

**REPRODUCTIVE ASPIRATIONS AND
INTENTIONS OF YOUNG WOMEN LIVING
WITH HIV, IN TWO SOUTH AFRICAN
TOWNSHIPS**

by

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Abstract

South Africa has an estimated population of approximately 47.9 million of which almost (51%) are female; according to the 2007 mid-year report of Statistics South Africa (Stats-SA, 2007). The availability of Antiretroviral (ARVs) that delay HIV progression and improve quality of life of HIV infected individuals and the roll-out of prevention of mother to child transmission (PMTCT) have brought renewed hope among many couples and individuals in South Africa. The four pillars of the Prevention of Mother to Child Transmission (PMTCT) programme include prevention of HIV infection among young women, prevention of un-intended pregnancies among HIV infected women, prevention of HIV infection to the child and provision of care and support services.

HIV-positive young women live by socially and medically constructed values that expect them to avoid becoming pregnant, but at the same time they are expected to marry and bear children. A more in-depth understanding of the reproductive decision making experiences of women below the age of 35 is needed because they are at reproductive age and most at risk of HIV infection in South Africa. The impact of a positive HIV diagnosis may be best understood when viewed within a social constructivist framework.

A few studies in South Africa (Cooper et al, 2005; Harries et al, 2007; Myer, Morroni, and Rebe, 2007; Orner *et al*, 2007; Stevens, 2008) have been conducted on fertility desires of HIV positive individuals and couples although not specifically exploring young women who are mostly vulnerable to HIV infection. Recognizing the gap in the desired public health care objectives, such as preventing mother to child transmission of HIV and the lived experiences of young women living with HIV, this qualitative exploratory research was conducted in two South African Townships. The purpose was to explore the reproductive aspirations and intentions of the women below the age of 35, in the light of the higher HIV prevalence in this population, compared to other groups. The research explored two theories of human behaviour; the theory of planned behaviour and Erick Erikson's human developmental theory. Eleven semi-structured in-depth interviews and two focus

group discussions were conducted through support groups at clinics in Soweto and Atteridgeville. Ethical approval was obtained from the University of KwaZulu-Natal and all participants signed consent to participate in the research.

Findings showed that women younger than 30 who did not have a child, desired and intended to have biological children. Health concerns such as CD4 count, concerns about HIV progression, early death and orphan-hood, previous loss of a child due to HIV and financial concerns were often cited. Tied to this were health workers' attitudes towards pregnancy among women who knew their HIV status. Women said that a child brought joy, strength and courage to the mother and was seen as an **image**, when the mother dies, due to HIV. Almost all the women were in support groups that openly discouraged pregnancy among HIV positive women, especially those who already have a child or children.

This research indicates that in practice, counselling and information around reproductive health and choices, is often offered in a quest to dissuade HIV-infected women from considering pregnancy. Health services, families and partners, as well as past experiences of motherhood, all play a role in decision making (Cooper *et al*, 2005). Sometimes policy guidelines alone are not enough to ensure that reproductive rights of women living with HIV are respected **at the different levels**. This research points out the population of women who have specific needs and who should not be treated as a homogenous group with all women. This recognition should go beyond policy recommendations into implementation and monitoring.

DECLARATION

Submitted in partial fulfillment of the requirements for the degree of Masters in Health Promotion, in the Graduate Programme in Psychology, University of KwaZulu-Natal,
Durban, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Masters in Health Promotion in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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Acronyms

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
OVC	Orphans and vulnerable children
PLWH/A	People living with HIV and AIDS
GBV	Gender-based violence
STI	Sexually transmitted infection
PMTCT	Prevention of mother to child transmission
VCT	Voluntary counselling and testing
WHO	World Health Organisation
FGD	Focus Group Discussion

DEFINITION OF KEY TERMS

Antiretroviral Therapy

Antiretroviral therapy for HIV infection consists of drugs which work against HIV infection by slowing down the replication of HIV in the body. The treatment consists of drugs that have to be taken every day for the rest of a person's life.

CD4 Count

CD4 cells, sometimes called T-cells are a type of lymphocyte (white blood cell) and an important part of the immune system. They lead the attack against infections

HIV-positive

Refers to people who have taken an HIV test whose results have been confirmed positive and who know their result

HIV status unknown

Refers to people who have not taken an HIV test or who do not know the result of their test

HIV discordant couples

Sexually active couple where one partner is HIV positive and the other is HIV negative

Health care worker

Any person who is involved in the provision of health services to a user, but does not include a health care provider. This includes lay counselors and community caregivers.

Mother-to-child transmission

Transmission of HIV from an HIV-positive woman during pregnancy, delivery or breastfeeding, to her child. The term is used because the immediate source of the infection is the mother, and does not imply blame on the mother.

Termination of pregnancy

Termination of a pregnancy" means the separation and expulsion, by medical or surgical means, of the contents of the uterus of a pregnant woman

“No woman can determine the direction of her own life without the ability to determine her sexuality. Sexuality is an integral, deeply ingrained part of every human being’s life and should not be subject to debate or coercion. Anyone who is truly committed to human rights recognizes that every woman has the right to determine and express her sexuality free of discrimination.” (The Equality Project, 2004)

Chapter 1

Introduction

South Africa with its population of over 48 million people, shares much of the beautiful landscape of Africa: the oceans and waterfalls, natural caves, game reserves, including the mineral resources such as gold and platinum (Statistics South Africa- Census, 2007). For many years this country was subjected to Apartheid rule that robbed most of its inhabitants of enjoying these natural resources. The economy of the country though, has been better off than most of its neighboring counterparts, a phenomenon that South Africa boasts to this day. It is very unfortunate that, this transformation was soon followed by the scourge of an HIV epidemic which affected mostly the already vulnerable groups of the society, young women and children. In 1994, in line with the new political dispensation, a democratic government was elected by all for the first time in its history, and a new South Africa was born. The new government had many challenges lying ahead of it, especially on addressing issues of the apartheid legacy, including poverty to the masses, unemployment, general societal violence and gender-based violence, and in the past twenty years the emergence of HIV and AIDS. Subsequently, the wellbeing and the quality of life of many in this country however paint an undesirable picture, which does not complement these environmental and economic gains.

Just under two-thirds of all people living with HIV are in sub-Saharan Africa, and 76% of the infected are women (Pettifor, Rees and Stevens, 2004). The estimated

HIV prevalence is 28% among pregnant women aged 20-24 and 38% of those aged 25-29 (South African Ante-natal Care HIV/Syphilis Report, 2008). A report from the University of Witwatersrand in April 2004 indicates that women make up to 77% of the 10 % of South African youth between the ages of 15-24 who are infected with HIV (Pettifor et al., 2004).

Not much research has been done in South Africa that focuses specifically on women who are below the age of thirty-five, their reproductive aspirations, and factors that inform their intentions to have or not to have to children. However, some remarkable research has been done on this subject among HIV positive women and men in Cape Town (Cooper et al., 2005). There is also some work on reproductive rights of HIV positive people (London, Orner and Myer, 2008; Harries et al. 2007) on Policy-maker and health provider perspectives.

1.1 Research Problem

In many instances an HIV diagnosis calls into question a number of issues that are commonly taken for granted, such as whether to engage in sexual relationships, the nature of these relationships, disclosure issues and decisions about reproductive health and rights issues. Motherhood and HIV should be viewed beyond the biomedical interpretation of disease and explored to the meaning and value that motherhood has for communities; so that socially acceptable alternatives to motherhood can be provided.

Even in the absence of a chronic illness, making decisions about pregnancy and childbearing are not always clearly defined, and highlight a need for research that examines the decision-making patterns among HIV positive women (Wesley, Smeltzer, Redeker, Palumbo and Whipple, 2000). The theory of reasoned action maintains that motivation to comply with subjective norms that the society places is a key determinant in decision-making (Ajzen, 1991). On a different note, the Centres for Diseases Control (CDC) made recommendations that HIV – infected women should avoid pregnancy and childbearing at all costs. The message is further echoed to women during post-test counseling and in the support groups which they

attend. This leaves them caught between socio-cultural expectations and doing the right thing (complying with the bio-medical messages that they receive from health care workers.)

The World Health Organization (2004) defines sexual health as a state of physical, emotional, mental and social wellbeing in relation to sexuality. In that case, sexual rights embrace human rights that are already recognised in national laws, international human rights documents and other consensus statements. For the purpose of this research, more focus was on the right to decide whether or not and when to have children and the right to pursue a satisfying, safe and pleasurable sex life. For a person living with HIV there is a potential risk of HIV transmission to the uninfected sexual partner, as well as the unborn child, in addition to the health risk to the mother.

Although adoption is an alternative to having a child, this may not be culturally acceptable to an average Black woman and some women may feel a need to have a biological child or children. Although more and more women, (especially in urban parts of South Africa) have become liberated and independent in different ways (www.adoptionsa.co.za), the HIV epidemic has made it challenging to lead pleasurable, safe, sexual lives. Some women may have been brought up to understand the importance of marriage and childbearing. With this kind of socialisation it may not be easy to carefully explore other safer alternatives to motherhood, particularly because these kinds of decisions do not lie with individuals, but with the collective that they are part of.

Lastly, pregnancy is not necessarily a rational process, as often assumed because in most instances, couples and individuals often react to pregnancy as a surprise rather than a carefully calculated and planned process. Adoption may not be a culturally acceptable an option for the population in this research.

While some women get to know their HIV status when they are pregnant or when their babies get sick, others get to know their status through voluntary HIV

counseling and testing (VCT). This however does not make it any easier to make reproductive decisions about pregnancy. The related stigma and the complexity of the expectations from family and others may prevent some women from wanting to know their HIV status. Women, whether HIV positive or not, have different reasons for wanting or not wanting to have children, and are exposed to similar forms of socialisation and expectations. In the case of HIV infected women, the anxiety may be minimised by the availability of potential and highly effective Prevention of Mother to Child Transmission (PMTCT) strategies and Anti-retroviral Therapy (ART) which are widely adopted at most major public healthcare service centres in South Africa.

Some women may be discouraged from bringing the pregnancy to term once they know their HIV status, and may wish to terminate the pregnancy. While termination of pregnancy is legal in South Africa, the decision to take this option may not be clearly defined for some women, due to issues of their own values about the termination of pregnancy, attitudes of those close to them, as well as cost and access to this kind of service (Mitchell, Trueman , Gabriel and Bock, 2005).

1.2 Purpose of research

This research explores the aspirations of Black women living with HIV in two South African townships with regard to having biological children and factors that relate to them. Ajzen's theory of planned behavior and Erikson's human developmental theory serve as a framework in exploring this subject. The research is based on the following assumptions:

- As women get older, they will feel a need to extend care towards something considered valuable in their setting, usually a child and they will need to resolve this.
- Women living with HIV, who aspire and intend to have children, have a positive attitude towards having children.
- Women's belief about society's (parents, partners, relatives, friends, colleagues, health care workers etc.) perceptions will influence their reproductive aspirations and intentions.

- Those women who feel in control of the decision-making are more likely to exercise their rights, irrespective of the approval of others.

