination**

People living with HIV have always suffered discrimination due to their positive status; however, the discrimination worsens when one is a woman living with HIV. Communities have a tendency to discriminate and cast out those living with HIV making it difficult for

them to leave peacefully. This also increases exclusions of those who are affected making it difficult for them to enjoy some of the resources available in the community. The study found that some of the participants feared being discriminated in the community and as a result they did not disclose their status. This is evident of exclusion because rejection and discrimination are the key tenets of exclusion. Once discrimination becomes severe exclusions take control and this is what women living with HIV in eThekweni district are faced with. She explained:

*“It is the fear of being discriminated, like I will be scared to show myself thinking what the community might say, like me, I am not indigenous in the area I am married to, I am from elsewhere, I came there because of marriage. The person I married no longer exists now it is even harder for me to disclose, and help maybe that I can get somewhere else, as I have chosen this support group that is away from my community because you do not know if the community will accept you in this condition” (IDI#3 p6).*

Another participant who shared almost the same experience discovered she was pregnant, and she had fear that she might be discriminated due to her health condition. Apart from having bladder problems the participant was also living with HIV. However, unlike the previous participant this participant was fortunate that when the health worker realised she was pregnant she did the opposite of what the participant expected. Participant shared:

*“My suffering from my back, bladder and etc I took myself as person who was not supposed to have a baby anymore, I separated with my husband he left and I stayed for four years. In 2004 I got a new husband and I unfortunately fell pregnant I do not know whether it was unfortunate or what. I hid my pregnancy from the hospital, I was their person, until the nurse saw that this stomach is not just a stomach, she said ‘go and pee lady, I went then she said you see you are going to kill a baby and that was that. After that I already knew I was positive, she then said ‘go to VCT clinic so this baby can get nevarapin while still inside, you are not wrong to be pregnant but you have to know your CD4 count” (IDI#2 p3).*

#### **4.5 Abuses/violation of rights**

There are many rights that are violated; these rights include right to employment; right to confidentiality; right to children; right to reputation (swearing and name calling); right to

choose family planning; right to treatment; right to abortion; right to freedom of choice; right to social security; and right to legal protection from violence and sexual abuse.

#### **4.5.1 Right to employment**

The right to employment is a crucial right to any human being because it enables one to sustain their livelihoods. Participants shared that once their status was known there was greater possibility that employment will be lost. Furthermore, they stated that there were those kinds of jobs where it was a requirement to test and testing was mandatory and once your status is known one might be retrenched or denied employment.

*“No, in many companies there is still oppression although it is said that a person should not be discriminated, but there are jobs that ask for your status when you are filling the forms. If you are being honest, it is a shame because you will never get that job. You see at the military, it was even written where your status stands, even if you say you are negative but when you get in you would be tested again. So now that means even if you have qualities for the job or you like it but being HIV positive will stop you. That still exists, and sometimes you find that you are working, maybe at a particular firm, if the boss finds out where your problem is, you will see, because you are now sick so there is that on and off at work, when they find out they just retrench you without complete reason” (IDI#3 p15).*

*“He does not have the right to fire me just because I have HIV, also the employer does not have a right not to employ me because of my status. He has never seen HIV with his eyes; I still have my hands, legs and mind. My diploma that I studied for at university is here, there is no HIV” (FGD#1, P6, pg11).*

Furthermore, participants shared that some people they knew were either denied jobs or retrenched from work after their HIV positive statuses were known. Being known to be living with HIV put these women in a more vulnerable position therefore affecting their socio economic status. Participants shared:

*“More people were denied jobs because they HIV positive and that also comes about when people don’t want to employ someone and they say well I need someone who’s here all the time and HIV positive people needn’t be” (KI#1 p8)*

*“There is one child whom we are with in this organisation who had that problem of losing a job because she revealed to her employer that she was positive, then she lost*

*the job after missing a day, when she came back they said it is over with you, there is many of them” (FGD#1, P4, pg23).*

One participant shared how her boss likes her but she expressed with certainty that if her boss could ascertain that she was HIV positive she will not hesitate to fire her. Participants explained:

*“You can see me laughing with her today but if I were to tell her that I’m infected ‘ziwa more’ she would set me up and make sure that with a minor mistake that I make she kicks me out of the gate”(FGD#2, P8, pg43).*

#### **4.5.2 Right to confidentiality**

According to participants confidentiality is breached. Confidentiality is breached in health facilities, working environments, and in some cases in organisations that others go to for assistance and support. Article 17 of the International Covenant on Civil and Political Rights (UNAIDS and OHCHR, 2007) it is stipulated that this right incorporates two requirements which are the need to respect physical privacy (for example, the duty to seek informed consent to HIV testing) and the need to respect the confidentiality of personal information for example, information relating to a person’s status. However, confidentiality is not only breached by healthcare workers disclosing their participants’ status. Participants highlighted that even the system of separating patients in health facilities where patients with general diseases are serviced on different points as those living with HIV. That on its own for participants breaches their confidentiality since people may be able to determine their status by the card/file they are caring or certain sections they go to in the health facility.

*“If another nurse comes in she will tell her, ‘yoh, she’s telling me she’s got this and this, she knows her status, she’s not using the condom’. How are you feeling? Women rights are being violated in different ways; I wouldn’t say sexual and reproductive rights but also their right to confidential. Confidentiality is bridged each and every day” (IDI#6 p2).*

*“It is like, maybe here at the clinic, we are at the clinic as we are all gathered and you are also my neighbour, the clinic for us who are like this, is set aside, our door is set aside, the neighbour can now see you that you entered to that door, because she knows that you were carrying that big “irherheba” file and entered to that door, now she will go and spread it around” (FGD#4, P1, pg7).*

Two participants shared how their confidentiality was breached by their employers and those who helped them put a meal on the table. Participants get hurt and angry when their confidentiality gets bridged because bridging of their confidentiality involves their HIV positive status being advertised to others which may exacerbate stigma and discrimination. Participants shared:

*“and also when a person is in an organisation, say maybe you have come for soup, she will say, to anyone who shows up, you see this one, she is ours, she got rescued from us. There is no need to say that about a person’ status. I got very shocked when a certain woman said that to me, but I could not see the help they were helping with. She is telling everyone that this one got help from us, she is one of us. I was very angry but did not show her, I even decided never to get bread there again because she goes there to make fun of me. How many has she told about me, how many?”* (FGD#3, P6, pg10).

*“The one thing that made me leave the job was the abuse I first hid it from my bosses, I hid it and kept on attending clinics I kept hiding it saying its TB but they wanted to know what my problem was, I ended up asking the doctor to write the letter and tell them. I gave them the letter what hurt me the most was that when I went to collect treatment I came back the whole factory knew”* (FGD#2, P7, pg44).

### **4.5.3 Right to children**

This study found that HIV places women in a position where they are not expected to bear children. This is due to the belief that since they are already living with HIV they might bear diseased children which will force the government to spend more on the so called “AIDS orphans”.

*“I think one thing they do wrong when it comes to reproductive rights is to make choices for women as in how many children you should have, if you are HIV positive you are not supposed to have children and they have this belief that you should use a condom knowing if I’m coming to the clinic pregnant it means I’m not using it”* (IDI#6 p2)

*“That one is going well if you know that you have a right but mostly if you go deep in rural areas, deep rural. They will say, ‘ey now I’m HIV positive I can’t have children; the sister in the clinic said”* (IDI#4 p13).