For any young woman and man, the pressure from family, partners and peers to have biological children to prove fertility or ability to reproduce, can be overwhelming (Cooper et al 2005).

Anecdotal evidence tells that, there is an expectation for young men and women to get married and have children of their own at some stage in their lives. When one does not conform to this ideal way of life, there are often verbal and non-verbal questions, irrespective of one's circumstances or choices. While for some young men this may not necessarily go beyond knowing and showing off that one has a child, for women this may be a serious defining moment and the future can be affected by such a decision. Although HIV has been initially perceived by many, as a life-threatening disease, there has been a significant shift in recognition that HIV can also be managed. The increased acceptability of people living with HIV and the disclosure of significant figures of society as well as the availability of ART which delays HIV progression has lead to renewed hopes and courage in lives of many. Whether these have also improved the desire to have children for HIV infected women, needs a closer look.

1.3 Objectives

The objectives for undertaking this research were:

- To explore the attitudes and intentions of young women living with HIV in Atteridgeville and Soweto towards having children and factors related to such attitudes
- To describe reasons and factors that influence aspirations and intentions to have or not to have children
- To explore the role of significant others in influencing attitudes and intentions towards pregnancy

1.4 Study Design

Qualitative methods aid the understanding of attitudes, perceptions and behaviours in a more thorough and concise manner. This qualitative research explored the reproductive aspirations and desires of young HIV infected women who know their HIV status. The research was carried out at Atteridgeville and Soweto townships in Gauteng province, South Africa. Participants were invited on the basis that they are over sixteen years of age and able to provide informed consent. Focus groups and in-depth interviews will be conducted. A total of 32 HIV positive women participated in the study.

1.5 Semi-Structured Interviews

Semi-structured interviews were conducted. In line with the theoretical frameworks applied in this study, the interview guide asked questions about meanings of motherhood. Specifically participants were asked what they think or feel about having children (attitudes and intentions), parity, how others (partners, friends, fellow support group members and family) would perceive them if they expressed their intentions (subjective norms), what they would do if their intentions were not agreed to by others (control) and what having a child meant to them (generativity) or reasons for wanting to have a child. Each interview took about an hour to complete.

1.6 Focus Group Discussions

Two focus group discussions were held, with 8 to 10 participants per group. Participants were limited to women living with HIV. Similar to the semi-structured interviews the focus group discussion guide broadly asked about intentions and attitudes of participants towards pregnancy among HIV positive individuals, perceived normative attitudes from significant others, reasons for wanting or not wanting to have a child, and the control that participants perceived themselves to have in exercising their choices.

1.7 Data analysis

All data were transcribed verbatim and translated into English where necessary. Primarily data were coded for emerging and common themes with the help of NVIVO 7, computer software that aids in the coding of qualitative data. Data analysis, interpretation and reflection were continuous and commenced during interviewing, transcribing, writing field notes, discussing and reading. The data was read thoroughly to identify patterns, and coded to identify emerging themes. The themes were examined for discourses used by participants. Data collection and analysis processes are explained in more detail in chapter 4. The subsequent chapters expand on the processes that include theoretical perspectives to the subject, the review of literature on the subject, methods, discussion and the conclusion.

Chapter 2

Theoretical perspectives on human behavior

A theory is a scientific but tentative statement of relationships among diverse phenomena (Ulin, Robinson and Tolley; 2005). Its purpose is to make sense, understand and anticipate how human beings will react to certain events or to one another. The research took into account two theories of human behaviour. The first one is a prediction of an action; which is based on health psychology principles of behaviour change. Attitudes, subjective norms, and perceived behavioral control are shown to be related to appropriate sets of salient behavioral, normative, and control beliefs about the behavior. Its relevance is in predicting women's decisions around getting pregnant, post testing for HIV, and knowing their status. The post test counseling offered to individuals encourages women to make informed decisions and plan their behaviour with regards to a number of issues, including making reproductive decisions. Ajzen's theory (1991) expands on the principles of planned behaviour.

The second psychological theory of human development (Erikson, 1959) refers to human needs and the importance of fulfilling the needs to avert negative outcomes. Erickson mainly asserts that failure to meet these needs which he calls 'crisis' creates an imbalance in their lives and negatively affects their ability to establish a healthy life. With regard to this study Erikson's theory is critical as it suggests that when individuals fail to resolve the 'generativity crisis' their future stages of development will be affected and that will create an imbalance in their lives.

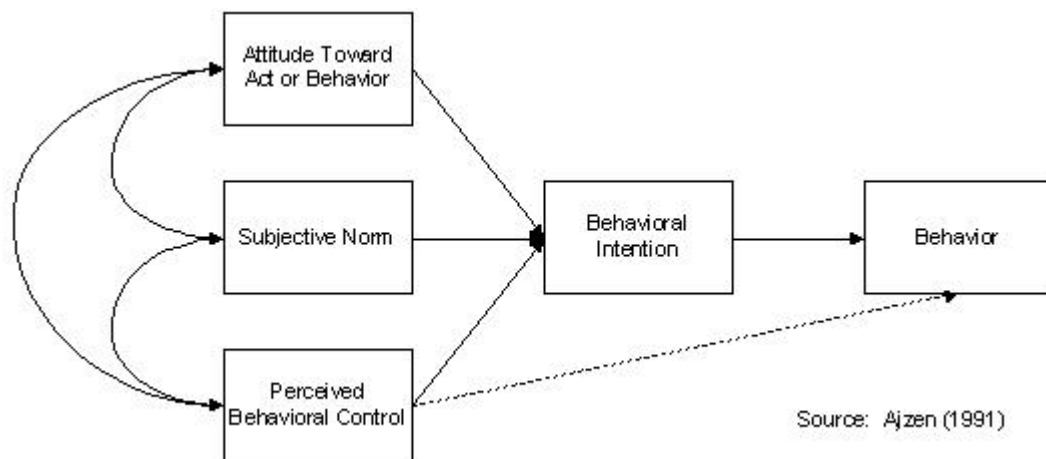
Ajzen's theory predicts human behavior beyond individual and natural factors, to include normative expectations which could influence decisions that people make. Erickson points out more of the 'natural' stages that could define behaviour and human needs and does not expand on the influence of their environment. In this research, context plays an important role and will actively be brought into both theories.

2.1 The theory of planned behaviour

The theory of planned behaviour emphasised that behavioural intention, attitude towards the behaviour, approval or disapproval of significant others as well as perceived behavioural control have an influence in the performance of a certain behaviour.

Figure 1: Illustrative Diagram of the theory of planned behavior.

Source: (Ajzen 1991) pg 179-211.



- Behavioural intention refers to the perceived likelihood of performing certain behaviour. For instance, not using contraception, getting pregnant and not terminating the pregnancy would be attributed to an intention to have a child because all these are in line with behaviour among those who aspire to have children (Peltzer, Chao & Dana, 2008). Even so, some research contests that failure to use contraception is linked with desire to get pregnant. Accessibility, availability, side effects, incorrect information, partner refusal and costs are cited as some of the factors that could hinder women from using contraceptives (Smits et al., 1999). In the same breath, Laher and Kaida (28 April 2008; unpublished report) also echo that in a study in Soweto, issues of accessibility, safety, availability and acceptability were mentioned and most women who did not desire to have children but were not using female controlled contraceptives. The pill burden, side

effects and partner disapproval clearly came out. This study however found an unexplained discrepancy between low reported desire to have children and non-use of reliable contraceptive methods. However, Smits et al., (1999) reported that, 70% of women who did not terminate their pregnancy cited the desire to have a child as the most important reason for carrying the pregnancy to term.

- Attitude is about the belief that performing certain behaviour has certain outcomes. Getting pregnant for young women in South Africa was viewed as a positive step in defining the future of a relationship particularly in long-term relationships (Cooper et al; 2005). Once again, Laher and Kaida (2008) found a low stated desire to have a child as well as both planned and unplanned pregnancy among women living with HIV. These are the same women who were not using female controlled contraceptives. However this study did not measure the period since HIV diagnosis which could influence women's responses.
- Subjective norm and motivation to comply describes the belief about whether the key people or significant others (partners, relatives, friends and colleagues) approve or disapprove of the proposed behaviour. This is also described as the motivation to behave in ways that gain approval from other people. In this instance, as women get older, there are expectations from them to complete studying, get stable employment, get married and have children. These would come mainly from the in-laws in cases of married women (Nduna, 28 April, 2008 conference presentation). This is more so in African, Black communities, where marriage is not only about the two individuals, who get married, but in-laws, particularly paternal grandmothers play an important decision-making role about the future of the couple including reproductive decisions.
- Perceived behavioural control and power is the belief that one has and can exercise the control over performing behaviour. However, as mentioned above, structural access to services, including contraception, abortion and

social expectations could make it difficult for women to act on some of the decisions they have taken.

2.2 Human developmental theory: Generativity versus self-absorption

There are several developmental theories that describe human behaviour from various perspectives, but for the purpose of this research, Erickson's theory was more relevant in defining expected developmental changes for individuals at different stages. While Erickson explains human development from birth to death, the focus of this research is on the middle adulthood stages which closely describe the sample.

Although the desire to have children and intentions thereof could result from developmental factors, outside the social influences from the community that women live in, Erickson in his seventh stage of human development which he terms middle adulthood, flips another side of the coin. This is the period during which human beings are actively involved in raising children. According to Erickson, for most people this is between the mid twenties and the late fifties and the main task or wish is to establish the proper balance of generativity and stagnation.

Figure 2: Illustrative diagram of Erickson's human developmental theory

Chart adapted from Erikson's (1959)

Stage (age)	Psychosocial crisis	Significant relations	Psychosocial modalities	Psychosocial virtues	Mal-adaptations & malignancies
VI (the 20's) -- young adult	intimacy versus isolation	partners, friends	to lose and find oneself in a another	Love	promiscuity – exclusivity
VII (late 20's to 50's) -- middle adult	generativity versus self-absorption	household workmates	to make be, to take care of	Care	overextension – rejectivity

Generativity is an extension of love into the future and a concern for the next generation and all future generations. As such, it is considerably less 'selfish' than the intimacy of the previous stage. Erickson maintains that the implicit expectation of reciprocity is not there with generativity and few parents expect a 'return on their investment' from their children. Also, those parents who expect it are not seen and thought of as very good parents.

Erikson (1959) asserts that, although the majority of people practice generativity by having and raising children, there are many other ways to fulfill this need, such as teaching, writing, invention, the arts and sciences, social activism, and generally contributing to the welfare of future generations. The consideration that at a certain stage in their lives, women and men will want to define their future by looking after children, either their own or adopted children is important. As mentioned in the research problem, for an average Black woman, having her own children is more acceptable and normal than raising adopted children or contributing to other community development activities such as charities.

Although Erikson points out that generativity can be practiced by getting involved in other activities apart from having and raising biological children, this may not be the case in some cultures and communities. This study addresses some of the gaps in Erikson's theory such as the social context which influence choices and decisions. From a human developmental point of view, Erikson's theory is relevant to the group of women who will be participating in this research.

There is not much literature that explores the value of children in the lower class Black community to substantiate the anecdotal conversations and documentaries about the meaning attached to having children as an investment. This theoretical background serves as a framework for this research and the methods employed in it. Subsequent chapters will link the findings of this research with these two theoretical perspectives.

Chapter 3

Literature review

A comprehensive review of the literature was conducted to identify studies examining the fertility desires and intentions of women living with HIV. The Pubmed database was searched because it specializes in indexing the social science and medical literature on the related topics of HIV, pregnancy and ART. Search terms relating to the concepts of HIV infections and/or AIDS; pregnancy, choices, and disease progression were used. The search strategy was limited to English language articles after the year 2000. Additional literature was sourced from the University resources.

Initially, a geographic limit was set to identify studies from South Africa setting, but eventually expanded to the rest of Africa and beyond the borders due to few published research articles obtained from South Africa alone. In addition, books and South African department of health reports were utilized to establish the context in South Africa. The Statistics South Africa reports were also instrumental in providing background statistical information about the state of the health of the country. Other sources included unpublished reports and conference presentations.

The review of literature elicited a range of issues related to HIV and reproductive health. These included the reproductive choices and rights, impact of HIV on fertility, family planning, conception and women's health, prevention of mother to child transmission (PMTCT) and integration of HIV services. Most research has been conducted in developed countries and was mainly on the bio-medical aspects of HIV and motherhood and very few studies were done in South Africa that addresses the social aspects of HIV. Only one study used the theoretical framework of human behaviour in reproductive decision making.

3.1 Reproductive choices and intentions

Worldwide there is an increase in the attention paid to the reproductive decisions faced by people living with HIV. Studies in both developed and developing world

suggest that many HIV-infected women continue to desire to have children despite knowledge of their HIV status (Delvaux and Nostlinger, 2007; Stevens 2008). Despite the increasing attention on the health care needs of HIV-infected individuals in low resource settings, little attention has been given to reproductive choices and intentions (Harries et al., 2007). While it is critical to understand the role of pregnancy in HIV progression and the influence of HIV on pregnancy outcomes, it is equally important to establish and describe the role of the social context in young women's decision making.

Peltzer, Chao and Dana (2008) investigated family planning needs, knowledge of HIV transmission and HIV disclosure among 116 HIV-positive women and 642 HIV-negative women in the Eastern Cape Province of South Africa. Although all women had received counselling on safe sex during pregnancy, only 65.8% and 62.3% respectively practiced safe sex. Postnatally, almost all women received counselling on family planning, yet use of contraceptives and condoms were low.

Among HIV-positive women PMTCT knowledge and the younger age of the mother were associated with pregnancy desire, and among HIV-negative women, the younger age of the mother and having a lower number of children were associated with pregnancy desire. High pregnancy desires and low contraceptive and condom use were found among HIV positive women. This means that counselling does not necessarily dissuade women from wanting to have children.

Similarly, in a cohort of 403 HIV infected women aged 14-35; participants had lower rates of pregnancy and higher rates of sterilisation and abortion than their uninfected counterparts (Bedimo, Bessinger and Kissinger, 1998). Younger women with a history of sexual assault were more likely to get pregnant. Factors associated with sterilisation included a CD4 count over 200, having one or more living children, and not living with a family member, while those associated with abortion included being White, having a history of sexual assault and living with a sexual partner. The study recommended counselling messages that are culturally sensitive, non-coercive, and that take into consideration the complexities of the decision-

making process for all HIV-infected women so that they can make informed decisions.

Another study conducted among 118 women aged between 18 and 45 found that one third of subjects desired future childbearing, including 12% of the 47% who had been previously sterilised (Stanwood, Cohn, Heiser and Pugliese, 2007). 90% of women who were sexually active but not sterilised were using reversible contraception. Factors associated with a desire for future childbearing were being of a younger age, not being on HIV medication, a higher current CD4 cell count, and having relationship duration of less than 2 years. Furthermore, the authors observed that HIV-positive women had similar reproductive patterns to HIV-negative women, with most having borne children and many wanting children in the future. Most of those who had been sterilised expressed regret. Clearly, in these three studies, age, parity and CD4 cell counts were instrumental factors that influenced aspirations and intentions. HIV status alone is not a reliable measure of whether or not, women will have children.

'HIV, Women and Motherhood' is a collection of 14 interviews which explore the many and complex issues in relation to motherhood facing women living with HIV. The audio interviews conducted by Alice Welbourne who lives with HIV herself describe how the 14 women learned of their HIV-positive diagnosis and what they did since knowing their HIV status (www.stratshope.org). The women were from different parts of the world that were either mothers or wanted to become mothers. Some of the experiences of these women were deeply traumatic and many have faced prejudice and stigma. But each displays great courage, resilience and a desire to live fulfilled lives.

Cooper et al. (2005) conducted a qualitative research among HIV positive men and women in South Africa. The findings of the study showed that health concerns had the main influence on reproductive intentions for most of women and some of the men. This study also found other concerns, such as personal factors, social factors

as well as health care provider and service factors. The following personal and social factors were highlighted from the research.

3.1.1 Concerns about orphanage

The men and women, who had no intentions of having children and feared infecting their partners or children, were concerned about leaving current or future children as orphans and were also concerned about the ability to support the children financially, in the light of their illness (Cooper et al., 2007). Those who desired to have children felt that the children gave meaning to their lives; they wanted to leave behind an image of themselves when they die, and claimed that children represented a realisation of hope or a sign of being normal. This is the only study from the reviewed literature that explored concern about orphanage as a factor influencing decision making about pregnancy for men and women living with HIV.

3.1.2 Social concerns

Married women wanted to have children due to the pressure from family to reproduce. This was more so if they had not yet disclosed their status. For some of these women and a few single ones, the pressure was from the partners to have children. For men, masculinity was tied to their ability to reproduce and maintain a family. The women who had disclosed their HIV status were more likely to be discouraged from bearing children. Most of women felt that the community would disapprove of them having children and this constitutes moral judgment on a highly personal issue. From both the personal and social factors, one can deduce that factors that influence decision-making are unique to most individuals (Cooper et al., 2005).

The influence of family has also been noted by Nduna (28 April 2008, conference presentation) in a discussion with older women in the Eastern Cape Province, South Africa. Women said there was no reason for a married woman not to have children in the marriage and one asserted that she gave birth to her son; therefore her daughter-in-law should also give birth to her own sons. In light of these norms around the meaning of marriage for a woman, it may be difficult to exercise

autonomous decision-making in this matter because it is not treated as private. In this instance, the normative beliefs about the meaning of marriage are clear. Failure to conform could threaten a woman's marriage.

3.2 Reproductive rights

The Amsterdam statement (2007) on Reproductive health rights of people living with HIV maintained that the sexual and reproductive health-related rights, needs and aspirations of people living with HIV are not different from those of people who are HIV-negative, including the right to decide whether and when to have children. To plan their families, women living with HIV have the same need for contraception. According to this statement, family planning methods are reliable options for HIV-positive women and some women with unwanted pregnancies may decide not to carry their pregnancies to term. An HIV diagnosis can prompt a pregnant woman to seek an abortion.

Current reproductive health guidelines remain ambiguous on whether or not pregnancy among HIV positive couples is advisable, and rely heavily on the counselling services to allow clients to make autonomous decisions (London, Orner and Myer, 2008). This ambiguity leaves a gap for health care providers to impose their own values and attitudes about what is right for clients. According to London et al. (2008), these provider's values and attitudes may impact significantly on the effectiveness of non-prescriptive guidelines, especially where social norms and stereotypes about childbearing are powerful. Health providers could be caught in dual loyalty pressures with undesirable impact on the rights of clients.

Promise Mthembu (2004) gave a personal testimony about her experience of living with HIV. She discussed, amongst other, reproductive rights, safer sex and access to health care.

Like some other women, Mthembu was pregnant when she tested positive for HIV at the age of 20. She did not want to have a child at that time and requested an abortion. Her doctors agreed to terminate the pregnancy, provided she consented to being sterilised.

HIV transmission can occur during pregnancy, childbirth or as a result of breastfeeding. (Simonds et al., 1998) It is very unfortunate that some women who are HIV positive are pressured not to become pregnant, to be sterilised, or in those cases where they are already pregnant, to terminate their pregnancies. Mthembu shared the angry response that health workers give towards pregnant HIV positive women, and the manner in which they personalise this. Her main concerns were around the health workers' lack of empathy and the violation of women's rights. According to Mthembu, all women have a right to decide whether or not to have children irrespective of their HIV status and should not be compelled into terminating the pregnancy under any circumstances.

3.2.1 Policy and health services

People living with HIV wish to have sex, to bear children, to prevent unplanned pregnancies and to protect their sexual health (Global Consultation Report, 2007). Yet, the stigma and discrimination that people living with HIV are confronted with in all aspects of their lives, is compounded by the fact that sexual and reproductive health policies, programmes and services often fail to take into account their unique needs. The report maintains that health systems in some countries have a shortage of human and financial capacity to meet the health needs as well and that specific gaps and weaknesses exist in policies. South Africa is a typical example of this, although positive strides are made in some HIV related policies relating to children.

Health care providers play a crucial role in determining access to reproductive health services and their influence is likely to be heightened in the delivering of services to HIV-infected women. Harries et al. (2007) examined the attitudes of health care policy makers and providers towards reproductive decisions of HIV-infected individuals. There were major differences in their approach, but bio-medical considerations were important to health providers, while policy-makers were more concerned about structural constraints that inform reproductive health care services. The findings highlighted a strong need for more comprehensible policies on reproductive health of people living with HIV.

It has been pointed out that illness alters one's participation in social life and relationships as well as one's sense of self. Cooper et al. (2005); Harries et al. (2007) and London et al. (2008) described the effects that HIV has on respondents' daily lives, by analysing the ways in which living with HIV has shaped their identities. The studies compared the experiences of HIV positive women with other populations and came up with the obstacles which they face. Among others, women, unlike their male counterparts, face challenges such as reproductive decisions, guardianship plans for dependent children, access to health care and social services.

3.3 Impact of HIV on fertility choices

Several studies have been done in Sub-Saharan Africa on the impact of HIV on fertility. Few decades back, programs were mainly targeted at stabilising population growth, including controlling reproduction through family planning services. The Population Council and other organisations have commissioned remarkable research in the field of HIV and reproductive health, including family planning and reproductive rights. Statistics South Africa estimates that fertility has declined from an average of 2,89 children per woman in 2001 to 2,69 children by 2007 and assumes a mother-to-child transmission rate (the proportion of babies born to HIV-positive mothers who will also become HIV-positive) of 32% if no HIV treatment program is followed and 11% if such a program is in place. The estimates take the administration of nevirapine treatment to pregnant HIV-positive women and the promotion of alternative infant feeding options into account.