#### **4.5.4 Right to reputation (swearing and name calling)**

The right to reputation is also an important right but for women living with HIV it gets violated all the time. These women are called by certain names and also sworn at. Participants shared that they are sworn at due to their status and also how people refrain from using their belongings after learning their status.

*“They swear at you, they discriminate us by refraining from things you use. They even abuse your children because they think you are no longer like other people” (IDI#1 p3).*

Furthermore, one participant shared how worthless she felt as women after her status became known. She went further to explain that the belief that HIV is contracted through sexual intercourse contributes to them being unimportant as women living with HIV making them even more vulnerable. This belief results in women living with HIV being portrayed as promiscuous.

*“It is because they see us as unrespectable disgraceful because there are those words that are used to curse women that you are a bitch, because they are not educated about HIV that you cannot get it from seat, from spoon I am using, but it is something used by another person, not that you will only get it because maybe you slept with someone, there are many ways you can get it. That is what making us to be disrespected or unimportant to other people” (IDI#1 p4).*

#### **4.5.5 Right to choose family planning**

Participants explained that HIV positive women do not have the power to make choices concerning their reproductive rights instead healthcare workers make those choices for them. Furthermore, participants shared that they were not given an option to decide to use family planning but they were forced.

*“But is it just to be forced, as it is done in clinics, into prevention? We are being forced to do that, the card for prevention is required, even if you tell them that you are not in a relationship they just push you, otherwise you will not get pills. I am not in a relationship but I have to go for prevention injection otherwise I will not get pills” (FGD#1, P7, pg17).*

One participant shared an experience she had with healthcare workers when she had to do a pregnancy test so that she could be started with treatment. She shares the suppression she felt having to use family planning knowing she did not have a partner. The participants experience further illustrate the lack of decision making power owned by women living with HIV or even the right to choose whether they want to use family planning or not. One participant shared:

*“.....you see I just see that now, firstly it was already suppressing me that I had to prevent knowing that I do not have a man but because I want this help I have to start by getting help by preventing, when I get there this preventing is now the one hindering me, I was very stressed” (IDI#3 p5).*

Another participant shared side effects she had as a result of having been on injectable contraceptive for too long. She further shares that she made a choice to stop the injection but she was instructed by a health care worker to start again the following month. Participant explained:

*“Because I remember very well, I took injection so much and then I told them that this blood now wants to come out as nose bleed and she said “listen, what happens down there has nothing to do with the nose”. I then decided by myself to stop and when she asked me the following date when I came for pills collection, she said “Are you continuing with injection?” I told her I stopped, she asked why and I told her I have a right to stop if I feel like it is too much for me but I condomise, she said “But then next month you are coming back, you are starting again” (FGD#1, P2, pg17).*

#### **4.5.6 Right to treatment**

Amongst other rights that women living with HIV are entitled to, the right to treatment is also an important one. According to participants they are denied treatment to other diseases, they are only given ARVs but whatever other minor disease they might be suffering from is not attended to. However, another participant believed that government is doing well in providing treatment to minor infections while nothing is done with those diseases like cervical cancer.

*“Same thing, when you mention your diseases at the clinic, it has happened many time with me that when I have mentioned more than three to Sisters, surely there is one that they are not going to give me medication for. I do not get complete*

*medication from her except when I go to the doctor, but you can see the doctor for a short time” (FGD#1, P8, pg22).*

Another participant explained:

*“With the treatment to minor infections everything is going well but the right to those treatments for diseases like cervical cancer the difficult ones. Government knows that cervical cancer is one of the opportunistic infections and its killing women everyday but he’s doing something but not much about it” (IDI#6 p10).*

The study found that participants were not accessing their right to treatment fully. Participants stated that they are required to be using family planning in order to be given ARVs.

*“You cannot afford to get pills #referring to ARVs# because you did not have injection” (FGD#1, P4, pg17).*

*“No, we are not alright as we said, in clinics they ask for family planning card first before they give you treatment, you have to go for injection first before they give you treatment” (FGD#1, P7, pg22).*

*“Killing the women and also if it’s not a women’s choice then it’s problematic and there should be no conditionality that is attached to accessing ARVs. If it is a right to health you must access your ARVs without meeting arbitrary conditions such as proof that you’ve taken a contraceptive you know” (KI#2 p5).*

Two participants expressed that they fought for their right to treatment. Participants stated that they were seen as not in the stage to be starting ARVs because of the body weight while the other was faced with a situation where the doctor wanted to change her treatment without consulting her.

*“I had an argument with a doctor in previous months; the doctor changes the treatment without telling me that he wants to change me because it may happen that I have drug resistance.....” (FGD#3, P7, pg7).*

*“I fought for my right to get treatment because they had a problem that there is no one who can take treatment with such fat body, I said but even though I’m fat you can see me fall because my CD4 is low” (FGD#2, P8, pg18).*

#### **4.5.7 Right to abortion**

The South African legislature grants its citizens the right to abortion; however, different people reserve different views, perceptions and beliefs about this right. Participants were not so clear cut on this issue, they just discussed it in a very general sense and only two participants gave an insight of what they have heard or understand with regards to right to abortion. In terms of whether the right is accessed or not, there as well participants were not specific. Participants explained:

*“Yes, like back when we had just started going to our clinic, they said if happens that you get pregnant you should immediately come to them so they can clean. If maybe you fell pregnant in a way that you did not want, maybe if you were raped you should immediately go there while it is still new so they can clean you” (IDI#2 p11).*

*“I think you can also have an abortion but you have to go to the doctor first so he can check you CD4 if it can withstand pain because they say it is more painful than giving birth, it is the doctor who can tell you, if you do it, which one can conform with your blood or what can happen even though you have rights but if you are giving your life a right you first have to consult with a doctor and counselling so they can tell you that if you do it this way you will not be in danger” (FGD#1, P6, pg25).*

#### **4.5.8 Right to freedom of choice**

The study found that participants do not have the right to fully make choices and decisions about their lives. Participants focused much on breastfeeding and illustrated in their discussion that the right to freely make a choice whether one will breastfeed or not is in many cases taken away from women. Participants said that with breast feeding health care workers always have a final word on what will happen.

*“It’s hard because a health care worker has to get involved all the time so I think they don’t have choices. Their choices are being infringed by these nurses because if I like to breastfeed my child and feed her the nurses will tell me no that’s not the way you supposed to do it” (IDI#6 p9).*

One participant said that other women get into the situation where they are forced to breastfeed their babies so that the neighbours and in laws will not ask many questions about why the baby is not breastfed. This means that due to the pressure and fear of discrimination which exists in families and communities women might risk infecting their children through

breastfeeding so as to avoid being questioned. Circumstances can force women living with HIV to breastfeed the child while taking away that right to make choices freely.

*“You have to know that it is breast only which gave others pressure because even if you want to feed the baby formula but you are scared of the in laws or people who surrounds you that they will ask you why are you not breastfeeding the baby. And that is where you will end; knowing you have a problem but you are forced to breastfeed because you are scared of what people might think” (IDI#3 p11).*

#### **4.5.9 Right to social security**

The NAT report (2007) states that, “States should ensure that people living with HIV are not discriminately denied an adequate standard of living and or social security services”. The study found that participants are not enjoying their right to social security to the fullest since they are not getting disability grants. Participants shared cases and situations where other people put their lives at risk and would rather get sicker so that they can receive grant.