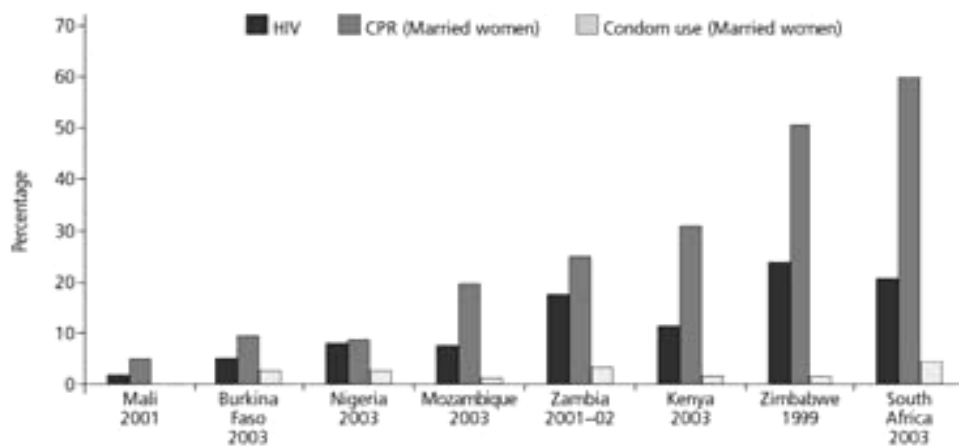
3.3.1 Attitudes towards Contraceptives

Delvaux and Nostlinger (2007) pointed out that more than 80% of all HIV positive women and their partners are in their reproductive years and most of them are likely to continue to desire children, irrespective of their HIV status. In South Africa and Zimbabwe there was a likelihood of higher contraceptive use among women living with HIV although at the same time, some studies indicated that the absence of HIV related symptoms may reduce the demand for contraception (Delvaux and Nostlinger 2007).

The illustration below, shows the contraceptive prevalence rate and condom use in several African countries including South Africa. Although condoms are viewed as protective against HIV transmission as well as reliable contraceptive methods, the use of condoms among married women was very low in South Africa in 2003, compared to other methods. This is an indication of the risk of HIV infection in married couples.

Figure 3: Illustrative graph on HIV prevalence and contraceptive use in selected countries

Figure 1. HIV prevalence, contraceptive prevalence rate (CPR) and condom use for contraception among married women aged 15–49 in selected countries in west, east and southern Africa, 1999–2003



Source: Demographic and Health Surveys, 1999–2002; UNAIDS country estimates, 2004.

According to the recent South African Demographic and Health Survey (2008), over half of sexually active women (56%) had ever used injectables and almost a third (29 %) had ever used the pill. For the male condom, only 38% of sexually active women had ever used it, but this figure falls to 28 % are women in current sexual relationships. Ever use of female condoms, since its introduction in 1998, was 3 % in sexually active women. In the 25-29 age group, ever use of female condoms was at 4.8 % and lowest in the youngest age group at 0.5 % The female condom was reported to be only available directly from a health service provider and is therefore not as accessible as the male condom. The method is primarily targeted at women and the responsibility falls on a woman to introduce the method into her relationship (South African DHS Report, 2008).

The advantages of using condoms as contraceptive methods go beyond preventing unintended pregnancies, to include a level of protection against HIV transmission and other sexually transmitted infections. In the theory of planned behaviour, use of barrier methods by women depend on their beliefs and attitudes towards these methods, coupled with the normative beliefs and the extent of control they may have in making such decisions. In reality, while one could want to use barrier methods, their partners may not be willing, and they may not always have the ability to negotiate this.

3.3.2 Termination of pregnancy

The Cape Argus, on August 09, 2007 (as cited in www.iol.co.za) reported that The Health Systems Trust (HST) has expressed that, “HIV-positive pregnant women should routinely be offered the choice of abortion in the context of the serious challenge the pandemic presents to maternal health,” The chief executive of this organisation, was reported to have further pointed out the 91 % decrease in abortion related maternal mortality and morbidity in the last three years, but also emphasised the challenge to maternal health presented by HIV and AIDS. This may however pose a concern about reproductive rights of HIV positive women, especially those whose unintended pregnancies are in fact wanted.

Services such as high quality antenatal and postnatal care, as well as the option of voluntary abortion as part of the continuum of care were not integrated, and HIV-positive pregnant women were not offered the choice to terminate unwanted pregnancies. She stressed that women should be afforded an unreserved choice to terminate or continue their pregnancies. The Health Systems Trust suggested a transformation of the health system to maintain and increase access to safe abortion, and that high quality abortion services form part of integrated sexual and reproductive health services, including HIV/AIDS services.

From observations during practice in the field it can be motivated that while all effort should be made to ensure accessibility and availability of contraception,

including emergency contraception, provision should be made for those pregnant women, who wish to terminate their pregnancy. In this instance, abortion services should be included as a comprehensive package to the management of HIV and PMTCT. All women should be able to access safe and quality abortion services when they need them. However, caution needs to be taken, not to coerce women into having abortions because of their HIV status.

All options should be explored, and should any woman feel that her unintended pregnancy is actually wanted, effort to increase positive pregnancy outcomes should be made. Once again, abortion may not necessarily be a woman's decision to make, given the social context and beliefs about the pregnancy that could discourage abortion on moral grounds.

On another note, depending on the parity and age of the woman, one may strongly feel compelled to continue with the pregnancy, despite the health risk that it might pose and other socio-economic circumstances. This is particularly true if one examines Erikson's developmental theory. If a woman does not have a child and is getting older, she could see an unintended pregnancy as a blessing and welcome the role of motherhood. There are three possible factors to this motivation, mainly to see to it that one has an image of themselves that gives purpose to life, or the hope that the child will look after them when they are sick and no longer able to take care of themselves. Some women may even wish to replace a child that they had lost due to HIV or other reasons.

3.4 Conception, HIV transmission, and Immune-suppression

One of the main concerns on conception for HIV positive women is transmission of HIV to an uninfected partner among discordant couples. Couples, who are both infected, often fear re-infection. Also, an HIV positive woman could fear the suppression of the immune system that could result from the pregnancy.

Several studies agree that advances in anti-HIV therapy and improved treatment of opportunistic infections have produced a significant increase in the life expectancy

and quality of life of HIV-infected adults (Wilde, 2008). Although the study was focused on HIV negative women and HIV positive male partners and was conducted prior to the expanded roll-out of antiretroviral treatment, the results have significant relevance to this research. The outcomes of the study provided alternative conception methods for discordant couples including timed ovulatory intercourse, artificial insemination of the female with washed sperm from HIV-positive partner, artificial insemination of the female with sperm from an HIV-negative male donor, and in vitro fertilisation of female with washed sperm.

According to Eriksen (2001), conception can occur naturally for couples where both individuals are infected with HIV, but with the additional risk of transmitting drug-resistant HIV to the other partner. This can be minimised if both partners have an undetectable viral load and carefully time the unprotected intercourse (not using a condom) at the mid-cycle, when the woman is most fertile. Eriksen (2001) emphasised the importance of commencing the treatment prior to conception as this would not only reduce the viral load to undetectable levels but also minimise the risk of vertical transmission.

Another research in Italy (Gilling-Smith, 2006), explored the reproductive desires of HIV-negative women and their HIV-positive partners who underwent assisted conception based on sperm-washing and artificial insemination. The findings from the study indicate that participants were highly motivated to conceive a biological child to bring purpose to their lives, and strongly desired options to conceive safely and most rejected spontaneous conception. Those who successfully conceived reported a positive impact on their quality of life, fulfilling their desire to be parents and restoring their sense of 'normality' (Sunderam et al., 2008).

Artificial insemination of the female with sperm from an HIV-negative male donor or partner is also an option because it reduces the possibility of transmitting HIV to the partner and leaves only the health of the woman and the child to worry about. However, artificial insemination is not readily available and accessible in public hospitals of South Africa and can only be afforded by the privileged few. The cost

of artificial insemination in South Africa was R800 (US\$104) in 2003, excluding consultation fees.

In South Africa the likelihood of heterosexual transmission of HIV is higher than any other form of infection and increases with the increase in the viral load of the partner and the presence of a sexually transmitted infection. London et al. (2008) argued that even though pregnancy is an immune-suppressed state associated with decreasing the CD4 count, there is no compelling evidence to suggest that pregnancy facilitates HIV progression. Therefore, from a medical point of view, there are few reasons why an HIV positive woman should not conceive if they wish to. Delvaux and Nostlinger (2007) on the other hand, while not disputing this, pointed out that the increasing availability of antiretroviral treatment which improves the quality of life of people living with HIV, may lead to a renewed desire and hope to have children.

With family planning choices, Delvaux and Nostlinger (2007) maintain that, with, the potential risk of transmitting HIV among discordant couples to the uninfected partner and the possibility of infection with other STIs should be taken into account and that, where both partners are living with HIV, possible re-infection with HIV has to be considered. These issues may be perceived differently depending on factors such as living in a resource-poor country with limited access to both antiretroviral therapy and STI diagnosis and treatment and the level of condom use.

3.4.1 HIV and Maternal mortality

“A maternal death is defined as the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to- or aggravated by- the pregnancy or its management, but not from accidental or incidental causes.

Several studies concluded that the level of maternal deaths in South Africa are unacceptably high, for a middle-income country with a considerable health infrastructure, availability of staff, legal abortion, free health care for pregnant

women and also given the 92% utilisation of safe delivery services reported from the Demographic and Health Survey (2007). All studies point out the impact of HIV, among others, as having a greater significance in explaining the higher mortality rates. This puts the country behind in terms of reaching the Millennium Development goal number 5, which is to improve maternal health and reduce the maternal mortality rate by 75%, even though gains have been seen at a global level (WHO, UNFPA, UNICEF and the World Bank, 2007). While the top five causes of maternal mortality account for 87% maternal deaths, HIV accounts for almost 38%. According to Garenne, McCaa and Nocra (2008), the level of the Maternal Mortality Ratio in 2001 (MMR = 646 per 100,000 live births) was higher than expected and certainly higher than estimates of the pre-HIV and AIDS period, implying that the reasons for the extraordinary high levels were mainly due to HIV and AIDS as well as external factors.

According to health department figures, 41 % of the more than one million women who attended antenatal clinics in 2006 were never tested for HIV, while antenatal HIV prevalence figures indicate that just less than a third of those women would have been HIV positive. This however contradicts London et al. (2008), who maintained that there is no evidence that suggests that pregnancy facilitates HIV progression. Not only did these women miss the opportunity of receiving the ARV drugs that would have reduced the likelihood of infecting their babies, they did not receive treatment to manage HIV either. In the majority of maternal deaths, the HIV status was unknown (Health Systems Trust, March 25, 2008).

As discussed earlier, an HIV diagnosis poses a lot of challenges for reproductive decision making. These include prevention of HIV transmission or re-infection to a sexual partner, prevention of HIV transmission to the child, and now prevention of maternal death. Managing HIV at all levels, and improved communication among the providers and the clients could help reduce the risks of maternal deaths. None of the studies reviewed suggested that HIV positive women should be deprived motherhood, by virtue of their HIV status to reduce maternal deaths from HIV and

AIDS. This contributes to the already ambiguous position of public health on the reproductive health rights of HIV positive women.