*“A person would go when she is sick and has lost energy to work. Now, when you get here they tell you HIV does not mean you can get disability grant. You have to have another disease on the side, you also find that you are diabetic and arthritis, which makes many people want to get sick even more so that they can find help, even when they are given pills they would not take them because they want their condition to worsen” (IDI#3 p3).*

Other participants said they stand in long queues when they go to apply for the disability grant and even when they want to check the status of their application. One participant shared that at times they get to SASSA offices as early as 4:00 o'clock in the morning but will end up leaving without being attended and the following day it will be the same until some official will claim to know you but for them to be attended or to cut the queue that day they have to bribe. However, not having the bribe means you will not be attended.

*“then a girl who works there, who is always drunk, will show up and say ‘Hawu, mother, how about a drink there?’ now, you are going to give away this R50 and she will say ‘let her pass’, ‘come this way mother’ once you have given out this drink, it is R50.....If you do not have this R50 you will go back, they will say nine has passed people who come after nine are not allowed to go in, they would say all people who are here woke up early, you must wake up too tomorrow” (FGD#1, P6, pg24).*

Furthermore, another participant shared an almost similar issue when she said the doctor that does the examination to determine whether you qualify to be given the grant or not also wanted her to bribe him in order for her to be deemed qualifying to get the grant.

*“it is when the doctor who examined you and found out how you are, and ask him to write you a letter for grant, the person who approves things then fails, then get nothing, now your rights are being spoiled and you do not get money, now this doctor wants you to always pay him you have to go there six time paying R180 six times. If you did not go he will fail you”* (FGD#3, P2, pg7).

The right to social security is very important for women living with HIV to be able to access because if women can access it, it will mean their socioeconomic status will improve. Improving socioeconomic status of these women will enable them to access the rights they cannot access due to unemployment. Furthermore this will enable HIV positive women to support their children and therefore enabling them to escape the poverty deprivation trap and violation/ abuse.

#### **4.5.10 Right to legal protection from violence and sexual abuse**

According to some participants with regards to legal protection from violence and sexual abuse there has been a huge difference, one participant said they don't even have to reveal their HIV positive status either positive or negative you are protected. Participants explained:

*“No, there is huge difference now, I see the difference because previously you would always see blue eyes from people and it would be like nothing happened now it is a matter of go and report.....”* (FGD#1, P8, pg26).

*“There is a friend of mine who had that problem and they wrote her peace order she does not have problem she is protected and does not have stress”* (FGD#3, P7, pg19).

Some participants said women are not yet enjoying their right to legal protection from violence and sexual abuse because you still find women being beaten every day. Another participant felt that women are not enjoying their right because perpetrators get arrested only for a short time and the next thing you see them they are released. With protection orders one participant felt that there are times where they don't work especially in cases where the perpetrator (mostly men) lives nearer to the victim they can come kill her or even beat her with that protection order and in some instances perpetrators will go as far as tearing that protection order. Another participant strongly felt that in some instances when you go to

report being abused police can drag their feet and you as a victim have to go through a long process before the perpetrator is dealt with, which can even lead to you being killed by the person who is abusing you.

*“They are not protected totally, because these things get arrested now and get out now, before the week ends he is already saying his uncle is going to get him out and his uncle will get him out and he comes back to abuse others again” (FGD#4, P4, pg22).*

*“There is still oppression there, you see most the times when you go to report to the police that you are being abused by man, they still have that thing of dragging their feet. You find that even when they come they are going to ask to go the magistrate for a letter, then a paper will come back, a paper that says to the man you are abusing so and so. Eventually the man might kill you but you reported this person is abusing you with this and this, the letter did not protect you, maybe he hit you then the case will go to court and he will come out on bail and come back to kill you” (IDI#3 p16).*

Another participant felt that women are still not protected from sexual abuse; she made examples of how children and the elderly are victims of rape. What creates more anger and questions to women is the fact that most perpetrators rape and get away with it without proper sentencing, those who get sentenced get in most cases less than five years which they might not even do the entire sentence. Participants felt the punishment given to rapists is nothing and does not teach them a lesson. There was also a comparison of rural and urban areas in terms of developments regarding rape cases. It came out that in rural areas there is still an issue of rapes that occur within and between family members which are not being reported due to the belief that those are family issues. Reasons for not reporting can also be because of being ashamed and not knowing how the community or other family members will react towards the person who raped.

*“There is still a problem especially in the rural areas because there that thing of saying it is a family thing, let the shame be not revealed, you find that a father has raped his children, the mother knows but she will want to hide that. Really it is still happening you will find that this granny was not this person’s first victim.....” (FGD#1, P4, pg27).*

Women living with HIV cannot access their rights at times just because of their gender. They are violated and abused physically and emotionally by men. The right to legal protection from violence and abuse is violated and further perpetuates abuse. Furthermore, due to gender HIV positive women can be abused physically for trying to negotiate condom use with her partner therefore violating her right to legal protection from violence and sexual abuse.

#### **4.6 Mechanism used for violating rights**

When women's rights are violated there is a certain mechanism which is used in violating those rights. The mechanism includes not specifically asking for consent, not adequately informed, withholding necessary service and coercion.

##### **4.6.1 Not specifically asking for consent**

This study found that in some institutions mostly in health facilities, participants are not specifically asked for consent. In most cases when they don't ask for consent they do not follow procedure as they should be doing. One participant who was sterilised without her consent gave an insight of how the doctor failed to follow procedure as per sterilisation Act. Furthermore she went on to explain how the doctor failed to explain the side effects of what was going to be done to her. She shared:

*“About that, isn't the doctor should explain the consent and read it to you and if you going to be sterilised they have to read the consent, they have to tell you why they are sterilising you, the side effects of sterilising, the procedure that they we going none of that was done. No one read the consent to me, no one told me what they were going to do to me; you know I signed the consent when I was ready to deliver my child because I had contractions around 1, 2 and when we arrived at the hospital my mother had to leave me” (IDI#6 p5).*

The participant went on to explain the stage or state rather she was in when she first heard of the word 'sterilisation' and how the doctor took advantage of her when she was most vulnerable.

*“For instance, for me when I heard of the word sterilisation I was 38 weeks pregnant so the doctor wanted to book me for a ceasar so at that stage I had to think about it. Then he asked me, ‘do you want to be sterilised?’ then I was thinking ‘eh, sterilised’?”*

*At the age of 19 just think about that, then he booked me. When I was in labour then they sterilised me, so they know that once you are in labour.....” (IDI#6 p2).*

Another participant who was a victim of forced sterilisation shared her story of how she was not given the choice to decide whether she will like to be sterilised or not and she believed that doctors took advantage of her because of her HIV positive status.

*“Yet I have only signed for the epidural I have never signed, no one spoke to me even my doctor about you being sterilised and that’s when I thought no she took advantage of me because of my status. Because I knew everything if she has explained I was going to tell her that no I’m not ready for that but I was not given that choice and that chance” (IDI#4 p2).*

Participant 6 in focus group discussion shared a different story where she was at a health facility and she requested for a pap smear to be done and the nurse decided to teach another nurse how the Pap smear is done without asking for the participants consent. Participant shared:

*“Mostly here in clinics they don’t have time you see like myself I use KwaDabeka clinic, I went there to do pap smear they told me you are not in your periods I told them I don’t go there anymore. When she had me to lie in bed she teaches others in me thereafter my results are lost.....” (FGD#2, P6, pg16).*

One participant shared an experience she had when she was at a clinic to start family planning so that she could start treatment but due to the fact that she was not on her periods a pregnancy test had to be done which the nurse did. When she went to the toilet to pee so that the nurse could test the urine, she came back two other nurses were in the consulting room and no consent of inviting other colleagues was asked from her. The participant explained:

*“I went to pee and came back, when I came back I do not know what happened but I found three Sisters from where I was testing” (IDI#3 p2).*

#### **4.6.2 Not adequately informed**

The study found that in most cases participants were not informed about certain things that involved their lives and bodies. Health workers took decisions without giving adequate information to them. One participant shared a situation where a doctor failed to explain to her that she was going to be sterilised but instead took advantage of her because of her status and sterilised her without her consent. She explained:

*“Yet I have only signed for the epidural I have never signed, no one spoke to me even my doctor about you being sterilised and that’s when I thought no she took advantage of me because of my status. Because I knew everything if she has explained I was going to tell her that no I’m not ready for that but I was not given that choice and that chance” (IDI#4 p2).*

Another participant looked at a different aspect and focused on counsellors, she looked specifically at what is said by counsellors in a session when explaining rights to a patient. Her concern was that counsellors explain that what you talk about in a session is between the two of you while they fail to explain what they as patients can do in case they discover that what they discussed together is now known by others. The participant explained:

*“You see when you are going to be counselled, they tell you what to expect and that your conversation is between you and your counsellor, that maybe she will tell you your conversation is between both of you. But she/he does not explain what steps should you take should it happens that you find something that you talked to me about I have passed it on. She just tells you about what you are there for, that since you have this right to do this, but she does not tell you about her that you can press charges against her if she talks about you elsewhere, and if you find out about that you can go from here to where, what steps should you take; they do not explain that” (IDI#3 p5).*

#### **4.6.3 Withholding necessary service**

The study found out that in most cases there is withholding of service that takes place in health facilities to ensure that they abide with what health workers want them to do. Participants shared that they had to use contraceptives in order to get treatment (ARVs) otherwise if they don’t go for contraceptives they will not receive treatment. In terms of exclusions this may be seen as an example of power relations where health workers are using the power they have to decide on the conditions or how treatment will be received (Adato et

al. 2006). One participant shared how stressful it was for her learning that she had to use contraceptives even though her husband had passed on and she had no partner. In most cases where a necessary service is withheld coercion results and this study it became very clear that the two go hand in hand. Participants reported being coerced into contraceptives which meant if they fought against that treatment will not be rolled out to them (necessary service withheld). Therefore, the study found that withholding necessary service and coercion resulted in the participants' right to choose family planning and right to treatment being violated.

*“Yes, now you do not know what they said when they talked about this story, what they saw, you have that; you see I just see that now, firstly it was already suppressing me that I had to prevent knowing that I do not have a man but because I want this help I have to start by getting help by preventing, when I get there this preventing is now the one hindering me, I was very stressed” (IDI#3 p5).*

Two other participants also shared that it is not the health workers concern that you are not in a relationship all they want is the prevention card as proof that you have gone for prevention or family planning and then you can get your treatment. If a woman decides not to go for injection or contraception that decision can have serious implications. Deciding not to go for contraception will result in the women being denied treatment/ ARVs. Participants explained:

*“We are being forced to do that, the card for prevention is required, even if you tell them that you are not in a relationship they just push you, otherwise you will not get pills. I am not in a relationship but I have to go for prevention injection otherwise I will not get pills” (FGD#1, P7, pg17).*

*“You cannot afford to get pills because you did not have injection” (FGD#1, P4, pg17).*

#### **4.6.4 Coercion**

The study found that participants are forced to use contraceptives. Participants shared different experiences where there is no negotiation between themselves and health workers. This lack of negotiation between the two parties can be attributed to the power struggle between the two which leaves these women living with HIV in less powerless position therefore putting them in a position where they are unable to negotiate their rights or what is rightfully due to them. Even though most of them do not have partners but they were still

forced to use contraceptives mostly injection. Refusing contraceptive use for these women means they will not be given their treatment (ARVs). Healthcare workers have made contraceptives a precondition to accessing treatment for women living with HIV.

*“When you get to the injection section they yell at you and send you to go and pee, they ask you why did you delay? And when you tell them that you are not in a relationship they yell at you. They tell us the blood that comes out is no longer supposed to come out since you are now sick, you have to take injection, that is what they say” (FGD#1, P7, pg17).*

*“.....in clinics they ask for family planning card first before they give you treatment, you have to go for injection first before they give you treatment” (FGD#1, P7, pg22).*

Another participant spoke of a situation where they are forced to collect condoms regardless of whether they have partners or not.

*“They explain but the problem we are complaining because we are forced even if you say you don’t have a partner now you have to collect these condoms and fill them in the room what are they going to do?”(FGD#2, P7, pg34).*

## **4.7 Places where rights are violated**

The study found that women’s rights are violated in different places. Three places were observed; health facilities, households and communities. Under health facilities the important issue that came out was the system and separation of patients at health facilities.

### **4.7.1 Health facilities / system and separation of patients**

The study found that in health facilities people living with HIV are still stigmatised and they exposed to those who are not infected. The openness violates the right for participants to keep amongst other things their status confidential.

*“.....You see, while we were still talking about clinics, I feel we are still stigmatised at other clinics, when us, people who have this disease do not “clinic” together with other patients. That exposes us to those who are okay; they are sitting at the other side knowing that this side is for people with HIV” (FGD#1, P4, pg12).*

*“Now you find that at the clinics, maybe have not disclosed to the community yet, maybe the family knows but the community did not know about you yet. When you come to the clinics everything is open, people already know that when you have this*

*type of file and going to that particular door, that particular door is for these kinds of people, you find that there are people who come to the clinics to check the people who go to those doors. Now you find that you have lost your self-esteem because everyone can see you. Even some Sisters are known that this particular Sister deals with diseases for people of this condition” (IDI#3 p4).*

Furthermore, the study found that other clinics here in KZN refuse to provide treatment to people who are not from this province and they are told to go to their home provinces to get treatment. That discrimination in health facilities violates and denies those who are residents in KZN but were not born here their right to treatment.

*“In other clinics, when you come to them for help saying ‘I am from a particular place and I am stuck for a while I cannot go collect my treatment’. They would tell you ‘we are working with people who tested here not elsewhere you know where you collect your pills, then you should go there, here we work with those who tested here.’ It is worse, I am here in KZN, we are from Eastern Cape, when you come and tell them that you are from Eastern Cape they would tell you to go to Eastern Cape where you were taking your pills” (FGD#4, P1, pg11).*

One participant shared her experience when at the health facility she was not given adequate information about what was going to be done to her at the time when she went to deliver her baby, she thought she was signing consent for epidural while she was signing for consent as at a later stage when she was trying to have another child after getting married she learned that she had been sterilised. Amongst her other rights that were violated, her right to children as well was violated. Participant explained:

*“I signed the consent form that I’m going to have epidural you know if you are going through ‘epidural’ you have to sign a form because they put injection at your back you get numb from all over the bottom area but now when I came back from theatre not at the same time after some time after having that caesarean section I find out that I was sterilised” (IDI#4 p2).*

The study found that there is a system that is currently used in health facilities which separates those who are living with HIV from other patients with general illnesses. Participants felt that this system exposes their status to people who might visit the clinic at the same time as them. Apart from them sitting on the different side as other patients

participants shared that their files and stickers are distinguishable that it's for those who are HIV positive. This system and separation bridges confidentiality, it advertises those who are living with HIV to patients with general illnesses. It does not only bridge confidentiality but exacerbates stigma and discrimination of those who are living with HIV. Furthermore this separation enhances the 'them' and 'us' labelling which can further exacerbate exclusions of those living with HIV.