Clear guidelines need to be communicated well to all health care workers involved in HIV management and family planning to have a clear position about the advice that they may give to clients. In the absence of these guidelines, or when those who should know about them, are not properly oriented, the HIV related maternal deaths will continue to increase.

3.4.2 HIV and infant mortality

Once again, conception for an HIV positive mother is not only about the right to have a child, but also comes with a responsibility of ensuring the wellbeing of the child. While services can be put in place to ensure that the mother is healthy and ready for conception and transmission is prevented from the mother to the child, services need to be extended to include the care and management of HIV for the infants. Unfortunately, South Africa is seeing rising child mortality related to HIV and AIDS.

According to Mickey Chopra of the Medical Research Council, “Children born to HIV-positive mothers are three times less likely to survive, regardless of the infant's HIV status. Their survival becomes even more precarious if the mother dies”. The report, *Every Death Counts*, produced jointly by the Department of Health, the Medical Research Council and the University of Pretoria, asserted that HIV and AIDS is one of the main reasons South Africa has failed to reduce its child mortality rates, while other countries with similar gross national incomes, such as Brazil and Mexico, are on track to meet the Millennium Development Goal of reducing child and maternal mortality by two-thirds and reversing the spread of HIV and AIDS by 2015. The authors of the report estimate that more than a third of maternal and child deaths in South Africa are AIDS related.

Reasons for South Africa's high infant mortality rate include lack of education and support of HIV-positive mothers in making the best infant-feeding choices,

insufficient testing and monitoring of HIV-exposed babies, and excessive workloads for the few nurses and midwives. Other factors are poor quality of care during childbirth, failure to prevent and treat childhood infections such as diarrhoea and pneumonia, and poor nutrition and living condition associated with poverty. Even sadder is the fact that in more than half the deaths, there were identified modifiable factors, such as lapses in both the coverage and quality of care mothers and children received at health facilities (HealthLink Bulletin, March 25, 2008).

3.5 HIV testing and Mother to Child Transmission

Counselling and testing is one of the entries to HIV prevention, treatment and care, and therefore is critical in reducing the spread of HIV and its impact. The South African National Department of Health has supported the implementation of this initiative since 2000 by establishing policies, guidelines, as well as legislating strategies to provide universal access to the adult population. Counselling and testing includes activities in which both counselling (pre-test and post-test) and testing is provided to those who want to know their HIV status. “Knowing their HIV status helps people protect themselves and others from STI infections and re-infection, conceive and give birth safely and obtain appropriate treatment, care and support. People living with HIV should be involved in the development of testing programmes in communities” Amsterdam Statement (2007).

Stigma is one of the major reasons discouraging people from knowing their HIV status. Sometimes, testing for HIV is voluntary, but in some instances it might be triggered by needs such as obtaining life cover from life insurance providers, planning to have a child, or as part of the prevention of mother to child transmission program for pregnant women.

In 2001 the National department of health introduced the prevention of mother to child transmission program. The primary aim of the PMTCT program was to decrease the number of infected babies born to HIV positive mothers, and those babies who might get infected during breastfeeding. The four pillars of the Prevention of Mother to Child Transmission (PMTCT) programme include

prevention of HIV infection among young women, prevention of un-intended pregnancies, and prevention of HIV infection to the child and provision of care and support services.

A comprehensive PMTCT program included HIV counselling and testing, counselling on infant feeding, safe non-invasive procedures, a single dose of a drug called Nevirapine and provision of infant feeding formula. Research suggested that, although effective, Nevirapine on its own did not yield the best desired results and therefore an additional drug, AZT had to be added to the single dose of Nevirapine (Health System's Trust, 2002) According to the PMTCT program in South Africa, all pregnant women should be offered HIV counseling and testing. Women who choose not to be tested should be offered HIV testing at every subsequent visit. HIV counselling and testing for pregnant women is therefore not mandatory, but emphasised.

Prevention of unintended pregnancies among HIV positive women forms one of the key elements of the program (The National Department of Health, February 2008). A European Collaborative Study (2003) examined the risk factors of mother to child transmission of HIV and found a 14.1% rate of vertical transmission. Transmission was associated with maternal p24-antigenaemia and a CD4 cell count of less than 200. Also, transmission was higher with vaginal deliveries in which episiotomy, scalp electrodes, forceps, or vacuum extractors were used, but only in centres where these procedures were not routine.

In South Africa today, information is readily available about the safety of a Caesarian section delivery, as compared to vaginal delivery, but the implications for practice tell a different story because these resources are not always available for those who need them. Again, most studies demonstrate an increased risk of postoperative morbidity, mostly infectious, in HIV infected women compared with uninfected control subjects, and the risk of complications is correlated with the degree of immuno-suppression (Jamieson et al., 2007). Therefore when making decisions about a method of delivery, one needs to consider both the wellbeing of the mother and the child.

In a recent study conducted in 2004 and 2005, McCord Hospital in KwaZulu-Natal reduced the transmission of HIV from pregnant mothers to their babies to less than 3% with dual therapy. The study assessed the babies of women who had enrolled. 44% of the pregnant HIV-positive women received highly active antiretroviral treatment. Of the 297 surviving babies, 290 (98%) received the antiretroviral drug, Nevirapine, after birth and 224 (76%) also received the antiretroviral, AZT. Six weeks later 239 (81%) of the babies were tested; only (2.9%) were HIV positive (HealthLink Bulletin 13 June 2008).

In another study, Chivonivoni, Ehlers and Roos (2008) investigated women's attitudes towards PMTCT in Zimbabwe and found that many pregnant women would not use the services available for the prevention of vertical transmission of HIV/AIDS for personal, financial and cultural reasons, and that the main reason was related to structural barriers, because only pregnant women who attended prenatal clinics and delivered their babies in hospital could access these services. These circumstances may differ, from rural areas to townships, but the message is that the availability of PMTCT alone does not suggest that every woman who should be accessing this service is indeed receiving it. Another critical pillar of this program is the prevention of un-intended pregnancy through family planning, which is not usually integrated.

The National department of health commissioned the Health Systems Trust to conduct an evaluation of the program in 2002 and key findings showed that the rate of HIV testing among pregnant women had increased slightly since the first evaluation covering the period January to December 2001 where it was found to be 51% and 85% of women knew their results.

Simonds et al. (1998) pointed out that chances of passing the virus to a fetus for HIV positive women are 1 in 4 and that this can be reduced to 1 in 12 when a woman takes a specific drug regimen to prevent mother to child transmission (PMTCT). Notably, the internal debate for the woman does not end at the level of pregnancy, but has other implications such as breastfeeding, the upbringing of the

child, the health of the mother and the financial circumstances. This is evident in a longitudinal qualitative study that looked at the infant feeding decision-making and practices among women living with HIV (Doherty, Chopra, Nkonki, Jackson and Person, 2006). The study examined the characteristics of HIV-positive women and their environments that contributed to success in maintaining either exclusive breastfeeding or exclusive formula feeding. The findings showed that women were not only influenced by their attitudes towards breastfeeding and their experiences of antenatal counselling, but also some of them faced pressures from health workers and family to change their decisions.

3.5.1 Mothers to Mothers Program- Mentoring for HIV infected women

This is a peer support initiative targeted at pregnant women and new mothers who are living with HIV in four provinces of South Africa. The program seeks to support women to access available health services including PMTCT and post-natal care. The initiative also aims to relieve some of the pressure on clinical staff by training HIV-positive mothers to mentor new mothers and pregnant women infected with HIV. The collaborative evaluation of the program in the KwaZulu-Natal province of South Africa by the Population Council and the Health Systems Trust, found that women who had received education and support through ‘mothers to mothers’ were more likely to disclose their status, accept PMTCT treatment and exclusively formula- or breast-feed, which have all been proven to reduce the likelihood of mother-to-child infection.

HIV interventions during pregnancy and birth are fairly widely available in South Africa, but the report points to a drop in such interventions in the crucial period soon after birth (Baek and Rutenburg, June 2007). The study concluded that this kind of program is critical in providing a range of care for HIV positive women and their babies, including greater psychosocial wellbeing, increased utilisation of PMTCT and its outcomes, as well as keeping women linked to health services.

3.6 Integration of comprehensive family planning services in HIV programs

Antiretroviral (ARV) that delay HIV progression and improve quality of life and the roll-out of prevention of mother to child transmission (PMTCT) have brought renewed hope among many couples and individuals in South Africa. Accessible, comprehensive sexual and reproductive health services are the cornerstones of efforts to enable people to make informed, safe, and healthy choices; particularly so for people living with HIV; and they need to be addressed within local, national, and international development plans. A severe shortage of skilled health care workers seriously hampers the expansion of comprehensive services for people living with HIV. The World Health Organisation estimates a current worldwide shortfall of some 4.3 million health workers, including 2.4 million doctors, nurses and midwives, due to a combination of factors including low or unpaid salaries and poor training, lack of supervision, and poor working conditions (Amsterdam Statement on HIV, 2007). A review by Delvaux et al. (2007) suggested that most contraceptive methods are both safe and effective for women and men who are living with HIV and emphasised the importance of ensuring availability of a wide range of options including information and access to emergency contraception. However, the challenge of promoting condom usage in long-term relationships remains, and this is very unfortunate considering the dual protection rendered by this method.

Effort has to be made to ensure that those women who have no intention of getting pregnant, whether HIV positive or not, have access to quality family planning information and services. Delvaux et al. (2007) echoed that people living with HIV and AIDS have diverse sexual and reproductive needs, and that information about options available to them as well as the fact that these needs might be better met if reproductive health services were integrated with HIV-related services.

Researchers from the US Centers for Disease Control and prevention found that nine out of ten pregnancies among HIV positive rural Ugandan women were unintended. Integrating maternal and child health into HIV not only helps HIV positive women to avoid unintended pregnancies, but also contribute to the prevention of mother to child transmission (PMTCT) of HIV. Training of HIV

counselling and testing providers in family planning service integration is critical. Most providers do not know how to advise HIV-infected women and couples about family planning. In Kenya, trained providers were more than twice as likely to discuss family planning use and desire for children, more than three times likely to discuss contraceptive pills and more than eight times likely to discuss other forms of contraception, compared to untrained providers.

A study in Ethiopia found that contraceptive use decreased after HIV diagnosis among 460 ART Ethiopian clients even though 55% of women and 65% of men said they did not want to have children. In a similar study carried out in South Africa, more than 60% of pregnancies among 235 women receiving HIV care and treatment were unintended (Family Health Research, March 2007).

The importance of family planning is sometimes forgotten in efforts to reduce mother-to-child transmission of HIV. However, with unintended pregnancies accounting for more than half of all births in some countries, contraception could prevent many vertical HIV transmissions. Family planning counselling for at-risk women of reproductive age helps increase their knowledge of HIV prevention strategies knowledge they might not otherwise obtain.

A USAID-funded analysis (2007) examined the costs and benefits of adding family planning services to programs for the prevention of mother-to-child transmission of HIV. The findings suggest that adding family planning to PMTCT sites can save the lives of thousands of women and children and significantly reduce the number of orphans.