*“ In many places there is that division now, they even say ‘sick ones this side, those with the thing on the other side” (FGD#1, P2, pg13).*

*“They take sick ones there and us there, and your file is different, the file for Mpumelelo is distinguishable” (FGD#1, P5, pg13).*

*“You are being seen even by people who did not know you have this” (FGD#1, P3, pg13).*

One participant saw it as a good thing that they have their own place in clinics because it meant they don't have to queue. She shared that she has all the pride when she goes to the place where she collects her treatment, she said even the way she walks when she goes there changes. Participant went further to explain the laughter in their side of the clinics that attracts even those who are not HIV positive.

*“And also that in clinics we have rights because we do not queue with other patients, we have our own place and we are fine with that. You see in these places where there is still separation they are wrong. They are not supposed to do it like that, you see, where we collect our cards they are issued to where we sit, and pills too. It is not important that everyone should see what type of pills I get but when I go there, to that white room, I go with pride “ngihamba ngizengitshikize”. I want even for a person who is sitting there to see that I am going there.....” (FGD#3, P6, pg11).*

#### **4.7.2 Households**

The study found that HIV puts women in a situation where they are stigmatised even in their households.

*“Eat on my own dish and not meet with other people because they believe my sickness has put them into some kind of trouble, that maybe they can get sick like me” (IDI#3 p2).*

### **4.7.3 Communities**

According to the study community is also one of the places where there is discrimination against women living with HIV.

*“I have a right not to be discriminated, say maybe I have been discovered, maybe by the church that I go to or by the community I live in, about the condition of my health, there is no need for me to be discriminated about that” (IDI#3 p2).*

### **4.8 Persons involved in violating rights**

The study observed three groups of persons involved in violating the rights of women who are living with HIV. Those involve health worker, family members and community member.

#### **4.8.1 Health workers**

The study found that health workers play a role in violating rights of women living with HIV. Participants expressed that healthcare workers violated their right to have children and also by forcibly sterilising women. There was also a concern from participants of not being accepted by nurses and commented on the way nurses react when assisting them, as if they are going to infect them. One participant shared a situation where her friend wanted to study further and her colleagues who are nurses thought her going to study was a waste of time since she is HIV positive therefore violating her right to education.

*“Some of the nurses were saying these people who have got TB and who are HIV there’s no need to go and study and one nurse was saying why are these people bothering. One of my friends in this group of 5 wanted to go and study staff nurse and people there said because they suspect that she is HIV, ey these people they mustn’t go study because some people are very sick they are wasting time” (IDI#5 p10).*

*“For health care workers sterilisation is an offered service, they offer it they demand you to do it” (IDI#6 p3).*

*“At the clinics as well, we would also like to be acceptable to nurse maybe you have come to a nurse she will ask you what sickens you today, she is sitting at her table and your chair is there and when you approach she suspects that you might infect her and then she would say move away your chair. That makes you think could there be something I am going to infect her with if I come closer? I thought this person was a nurse, she is educated ....” (FGD#4, P7, pg6).*

### **4.8.2 Family members**

Amongst persons violating rights of women living with HIV family members were found to be one of them. Participants stated that they had a problem that once their families knew that they were sickly due to HIV they were discriminated, as a result their dishes and bath basins were put aside. Participants shared:

*“I have a right to live my life fully and like everyone else who does not have HIV. I also have a right to be respected in my family because sometimes you find that in families we are in, you find that I had been sick before they knew about my status, and once they find that I have this diseases you find that they are now having this discrimination, like not wanting to use the same dish as me, they do not want me to use other rooms, say maybe we have a sitting room in the family, I now have to be always in my room. That is killing my right” (IDI#3 p2).*

*“That s/he has to stay there because s/he is sick no one will touch her/him even taking food becomes a problem even the dishes of that person are put aside and the bathing basin” (FGD#2, P2, pg26).*

### **4.8.3 Community members**

The study found community members to be violating HIV positive women’s rights. Participants expressed that as people who are HIV positive they are discriminated against by other people. One participant also shared a case where her cousin sister disclosed to the whole family about her status of which her brothers ended up cursing her with it and the whole area became aware of her status as well.

*“It is just that people are discriminating us people who are HIV positive” (IDI#1 p2).*

*“So my cousin whom we come here with, she told this story at home that she is sick like this. And through misunderstanding her drunken brother went out and shouted that [ND: participants name] is like this, whereas she was just talking, she did not speak with one person. She should have asked her mother or sister on the side, so she spoke in front of children and they told uncles. The uncles are drunkards and now [ND: participants name] is known in the whole area that she is like this and she had just accepted that it is known because even when she has a relationship with someone or people say you and [ND: participants name] whereas she does not have anything you can see her, it is just that she is not here today, she is like me” (IDI#2 p10).*

## 4.9 Feelings/reactions

The study found that the situations that participants go through or have to deal with due to their HIV positive status interfere a lot with their feelings. One participant shared how she felt she has lost her self-esteem after knowing her status, she further talks of the anger she had when she had to deal with her in laws who had to care for her at the time when she was sickly and the person who brought her to this family had already passed on. Another participant shared her feelings about her forced sterilisation where she was sterilised without her consent but what was clearer was the anger she has against the doctors who did the procedure on her. It goes without saying that when the rights of people are violated their feelings get interfered with.

*“I had anger and noise [ND: participant is referring to inner emotion where she was asking herself lots of questions], and would cry when they brought me food because I never wanted to eat” (IDI#3 p10).*

*“And what frustrates me and makes me angry is the fact that it’s done by the doctors some are black who understand the society that we live in, the cultural practises and expectations. How can you sterilise a married person, there was a woman who begged and said can I at least contact my husband the doctor said ‘no just sign the papers’” (IDI#6 p6).*

## 4.10 How rights are accessed

The study found that women living with HIV access their rights by gathering in support groups, communicating, standing up for themselves and interacting with different organisations. Participants also shared that gathering into support groups is an advantage in that it makes it easier for them as women in cases where they need to share information to organise someone to come address them as a group rather than as individuals. These support groups enhance discussions of various issues and also in many instances becomes a platform where most women begin to gain knowledge about their rights.

*“Sometime it is by, maybe forming organisations like support groups because when you go there you go to the people who know your condition so maybe when you have a problem you will find that maybe there is another one who has had a similar problem and she will advise you. And also that in support group it is easier, when you*

*have organised someone with information, for her to come to a group than to an individual. It is really easy if you can gather yourselves.....” (IDI#3 p6).*

*“I knew them through meeting with people in support group talked and discussed then I ended up knowing my rights” (FGD#3, P7, pg5).*

*“You have to go to support groups, discuss and share information; get someone with knowledge because if you are alone you cannot be able to speak on your own” (FGD#4, P1, pg13).*

Another participant said it hasn't been easy for her to access her rights because she does not feel she has the power to tell a health worker what should be done so in other words she did not see herself as having the right to freedom of choice.

*“I must say I haven't, I may talk like this but it's hard to sort of; you can't tell a nurse I want to have five children because she'll tell you 'you are going to die you can't have two children' and you just shut up. Because if a doctor says I must cut this thumb today and next week he tells me that I must cut this hand I'll say the doctor is right I won't say I can't I still want my hand are there other things you could give me?” (IDI#6 p4).*

#### **4.11 Policy inclusion**

The study found that women living with HIV are not included in implementation of policies. Participants said they are not consulted or contacted as people who will be affected by those or that policy they only see with policies whenever they have been finalised. According to Esplen (2007) policymakers together with health practitioners in addressing the needs of women and girls living with HIV/AIDS should prioritise these demands as well as recognise the expertise of positive women themselves. Participants explained:

*“Wooh! Ah, ah we don't have. We don't, we don't. They don't involve us at all like I was saying they make porch and lovely policies and just put them all over. If they looking very nice and they've got this bright colour its ok and this logo” (IDI#4 p14).*

*“Did they contact women, no;.....I mean this is one of the wrong things they do, you can't draw up a policy without contacting people from the ground” (IDI#6 p4).*

*“I think there's been a limited focus to ensure that HIV positive women are seen as a vulnerable group so to speak and then their social rights are then respected, there's a*

*lot that one can say about the rights of HIV positive women to participate and access political spaces” (KI#2 p8)*

#### **4.12 What makes it easy to access rights?**

Some participants said that one’s commitment, not being afraid, talking about ones needs as well as having information makes it easier to access rights. Participants shared:

*“I think getting more and more information it makes things much easier because there are organisations that are willing to help without you paying a cent. I think more and more information” (IDI#4 p5).*

*“I think its talking, not being shy, not being afraid, talking about what we need, fight for and stand for our rights and come together to form a group to say this and that so that we are heard because if you talk as an individual you won’t be heard. Its better if you are gathered together and say the rights you need as people living with HIV, we wish for this and that this is where we are abused” (FGD#2, P2, pg26).*

#### **4.13 Difficulties/challenges and hindrances in accessing rights**

The study found that they are challenges/difficulties and hindrances that women living with HIV are faced with in trying to access their rights. Participants said that they couldn’t access their rights because of the power dominance between themselves and the health worker and also power dominance between themselves and men. Other participants stated that lack of communication and locking oneself inside the house does hinder access to rights. Another reason which was mentioned by women as one of the things which hinders them to access their rights is their financial instability. The major difficulty is the fear of being discriminated. One participant shared her personal experience where she is new in the area that she lives in but went to that area because of marriage. This participant discovered her status after her husband passed on and decided to join a support group away from her area because of the uncertainty of whether she will be accepted in the community as well as the fear of being discriminated.

*“It is the fear of being discriminated, like I will be scared to show myself thinking what the community might say, like me, I am not indigenous in the area I am married to, I am from elsewhere, I came there because of marriage. The person I married no longer exists now it is even harder for me to disclose, and help maybe that I can get somewhere else, as I have chosen this support group that is away from my community*

*because you do not know if the community will accept you in this condition” (IDI#3 p6).*

One key informant took this issue to an organisational level and pointed that the reason why there are hindrances in accessing the rights is that there are few organisations who take interest in the rights of women living with HIV. She explained:

*“I think legal services and I also think there are very few organisations that are interested in the rights of HIV positive women suppose it’s because of the exclusion and stigma that is associated with being HIV positive and I think marginalisation as well because I think women in general are marginalised because they are women but if they have HIV they are marginalised even further so it’s difficult for them to access like local power structures, chiefs and whatever else” (KI#2 p9)*

#### **4.14 Knowledge and behaviour change/ Choices being informed by knowledge of rights**

The study found that knowledge of rights did in most cases lead to behaviour change. Participants stated that knowledge of their rights helped them make their own choices. Furthermore, participants shared that once they knew about their rights they gained information and therefore were better empowered to make informed decisions about their lives. Once participants had knowledge they were able to make decisions concerning the right time to have a child, the correct treatment one should be receiving as well as ability to claim and demand what rightfully belongs to them and not letting their HIV positive status determine where they go.

*“Knowing about your rights helps because you get what you want when you want. Ignorance about rights will end you up doing something against your will, something you are not supposed to do and you would not see because you do not know anything about your rights” (FGD#3, P3, pg17).*

*“I think here, the knowledge of the rights gives you more information in your choices so you know if oh I still want to have a child it’s my choice I can have a child. Or ok, my CD4 count is down and my viral load is still flying high so I can’t have a child I have to wait. If you know, if you are informed then you can make a choice ok let me wait up until my CD4 goes up and my viral load goes flat down then I can have a child and the child will be negative” (IDI#4 p6).*

One participants felt differently about this issue, they stated that knowledge of rights will not always mean behaviour change because there would still be situations that oppresses them as women. The participant made an example of a common case in South Africa where women still don't own the power to negotiate condom use with their partners but instead they are forced to succumb to any behaviour from their husbands because they depend on them financially. Women fall into the trap of reinfection simply because of the power struggle which exists between men and women and also because of the fact that contesting or going against the husbands word will mean children might not be sent to school, the household will no longer be maintained since the husband is the sole breadwinner or even worse.

*“It happens that you have knowledge but find that it is the situation you are in that oppresses you, like say you are married now if you are in this condition you have to protect yourself and use a condom but you find that the husband.....you are unemployed and the husband is employed and also that you cannot change the way you use to do things. You find that maybe he has a disease, maybe you have been married for twenty years, you cannot come out of the blue and say ‘my husband let us change now we are using a condom’ and do that. You find that you know about your right but because of the situation you are under, it is you who suppresses that right”* (IDI#3 p8).

Another participant stated knowledge of rights does have an impact in ones behaviour but she made an example of her situation where she has to go for family planning even though she is not in a relationship but because she does not have courage to contest that and she wants to get ARVs so she prevents. This clearly illustrates that it will not always be the case that when women know about their rights they will be empowered to contest when they are not treated the way they should but instead they will be put in an inferior position even more because of their vulnerability.

*“It does have an impact and also, as I said that in clinic they do not give you ARVs without going through family planning first. That is because we do not really know what is going. You end up not getting your ARVs whereas if we really knew our rights and had courage to go to the right people and fight for these rights, ask why we are forced to do something we do not like, I am not in a relationship but I am forced to prevent”* (FGD#1, P4, pg21).

## **Summary**

This chapter presented the key findings of the study conducted in eThekweni district, KwaZulu-Natal, amongst women living with HIV. Findings of the study indicate that women living with HIV have little knowledge of their rights. The women revealed a few rights which they are able to access and enjoy because most of their rights are violated mainly in health facilities. Right to children, right to social security, right to freedom of choice and right to treatment are some of the rights which are violated.

## CHAPTER FIVE

### DISCUSSION AND CONCLUSION

#### 5.1 Introduction

There is lack of research investigating the impact of knowledge and stigma on women's access to rights and their ability to make choices. This study explored the rights and choices of women living with HIV in the eThekweni district. The study draws on in-depth interviews and focus group discussions conducted with women aged between 24- 63 years.