Integrating HIV services in family planning does not compromise the quality of family planning services and is cost effective compared to having a separate HIV counselling and testing service. Also, partial integration can be considered if the health workers are too busy. As noted above in the contraceptive choices and access, consultation session with HIV positive clients of child-bearing age should go beyond just the disease and incorporate other critical aspects, which include aspirations and intentions to have children. These should provide space for the health worker and the client to discuss options and family planning in detail.

Training of health personnel on integration is therefore important and the research findings on integration of services should be maximised to benefit the clients especially given that even partial integration is possible and yields desirable results within the limited health personnel in the public health sector.

The studies presented here point out the nature and the complexity of pregnancy decisions and experiences for HIV infected young women and factors around these decisions. However the authors agree that an HIV diagnosis is not a death sentence and should not lead to diminished hopes, because there is no compelling evidence that pregnancy speeds up HIV progression. Unfortunately most of the information about the biological aspects of HIV progression and pregnancy is available to the elite and archives and is not available to the ordinary woman in a township.

Also clear in this review of literature is that pregnancy is a social phenomenon and cannot be understood only in physical and biological terms in which attitude, intention, behavior or disease occur, but also through a historical, social and all external factors that influence it. The literature also presents other alternatives that are presumed to be available to women to prevent and manage unintended pregnancies, such as family planning and termination of pregnancy and points out that these are not often utilized as expected.

The discrepancy is evident between the expressed desire not to get pregnant and the actual pregnancy. This divide cannot be interpreted in medical terms and required a deeper in-depth interpretation from a social context. Reproductive rights of people living with HIV have also been clearly articulated in this literature. This point out the gap between the ideal and the reality in the public health provision for many. However the violation of reproductive rights of women living with HIV may not be a new thing, given the moral dilemma that service providers find themselves in. Even those who have knowledge about their rights do not seem to always advocate for them, due to various reasons and lack of solidarity.

Chapter 4

Research Methodology

This was an exploratory research based on a qualitative study design. Qualitative research emerges from an interpretive perspective which views the world as constructed, interpreted, and experienced by human beings as they interact with each other and other social norms and values. This method of research explores and describes a theoretical and methodological focus on the complex relations between personal and social meanings, individual and cultural practices, and holistic social context. Subjective perceptions and understandings from experience, objective behaviors, and context are the key components of the qualitative framework. Through open-ended questions, discourses on the meaning of pregnancy and motherhood to women, are extracted. This methodology is applied to obtain a better understanding of human behavior in order to contribute to rational decision making processes at all levels of health care and to improve the effectiveness of health programs. It is also meant to answer some of the complex questions that quantitative methods may not be able to unravel.

4.1 Setting

The research was carried out in two similar townships of the of the Gauteng province, South Africa. The two townships were Atteridgeville in Pretoria and Soweto in Johannesburg. Although women in Soweto were recruited from Zola, Diepkloof, Orlando and Dobsonville clinics, they came from the different parts of the township, including, Orlando West, Katlegong and Meadowlands.

Gauteng province has the biggest multi-racial, multi-cultural and multi-lingual population in the country and is also known as the “economic hub” of South Africa. It is the smallest of the nine provinces but it has a population of about 9, 178, 673 (2nd highest provincial population) therefore having the highest per capita population. The population of the province is 75% Black, 19% Whites, 4% Coloureds and 2% Indians. About 44% of Gauteng’s working population (i.e. 15 to 65 years) are employed either as civil servants, miners, traders, or in other industries (private sector), whilst 26% of the working population are unemployed,

with the rest (30%) being economically inactive. About 22.5% of Gauteng's households are informal settlements (shacks); almost 4% of the households have no sanitation method whilst 2% of the households still use the bucket-system. In Gauteng, the majority of the households (65%) are male-headed.

Soweto is an urban area in the City of Johannesburg. The name is an English syllabic abbreviation, short for *South Western Townships*. The history of African townships south west of Johannesburg that would later form Soweto was propelled by the increasing eviction of Africans by city and state authorities. Soweto's only hospital came courtesy of World War II. The Royal Imperial Hospital, Baragwanath, was built (in what is today a township called Diepkloof) in 1941 for convalescing British and Commonwealth soldiers. In 1963, the name Soweto was officially adopted for the sprawling township that now occupied what had been the farms of Doornkop, Klipriviersoog, Diepkloof, Klipspruit and Vogelstruisfontein (Beavon, 1997).

Soweto came to the world's attention on June 16, 1976 with the Soweto Uprising, when mass protests erupted over the government's policy to enforce education in Afrikaans rather than English. Police opened fire in Orlando West on 10,000 students marching from Naledi High School to Orlando Stadium, and in the events that unfolded, 566 people died. Since 1991, the day of June 16 and the death of the school children is commemorated. It has been estimated that 65% of Johannesburg's residents live in Soweto. However, the 2004 Census put its population at 896,995, about one-third of the city's total population.

Soweto's population is predominantly Black. All eleven of the country's official languages are spoken, and the main linguistic groups (in descending order of size) are Zulu, Sotho, Tswana, Venda, and Tsonga. Various non-governmental organisations and research institutions as well as the department of health continue to invest resources to reduce the spread and impact of HIV in this township (Statistics South Africa, Census (2007)).

Attridgeville, part of the City of Tshwane Metropolitan Municipality, is a township located in the west of Pretoria, South Africa. It is bordered to the west by Saulsville, to the east by Proclamation Hill, to the south by Laudium and to the north by Lotus

Gardens. It was established in 1939 for black people by the apartheid government but development was frozen between 1968 and 1978 in accordance with the government's policy that housing provided for black people be limited to the homelands. In 1984, Atteridgeville was granted municipal status. This township is commonly known as "Phelindaba" or "Pheli" which is an isiZulu expression for "End of Story", because of its proximity to the now defunct nuclear power sites of "Phelindaba" and "Valindaba. Atteridgeville is also a diverse township whose residents speak many languages. The most commonly spoken language is Sesotho, which is closely related to Setswana and Sepedi. A mixture of languages such as Afrikaans, Sesotho, English and isiZulu are sometimes fused together to form what is now a unique language-style of the township with a slight inclination to a slang known as *tsotsitaal* (Statistics South Africa, 2007).

South Africa shares much of the beautiful landscape of Africa, the oceans and water falls, natural caves, game reserves, including the mineral resources such as Gold and platinum. For many years the country was subjected to apartheid rule that robbed most of its inhabitants from enjoying these natural resources (Statistics South Africa, 2007).

In 1994, in line with the new political dispensation, a democratic government was elected by all for the first time. The new government had therefore many challenges lying ahead of it, especially on addressing issues of the apartheid legacy, these included poverty to the masses, unemployment, general societal violence, and in the past twenty years the emergence of the challenges and sting of HIV and AIDS.

4.2 Sample

Young, Black women between the ages of twenty-one and thirty-five were recruited to participate in the study. Most women were active members of a support group in their community and two who had access to the support groups, were not necessarily members. The support groups met either at a local health care centre or clinic once a week. Few women were living with a partner, three were married, three were engaged and the others were not in a long-term relationship. Two of the women were employed as coordinators of the support group and a few received a disability grant, while the rest were dependent on parents and partners. None of the

women were studying. More than 50% of the participants were enrolled in the antiretroviral program.

4.3 Data collection

In Atteridgeville, entry to the support group was obtained through a colleague who was acquainted to the support group that was run in this community. Four women were interviewed. In Soweto, three support group coordinators of an organisation that provides HIV prevention, support and care services were contacted and their details were obtained through word of mouth from individuals and colleagues who worked in that organisation in the past. The purpose of the research and how it would unfold was explained to the coordinator and then a visit was scheduled to explain the research to the members of the support groups. Some women once enrolled in the organisations; but never participated in the support group, were also contacted to participate at their own will. The dates for explaining the study were the same days that the support groups met, which was once a week. After explaining the study, women below the age of thirty-five who were interested in participating enrolled and were given the information documents to read before interviews could take place in the weeks that followed. Participants who used a taxi or train to come to the support group were refunded the fee for transport.

Interviews were conducted in the clinic rooms, support group meeting room and sometimes in the car. Consent to use a tape recorder was requested and obtained from all participants, and notes were taken as backup and to clarify key points. All tapes were labeled with different codes. Open-ended interview guides were used for both in-depth interviews and focus group discussions to explore aspirations and intentions of women. Eleven in-depth interviews and two focus group discussions were audio taped in the language of the participants (Zulu, Tswana and Sepedi), and later transcribed verbatim and translated into English. Focus group discussions were used as an initial step in data collection to explore in a non-judgmental environment what the issues were that participants experienced around reproduction and HIV. All women had a positive HIV status and therefore there was very minimal sensitivity on the subject. In depth interviews were used to further gather an in-

depth understanding of the issues broadly raised in the FGDs and personal experiences of participants about pregnancy and HIV

The questions in the interview guides asked broadly about meanings of motherhood. Specifically participants were asked what they think or feel about having children (attitudes and intentions), parity, how others (partners, friends, fellow support group members and family) would perceive them if they expressed their intentions (subjective norms), what they would do if their intentions were not agreed to by others (control) and what having a child meant to them (generativity) or reasons for wanting to have a child., as explored in the theoretical framework and the review of literature. (See Appendices 1 and 2)

4.4 Data Analysis

Babbie (2008) describes qualitative analysis as the nonnumeric examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships. Qualitative data analysis distinctly establishes how data comes together in terms of context and meaning (Ulin, Robinson, Tolley and Mc Neill, 2005).

In this qualitative exploratory research, a cross-case thematic analysis was used to deduce what factors influence women's decision to desire children. First, data was transcribed verbatim and translated into English, where necessary (Babbie and Mouton, 2001). Using the guidelines for qualitative data analysis, as described by Ulin et al (2005) and Babbie (2008), the five interrelated steps were followed to aid analysis and presentation of data and they build upon each other.

1. Reading for content, noting quality and identifying patterns. This process starts with the very first transcript and start asking more questions and identifying patterns. Firstly, data is read for content to establish whether the researcher is getting what they intended to collect, and recognises that the first data may not be as rich as desired. In some instances the questions are not framed adequately, hence the responses do not address the research

questions. This is a chance to rephrase questions in a manner that will yield better outcomes. Emergent themes are also identified in this stage, and the researcher notes unexpected new topics and those that were not sufficiently addressed when the data was collected. Secondly, data is read to note quality, including determining whether responses appear plausible with sufficient contextual detail. Credibility of data is determined at this stage. Lastly, data is read to identify patterns. Important themes are identified here and then patterns are examined, and relationships or contradictions identified. The researcher may want to adapt the study design or seek different sources, if a need arises. These step is described as discovering patterns in Babbie 2008 and Lofland (2006, as cited in Babbie, 2008) suggested six different ways of looking for patterns. Frequencies, magnitude, processes, structures, causes and consequences of the subject or behaviour.