#### 5.2 Discussion

This study found that women who are living with HIV don't know about their rights and that they lack information about their rights. Participants were not only ignorant about their rights as women living with HIV but they were also ignorant about their general rights as women. Their responses to questions showed that they lacked knowledge about their rights, so they responded in a way that made sense to them.

Another aspect that was investigated by the study is the link between level of education and knowledge of rights. The study showed that education is linked to decision making power and awareness of what one rightfully deserves. The majority of participants had high school education only. With this level of education it may be less likely for a woman to challenge or object certain actions opposed to her due to lack of or her ignorance about rights.

The study found that women have access to a few rights. The right to education, right to housing and right to marriage were some of the rights that women attributed to having easy access to. Participants used the example of access to housing in which they explained that when one applies for a place to stay they are not asked about their HIV status which means they can access it. With the right to housing, the study found that women could access this right because they were not required to divulge their status in order to apply or to be granted the government house. Thus, ones' HIV status may hinder access to other rights as this suggests that where the HIV status is disclosed, it would hinder their right to housing. The right to marry, is the only right that women had access to regardless of status. However, a man's family might object to the marriage if they had knowledge of the woman's HIV positive status but their behaviour might differ if the man is also known to be HIV positive.

Having a right, does not necessarily mean being able to take advantage of that right. Women living with HIV may have access to these abovementioned rights but taking advantage of these rights may be a challenge especially in relation to the right to education.

In relation to access, the study showed that women living with HIV access their rights by gathering in support groups and interacting with different organisations. Participants believed that being in a support group made things easier even in situations where information is needed on something as a group you can easily identify someone who can come address you on that issue. This however, means that if you are a women living with HIV and you don't know any support group or you are not part of any support group you are at a disadvantage and as an individual you can't do much by yourself. In terms of the power dynamics, this highlights the power women have as a group as opposed to individual beings. Therefore, women living with HIV can only have power when acting as a collective and cannot exercise that power as individuals. Furthermore, support groups provided far more than emotional support, as they were also reported to provide food and sometimes clothing for these women. However, participants in this study strongly believed that support groups can be used as a platform where information can be rolled out while providing the support, as a result women felt that being part of a support group made things easier. According to Simbayi et al (2007: 1830) support groups are common in southern Africa and may be used as a starting place for the development of social support interventions.

With access of rights there were also difficulties and hindrances that women faced in trying to access their rights. The main difficulty was the issue of power dynamics. Participants were referring to power dynamics in relation to themselves and healthcare workers as well as between themselves and men. "The existing imbalance in power between men and women has serious implications for women's ability to protect themselves from infection, to feel safe in determining their HIV status, to seek support and care when infected, and to make choices for their own welfare independent of others" (Hasnain, 2004: 81). Women felt they don't have the power to go against what is said by the health care worker because there is that belief that because they know better since they are educated, and due to the conception that eventually as patients they need to be served by the same health care workers and thus going against health care workers, may mean no treatment or care for them. Another hindrance found by the study, is the fear of being discriminated against. This fear comes with a high level of uncertainty as to whether one will be accepted once their status is known. Furthermore, a key informant pointed out that the reason there are hindrances with accessing

rights was because there are few organisations who take interest in the rights of HIV positive women.

This study suggests that stigma hinders women from accessing or enjoying their rights. Participants shared that there is stigma attached to being HIV positive, the stigma being that the virus only infects promiscuous individuals. Most participants agreed and stated that the fact that HIV is transmitted through sex creates a notion or mentality that the disease is a means of punishment for those who are promiscuous and careless. Apart from stigma women living with HIV get discriminated a lot. Community members, family members as well as health care workers play a huge role in discriminating women living with HIV. A study conducted to examine internalised AIDS stigmas among people living with HIV/AIDS in Cape Town, South Africa, reported that in a sample of 643 HIV positive women and 420 HIV positive men; more than 40% had experienced discrimination as a result of the HIV infection and one in five persons living with HIV/AIDS had lost a place to stay or a job due to their HIV status (Simbayi et al, 2007).

This study found that knowledge of rights does lead to behaviour change. Participants shared that once they are knowledgeable about their rights, they gained information and therefore were better empowered to make informed decisions about their lives. Some of the things that participants were able to make decisions on were, the right time to have children, the correct treatment one should be receiving as well as ability to claim and demand what rightfully belongs to them. However, knowledge of rights will not always lead to behaviour change. One participant felt that knowledge of rights will not always mean behaviour change because there will still be situations that oppress them as women. Situations such as being forced to use contraceptives even if you are not in a relationship and so on.

This study also found that the rights of women living with HIV are violated. These rights are violated in the households, healthcare facilities as well as in communities where women live. Family members, community members and healthcare workers were reported to play a huge role in violating the rights of women living with HIV. When the rights of these women are violated there's a certain mechanism which is used to violate their rights. This mechanism further perpetuates social exclusions in the lives of HIV positive women.

This study found that there is a certain mechanism that is used to exclude women who are living with HIV. The first mechanism is where healthcare workers don't specifically ask for consent from women. This results to violation of rights of women living with HIV in that when healthcare workers don't ask for their consent, they don't follow necessary procedures. Furthermore, when healthcare workers don't ask for consent they don't give women a choice to decide on whether they want to go through the process or not. For instance, two women who were victims of forced sterilization shared how healthcare workers failed to follow procedures as outlined by the Sterilization Act as well as the failure to explain what the procedure entailed. This contradicts what medical professional define as "doctrine of informed consent" which requires that patients consent to all surgical procedures and that they understand the procedure before they give consent. Informed consent is not only an ethical obligation but it's also a legal requirement which means that healthcare workers need to do more than just getting the patient to sign (Nair and Candidate, 2011).

The International Community of Women Living with HIV/ AIDS (ICW) conducted a survey of HIV positive women in Namibia and found that out of their 230 subjects 40 had been sterilised without their consent (Nair and Candidate, 2011). Women reported being given forms when they were minutes away to giving birth (Nair and Candidate, 2011). These findings are similar to the results of this study. Furthermore, in a study conducted in two South African provinces which is Kwazulu-Natal and Gauteng province, 4 participants reported being sterilised without their knowledge and 18 reported being involuntarily sterilised. 21 participants reported being sterilised at a health care facility while one participant reported being sterilised at a private health care facility (Strode et al, 2012). It's important to mention that many of the cases of sterilisation that were reported by participants in the latter study occurred before ART became widely available in South Africa.

Apart from not specifically asking for consent, this study found that healthcare workers didn't provide adequate information to women. Healthcare workers either provided insufficient or no information at all. Withholding necessary service is another mechanism used by healthcare workers to violate the rights of women living with HIV. This study found that healthcare workers withhold certain necessary services from the women to ensure that they abide with whatever they set for them. For instance, women are forced by healthcare workers to use contraceptives/family planning even when they are not in relationships. Failure to go

for contraception leads to no treatment. Majority of participants shared that trying to go against contraceptive use only means that treatment will not be rolled out to them. Coercion is the last mechanism of exclusion. Participants shared that there is no negotiation between themselves and healthcare workers. This lack of negotiation is attributed to the power struggle between the two parties which leaves women powerless therefore putting them in a position where they can't negotiate their rights or what is rightfully due to them. Participants reported being coerced into using contraceptives. This study found that where a necessary service is withheld, coercion results which made the two go hand in hand. Therefore, this study revealed that withholding necessary service and coercion results in the right of women to choose family planning and right to treatment being violated.