2. Coding to identify the emerging themes. This step involves having all pieces of text that relate to a common theme together and establishing sub-themes as they arise, and labeling text. Babbie (2008) considers this step to be key in analysis of social research. Terms from the social science literature can be used because they represent more abstract concepts and can be understood by a wider audience. Ulin et al (2005) suggest a few computer programs (CDC EZ-Text, Ethnograph, QSR N6 and Nvivo2) that are available to aid coding and managing data. In this research Nvivo 7, was used because it makes the coding process quicker and consistent. Nvivo also has additional features such as the ability to create models based on analysis, create matrices of data and display all codes that have been assigned. Other computer programs such as Aceste, AnSWR, Atlas.ti, Ethno 2, and NVivo 7 have also been suggested in Babbie (2008).
3. Displaying data and distinguishing nuances of the topic. This means laying out or taking an inventory of what the researcher knows related to the theme capturing variation or richness of each theme and separating qualitative and

quantitative aspects and noting differences between individuals. Once data was coded, each theme was explored, by displaying relevant information and reducing it to the essential point in responding to the theory and the research question. Similar to this step is concept mapping (Babbie 2008), the graphical display of concepts and their interrelations. This can be done using a single sheet of paper, multiple sheets, a black board, magnetic board, a computer program or other media. Babbie (2008), also included a step that follows coding and termed this memoing, which simply means writing memos or notes from what comes out of the data. Strauss and Corbin (1998:217 as cited in Babbie, 2008) distinguish the notes into three kinds, and these are code notes, theoretical notes and operational notes.

4. Data reduction. This is a process of distilling the information to make visible the most essential concepts and relationships, which often happens once all the data has been read, coded and displayed. (Ulin et al, 2005) This is often referred to as data cleaning in quantitative research. Data reduction involves stepping back from the data to get an overall sense of data and establish main and secondary themes. Visual devices such as matrices and diagrams for each thematic area are recommended because they enable the researcher to put together most of fragmented text together. For this research, data reduction was very useful because it helped the research distinguish from themes that respond mainly to the primary objectives and secondary themes that came out from the analysis.
5. Interpretation. Primarily, research questions were used as a guide to group data and establish similarities and differences. Interpretation of the findings, to establish whether the themes responded to original study questions, and secondary findings. Descriptions of social phenomenon, and patterns were presented.

At all stages of the analysis, the following principles of qualitative data analysis were observed and adhered to as described in Ulin et al (2005).

1. Individuals differ in their experiences and understandings of reality, and as such may respond differently from the researcher's assumptions.
2. A social phenomenon cannot be understood outside its context and therefore the influence of the social, political, economic and individual factors cannot be ruled out.
3. Theory both guides qualitative research and results from it.
4. Certain cases may bring about insight into a problem or new information for further enquiry.

4.5 Establishing authenticity

Ulin et al (2005) presents four criteria that are critical in establishing the trustworthiness of qualitative findings. These criteria are credibility, dependability, conformability and transferability.

To establish credibility, different techniques can be used to offer explanations that are consistent with the data collected and are understandable to the study population. In this research, triangulation of respondents as cited by Babbie (2008) was used. Probing was very instrumental in obtaining as much truth from participant statements, to establish any underlying information and nuances as well as obtain a more in-depth perspective. A relaxed environment was established for participants to feel comfortable to share their thoughts. A conscious comparison of final interpretations with the original expectation was made, to identify new information.

In establishing dependability which is essentially an important test of reliability that findings can be replicated, another independent social scientist did some of the analysis using the steps mentioned earlier in this chapter and the researcher drew conclusions from both perspectives. The independent investigator also conducted life skills workshop called stepping stones (Jewkes et al, 2000). The workshop covered communication in relationships, fertility, family planning, sexually transmitted infections, HIV and AIDS, gender-based violence and dealing with loss and death (refer to: www.steppingstonesfeedback.org). The discussions which were captured on the flip charts were also analysed and presented to the researcher.

Conformability involves qualitative researchers checking whether they have satisfactorily maintained the difference between their own ideas and those of the subjects. In this research, an audit trail was used. An audit trail is a record that enables the researcher and others to track the process that has led to the conclusions which is created from notes and other field material.

Lastly, establishing transferability involves three main features. The first aspect is about ensuring that conclusions that are drawn are supported by the data. The second phase is about giving a sufficient description of the research context. Lastly the findings become more transferable one objective of the original research design was to test a model or theory. As describe both in Chapter 3 and Chapter 5, these features were part of this research.

The researcher has observed few qualitative publications on this topic (Cooper et al, 2005). It is intended that the data collected and presented here will increase understanding and address preemptively the concerns faced by young women living with HIV in South Africa. I will draw on empirical qualitative findings and look at the nature of women's aspirations and intentions in this sensitive sphere.

4.6 Ethics

All ethical principles of autonomy, beneficence, non-malaifcence and justice applicable to this kind of research were considered and effort was made at all times to keep information received from participants confidential. Also participants were given the details of the research and other help lines in the event that they would wish to discuss matters that arose from them being interviewed. All participants gave written consent to participate in this research and were made aware that they could withdraw at any stage of the interview.

Chapter 5

Research Findings

Five main themes emerged from the data. First, women who aspired to have children were younger, had one or less children, had lost a child or wanted to leave an image of themselves. Second, women had health and financial concerns. Thirdly the attitudes of support group leaders, health workers, and structural issues were significant. Fourth, reproductive rights and social attitudes were important in decision-making. Lastly not all women who desired to have children had intentions of having them. All women had a positive attitude towards motherhood and pregnancy in general, and then their intentions were defined by the different circumstances.

5.1 Age, parity, loss and child as an image

Age and parity had a major influence for women who aspired and intended to have children. Age and PMTCT knowledge were also cited by Pelzer et al (2008) in the Eastern Cape province of South Africa and younger age was also cited by Bedimo et al (1998) as factors associated with desire to have children. The age factor was further echoed by Stanwood et al (2007) associating being of a younger age, and having a relationship duration of less than 2 years with a desire for future childbearing. Again, Erickson mentioned in his human developmental theory that as individuals reach their late twenties they want to generate and extend love to other things which in most cases is the child. In these interviews, this need was expressed as the importance of leaving an 'image' of oneself.

"I would want to at least leave behind a picture of me, so that when I die, at least it could be said that I left a child behind." (FGD, Soweto)

"I believe that the child gives you the strength. When you think of the child, even when you wake up feeling weak, because of the child you will get strong. It is okay to have a child when HIV positive because the child will give you strength to carry on."(24 years, Attridgeville)

A mother in Soweto said that when she fell pregnant post-knowing her HIV status was positive; she wanted to leave her image behind when she died. This was also the case for a mother of two in a focused group discussion.

“Yes, I wanted a child, even though I was positive. In the beginning when I heard about my status, I thought I had to leave behind an image of me. I had the child and then I started worrying about who will look after him when I die.” (22 years, Soweto)

Three women below the age of twenty-five who did not have a child, and two, who had one child, intended to have children. One married woman who had two children and was above twenty-five wanted to have more children. Two women who already had one child who were below twenty-five were also intending to have another child. One of these women was married, and was waiting for her CD4 count to go up so that she could conceive. One unmarried woman who had two children, still wanted to have more children, and did not share any concerns about the effect of that on her own health or the health of the children. Most women, who had two children or more, did not want to have any more children. This was more so, for the women who were not married and unemployed.

‘I have two children already, so I don’t need any more kids.’ (FGD, Attridgeville)

Women attached different meanings to having a child, but what stood out was that children brought joy, strength and courage to them. The reproductive right to have a child was also described several times. At least two women in Attridgeville and one woman from Soweto expressed that having children gave purpose and meaning to their lives. The perception of a child as a positive step in defining the future was also described in the findings by Cooper et al. (2005)

“Even when I’m sleeping feeling tired, when they (two children) come back they ask me, ‘Mama what is the problem? Are you sick?’ I tell them that ‘no, I’m just tired’. They are the ones who were looking after me very well even

more than my sister. To tell you the truth these children have changed my life. They have taught me what life is. They taught me that when you are a human being you have to stand up for yourself.” (29 years, Attridgeville)

“Eish, maybe if I didn’t know the experience of having a child, I wouldn’t want one, but I know the experience of having a child. How it is. It’s a joy to have a child; I cannot even describe how it feels to have a child.” (31 year, Soweto)

Four women reported having lost a child to HIV before and two of them wanted to have a child to ease the pain from the previous loss.

“I wanted to have a child because I was still hurting from loosing the other child. I had told myself that I want to have two or three children, and I did not know that I will loose that one. But also my husband did not have a child.”(34 years, Soweto)

However the two other women who had also lost a child had mixed emotions and ambivalence and concerns about HIV progression. They described confusion about having another child because of the experience that they had, despite the medication and management to prevent HIV transmission to the child.

“Well, for me I’m really confused. I want to have a child, but I’m scared. I had a child, my second born, I got sick. The child got all those things and drops (Nevirapine), but they did not help. Sometimes I think about having a child, but I get scared that what if the same thing that happened with the second child happens again. So I am not sure about having a child.” (FGD, Soweto)

“I am undecided, because I also lost a child. So, there is always this thing at the back of my mind that this thing once happened.” (FGD, Soweto)

All the other women who had children mentioned that their children had been tested and were HIV negative. This was said with a sense of relief and faith that should they get pregnant again, they would ensure that their children receive the treatment that will help protect them against infection. Having an HIV negative child came across as a main priority for these women. Breastfeeding options and practices of women were not explored in this study, and none of the women mentioned whether they breastfed their babies. Marriage and stability, as well as the needs of the male partner had some influence in this discourse as discussed in subsequent chapters.

This research and others all echo that age and parity play a key role in determining whether or not one would get pregnant and women who are below the age of 35 are most likely to get pregnant irrespective of their HIV status. The idea on leaving an image of oneself comes out strongly and cannot be ignored. Health providers may lose sight of this when providing HIV related services to young women.

5.2 Health, orphan-hood and financial concerns

From a bio-medical point and health care worker perspective, the general message sent to young women who live with HIV is “do not get pregnant”. The main argument in this case is mainly to point out the implications of pregnancy on the health of the mother and subsequently death and leaving an orphaned child. This often sends women on a guilty trip as they would be seen as irresponsible for bringing a child in the world and creating a burden to others. In some instances, women considered their health condition, mainly their CD4 cell count and/or their financial ability as critical for them to consider before pregnancy. Stanwood et al (2007) alluded that not being on HIV medication, a higher current CD4 cell count were associated with desire for future childbearing.

5.2.1 Concerns about horizontal transmission and orphan-hood

Starting a new relationship for anyone, HIV infected or not, can be challenging, but in the presence of HIV, the future of relationships often revolves, among other things, around the HIV status of the two people. Women find themselves worrying about, ‘what if they infect the uninfected partner? What if the child gets infected?’

What if they progress to AIDS and leave orphaned children?’ It is often expected of the HIV infected partner to take responsibility not to infect their HIV negative partner or a partner whose HIV status is unknown.

Two women in the study who were in discordant relationships had more challenges in deciding whether or not to conceive. They both aspired to have another child, and their partners did not have children. This posed a range of issues to consider, including infecting their partners, cost of artificial insemination or other alternatives, the women’s immune systems and the future of their children. One woman was more concerned about infecting her fiancée or losing him because of not being able to give him a child.