### **Recommendations:**

- Women should be provided with information, education on human as well as women's rights.
- Government departments and organisations that are devoted to fighting HIV/AIDS, and AIDS policy makers need to formulate interventions that will help to assist the women. These policies need to be specific to HIV positive women.
- Campaigns within communities to provide relevant and sufficient information to community members with an aim to fight stigma and discrimination need to be developed.
- Programmes to empower women should be developed and implemented.
- There is also a need for future research.
- The Department of Health needs to come up with a new system in clinics which will not breach confidentiality of women living with HIV.
- Implementation of inclusive campaigns on sexual and reproductive health and rights affecting women living with HIV should be prioritised.
- The education system should embrace a culture of diversity as well as be cognisant of the specific issues affecting women living with HIV.
- There should be effective capacity building and organisational strengthening strategies to ensure sustainability while limiting dependency.
- HIV/AIDS programmes can address detrimental gender norms and stereotypes by working with men and boys to change these norms associated to fatherhood, sexual responsibility, decision-making and violence, and by providing comprehensive, age-

appropriate HIV/AIDS education for young people that addresses gender norms.

### **5.3 Conclusion**

This study was aimed at documenting how knowledgeable and aware women living with HIV are when it comes to their rights. The findings have shown that women are not so knowledgeable about their rights. Furthermore, with the few rights that women living with HIV were aware of they still could not enjoy those rights fully due to the fact that those rights were violated. Health workers were said to be playing a major role in violating the rights of these women. There were still issues of stigma as well as the fear of being discriminated which exacerbated exclusions of the women. Factors like gender, level of education also had an impact in how the rights are known as well as accessed. The rights that women are fully accessing are the right to housing, right to education as well as right to be married. Furthermore, the mechanisms used to perpetuate exclusion of fundamental rights to women living with HIV are as subtle as not being fully informed and as blatant as coercion. These were explored in this study and it became clear that these play a huge role in excluding women even further.

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## **APPENDIX A: INTERVIEWER GUIDES**

### **Participant IDIs/ FGD**

#### **Demographic Characteristics**

##### **Age:**

##### **Marital status**

- Married, husband lives in same household
- Married, husband lives separately (eg. for work)
- Separated
- Divorced
- Widow
- In a relationship, living in same household as partner
- In a relationship, partner lives separately
- Not in a relationship

##### **Race**

- African
- Indian
- Coloured
- White

##### **Home language**

- IsiZulu
- IsiXhosa
- English
- Sesotho
- Other (specify)

##### **Level of education obtained:**

- Never attended school or only attended preschool
- Primary school
- Some Secondary School
- Completed grade 12
- Some technikon, college, or technical school
- Completed technikon, college, technical school
- Some university
- Completed undergraduate degree
- University postgraduate

## **Employment Status**

Are you currently?

- Employed: specify job:
- Self-employed: specify:
- Unemployed, looking for work
- Housewife
- Student
- Retired
- Unable to work

**What is your main source of income?**

### **Current Place of residence**

- Township
- Suburb
- Informal settlements
- Rural area

**Place where you lived most of your time as a child?**

- Township
- Suburb
- Informal settlements
- Rural area

**Do you have children?**

- Yes (how many?)
- No

**Questions relating to the organisation:**

1. How did you find out about this organisation?
2. Why did you come to the organisation, why did you make contact with the organisation?
3. How long have you been a member OR have been receiving services in this organisation?
4. What kind of activities have you been involved in? OR What kind of services have you received from this organisation?
5. What other kind of activities or services are offered by the organisation?

## **Opening, broad questions:**

### **9. Please explain what you understand the rights of an HIV positive woman to be?**

How would you describe the rights that HIV-positive women have? OR What rights do you think HIV-positive women have? Please list different rights that you have access to.

Please explain how you have managed to access those rights

What would you say made it possible for you to access those rights?

12.3. Could you explain what challenges/hindrances you met in accessing other rights?

Probe: Why do you think your rights may not always be respected?

### **Please describe any incidents of how those rights may not be respected?**

### **How do HIV positive women become aware of their rights?**

How do HIV positive women access these rights?

9.1. What makes it easy for HIV-positive women to access their rights?

9.2. What makes it difficult for HIV-positive women to access their rights?

Probe: Why do you think the rights of HIV-positive women are not always respected?

12.2. How does the knowledge of their rights inform their choice?

### **Rights in a relationship**

1. What do you understand about the terms discordant and concordant couples?
2. What do you think is meant by dual protection?

Probe: According to your knowledge, what is the understanding of other women about dual protection?

10. If you had access to safe conception practises such as artificial insemination would you consider having children?

11. Could you please explain your spouses' level of involvement as far as choices/decisions in falling pregnant is concerned? (ask pregnant women or those who have already given birth)

### **BREASTFEEDING**

12. Could you explain your experiences regarding access to education on breastfeeding?
13. What is commonly said about breastfeeding while you are HIV positive?
- Probe: what are your feelings about this?
14. From what you know/have experienced, can you describe how decisions about infant feeding choices are made?

### **CONTRACEPTIVES**

15. Did you receive any counselling regarding contraceptives and their availability?
- Probe: If yes, who was offering that counselling?
16. Would you explain how decisions are made as to which type of contraceptive would be used?
17. How does knowledge of rights, information or lack thereof contributes to your health seeking behaviour?

**Right to confidentiality**

**Right to treatment**

**Right to education**

**Right to employment**

**Right to housing / property**

**Right to public services**

**Right to social security**

**Right to be married**

**Right to sexual health (contraception, STI services etc)**

**Right to abortion**

**Right to legal protection from violence**

**Right to protection from sexual abuse and violence**

**Right to legal services in divorce, child custody, child maintenance issues**

**Right to children**

**PMTCT in pregnancy**

**PMTCT in breastfeeding**

**Right to consultation in the development of policies and programmes**

### **CLOSING QUESTIONS**

18. Since being diagnosed with HIV, what do health workers at this facility OR at health facilities OR at your last visit OR at today's visit ask you regarding your social and financial circumstances?

## **Key Informants (KI) IDIs**

1. What is the vision/mission/purpose of the organisation?
2. When was the organisation formed/found?
3. Who are the main founders of the organisation?
4. Who are the beneficiaries of the organisation?
5. How do the beneficiaries find out about the organisation?
6. What activities does the organisation undertake?
7. Do some of your activities include rights?
  - If **yes**, which rights?
8. How are these activities funded?
9. What information is used to measure whether the activities are successful?
10. How did you come to work for the organisation?
11. What is your role in the organisation?
12. Which areas does the organisation service?
13. Why do most of the women who access services at PHAKAMISA/HRI come to the organization?
14. What pushes them to make contact with you?
15. Please explain what you understand the rights of an HIV positive woman to be?
16. How would you describe the rights that HIV-positive women have? OR What rights do you think HIV-positive women have?
17. Please list different rights that HIV positive women have access to.
18. What would you say makes it possible for HIV positive women to access those rights?
19. Could you explain what challenges/hindrances HIV positive women typically meet in accessing their rights?  
Probe: Why do you think their rights may not always be respected?