“Eish...we do (talk about having a child). It’s a problem. Sometimes I fear that I might loose him because of that, you see? I’m still in this dilemma because there is a lot that I think about. If it wasn’t that I would have a baby, like today, but unfortunately, our situation is different, and again, in my part the partner is negative, how do we think we can have a child?” (31 years, Soweto)

It is often expected for HIV infected individuals to disclose their status to their partners. Some women already knew their HIV status when they met their partners and found it very challenging to disclose. They shared how supportive an HIV negative partner can become in the beginning when he hears the news and then pull away gradually. Anecdotal conversations also confirmed this. Reasons for this differed from fear of the rejection from family members about bringing a person who is living with HIV, to issues such as pregnancy and childrearing.

“I could sense that rejection was there, but not complete. Not really rejection, but shock about how he is going to handle it... He kept calling me, he did not stop calling. You know people, when you say you are positive they think that you are sick. I saw that he is pushing me away, because he started

telling me about his girlfriends. He had two girlfriends at that time.” (31 year old mother).

All women had disclosed to more than one person and seemed to be receiving a lot of support from the people that they disclosed to.

It seems women have concerns, not only about their own health, but often find themselves worried about the health of their partners and unborn children. In some instances women would still be asked why they wanted to get pregnant after being given information about conception and HIV transmission.

‘I was told that if my partner is negative and I’m positive, it is dangerous for me to have a child, because I may infect that person. And then if we are both positive, we do not know who is worse between the two of us and one of us can get re-infected...if ever we do it the natural way we may infect the child’ (24, Attridgeville)

“What happens is that you become curious, you think that if you do not test (for HIV), what if? The child could have got Nevirapine and be protected, such things. You end up going for the sake of the baby.” (FGD, Soweto)

As indicated earlier, women were more concerned about their child not turning out to be HIV infected in case they are blamed for putting an innocent child through pain and suffering. The concern about disease progression needs to be validated with compelling evidence and be treated on a case by case basis, because not all HIV infected women are at risk of dying due to immune suppression.

5.2.2 HIV related stress and Immune suppression/HIV progression

Mothers are often seen a source of courage and support in most families. Even couples and single parents who are not living with HIV sometimes rely on their mothers to be able to look after their children when they are away for various reasons including holidays and trying times, such as going through a divorce. In this study there was little indication of hope for this kind of support from mothers. In

fact four women explained that they did not have good relationships with their mothers and could not count on them to look after their children if they die.

“When your family is right and supportive, yes it is okay (to have a child). Right now, I am stressed that when I die I will have no one to leave my child with. That stresses me” (22 years, Soweto)

This suggests that some individuals can no longer rely on their immediate families, even though they influence some of their reproductive decisions. This may seem strange, given the magnitude of grandmothers who look after their grandchildren whose parents died of AIDS. Do some of these grandmothers feel compelled to assume this role, despite the kind of relationship they had with their own children?

“Because of my HIV positive status, I feel that I will stress myself by having a child. A child takes a lot from your body, personally I am still weak” (FGD, Soweto)

None of the women reported actually having experienced stress while pregnant, due to their HIV status. Could this concern about pregnancy related stress be an outcome of what they have been told? Sources of stress that were in fact experienced by at least two women were not related to their HIV status or pregnancy.

“When my husband is not working, I feel stressed and sick because I cannot buy myself boosters” (25 years, Soweto)

This woman expressed intentions to have another child and was still unemployed, but she mentioned being stressed by not being able to get boosters herself. Another woman was unemployed expressed her frustration about her situation.

“Not working and the challenges of having to worry about the baby. That’s when stress starts, because I don’t know what to do” (22 year old mother)

Although women kept saying that they needed to consider their CD4 count before conception, very few women reported the importance of the viral load. Again, women did not really know exactly at what level the CD4 count would be acceptable for them to conceive and the other factors to consider such as changing the treatment regimen. As described in Chapter 3, when the viral load is below detection, chances of transmission are reduced. Also women were not sure exactly what CD4 count is desirable, before conception.

“I want to have another child, and my husband also wants us to have another child, but we are delayed by the situation that my CD4 count is still low but I told myself that I will wait for it(CD4 count) to go up to six or seven hundred an more.” (25 years, Soweto)

“And then, apart from that (fear of loosing another child), my CD4 count doesn’t allow. It is too low, for me to have a child. I wish for a child when I see others, but I don’t have the energy.” (FGD, Soweto)

Stress has been proven to have an effect in suppression of the immune system and sometimes sources of reliable support are critical from a family and community level, to provide comfort and assurance to women living with HIV. These also contribute to an improved quality of life.

5.2.3 Absent fathers and the burden on women

In most instances the role of men in the reproductive health equation is left out from various levels, and thereby placing more burden on women. Most women mentioned that they were supported by the people in their lives. In many instances it is expected of mothers to be there for their children. When this does not happen, women are viewed as irresponsible, and often take part of the blame for unpleasant experiences of their children. A 25 year old woman mentioned that her mother only showed some caring when she was sick in hospital; otherwise it was her father who was taking care of her. It was encouraging to learn that some partners and fathers

still care about their children beyond providing for shelter and financial security. Resolving childhood crises from their own experiences, according to Erickson could have an influence on their decisions about parenthood. This woman spoke about how her mother used to tell them (her & her sisters) to go and make living on their own when she was younger.

“My mother was not working. And then my sister left her with the four month old child. I was doing standard seven at the time. I had a boyfriend, but it was not a kind of a boyfriend who wants to sleep with me. And then my mother said, ‘can you see that there is nothing in the house. Everyone has to be on their own...’”

Because of the expectation from her mother, for her to be on her own, she started to depend on her boyfriends and sexual partners for a living.

“He said (boyfriend), ‘you shouldn’t go to school without a lunch box’ then I became addicted to a boyfriend in that way. Because he started giving me the money, he wanted to touch me. When he bought clothes for me, he wanted to touch me.”

One would wonder, when listening to the financial concerns of women, about the role of the biological fathers of their children, but these fathers are usually alive and employed. This raises concerns about the involvement of fathers in the upbringing of their children. Most women were struggling financially to make ends meet for their children, but the fathers were still alive. This matter questions the legislation on paternity and child maintenance. This does not however suggest that, fatherhood is about financial contribution, but this is one of the critical areas where fathers need to take responsibility. A twenty-two year old woman found out about her HIV positive status after a third rape incident. She then met a partner and moved in with him after giving birth to their child. She hoped that moving in would lessen the weight from her shoulders but she has been beaten and abused emotionally.

“If the baby cries, he won’t attend to him he says it’s my responsibility. He doesn’t have time for him. I ask him why he can no longer take the baby, or even a glass, anything. If I am not around, he leaves the dishes dirty, even the one he was eating from. He no longer wants to buy milk. He tells me about the child’s grant. I made a mistake of telling him that I receive the child’s grant of R200, so if he did not buy milk, he tells me about the child’s grant, and ask what I do with it. He sometimes says hurtful things to me; maybe he sees that I am dependent on him.” (22 year old woman)

This woman continues to endure this pain in order for her child to have shelter, because she was not on good terms with her own mother. She reported that she could not have another child under the circumstances, but was not using a female controlled contraceptive method. Earlier, she mentioned that when she had a child, she wanted to leave an image of herself and then started worrying about who will take care of the child afterwards. This suggests that quality of life and happiness are not clearly articulated when decisions about getting pregnant are made.

In another instance a woman had more than one child with different fathers none of whom were involved in any way in the upbringing of the children.

“They (fathers) are all not there, the three of them. The one of the first born, I used to stay with him but he is sick now, so I understand. The other one is around but I don’t have his number, so I don’t know how I will get hold of him. He stays with a woman. He is working. The last one is fine (not sick, and employed), but he is not helping me.” (29 years, Soweto)

In another interview, an unemployed mother of a four-year old said that she and her unemployed husband were planning to have another child in the next year and that their only source of income was the child support grant and some casual jobs that her husband goes to when he is not sick. Job security was not tied to the upbringing of the children and living expenses for her. Often, people are expected to be employed before considering having more children. However there is no support

available from the families due to the disintegration of the family system and unemployment.

Some women however showed a lot of resilience, given their childhood and life experiences. A thirty-one year old woman who had unpleasant life experiences of rape and neglect when she was younger, and then later discovered that she was HIV positive, demonstrated a level of coping with the continuous challenges that life kept dishing out to her. After giving birth to her first child, she decided to go back and enroll in a microbicide study that used to give her R50 (\$US6.5), which she felt was helpful at the time, because she was struggling with the child and the father was not taking responsibility although they were living together. Unfortunately she was no longer eligible to continue with the study because she had acquired HIV, and therefore couldn't get the money so badly needed. There were instances when she thought that she was being punished by God, especially during her encounters of abuse and when she found out about her HIV status.

“I have been through rape, I've been through neglect, I've been through emotional abuse, physical abuse, and I've been through it all. Suicide, I've been through it all. And at first I thought that this is... something like a curse. That God doesn't love me”.

She reported that her new un-infected partner, who did not have a child, was supportive. She subsequently got employed as a leader of a support group and believes that she gets stronger and stronger.

Men as partners should play an active role and take responsibility for their actions. The burden of caring for a child should not only lie with the mother and corrective action should be taken to ensure that men are accountable for their actions.

5.2.4 Financial concerns

The issue of raising children extends beyond the physical ability of being present into providing all the needs of the child. An unemployed mother of three children said that she couldn't afford to have another child because she was already

struggling financially with the ones she had. This woman was in a relationship at the time of the interview and not using any form of contraception.

“I’m a single parent, I’m not working first of all, and it is hard to raise the ones I have as it is because the little one is not breastfed. I have to buy formula and I have to look at what is at stake. Having another child would force me to sleep around with everybody to make a living. So I’m not doing that. Currently I am suffering and sometimes I borrow money and pay it back.” (29 years, Soweto)

The child support grant is not a solution to the millions of women who cannot afford to raise children. Health care programs alone are not sufficient to solve the many challenges faced by women living with HIV, and other sectors should provide survival opportunities to individuals and families on a long term basis.

5.3 Health provider and structural factors

HIV and AIDS support groups are set to offer participants a non-judgmental space to connect, vent, share, learn, and meet others who have similar circumstances. They also provide a range of medical and socio-economic services and knowledge, practical advice to emotional support, an improved sense of well-being and quality of life. There are many issues experienced by people living with HIV and AIDS, including stigma, medication compliance and interactions, illness exacerbation, and coping with a chronic disability. In this research, thirty of the thirty-two women were active members of a support group in their community. Participants were asked whether they have discussed their aspirations to have children or family planning with the health care workers and most of them had not received such communication. A woman in a focus group discussion sobbed as she shared with the group the kind of treatment she received from the healthcare workers in a local hospital when she was pregnant. Although she personally did not want any more children because two was enough for her, she discouraged the other women from falling pregnant because of the treatment she received. Participants had different

experiences that led to HIV testing. Many were not sure whether an HIV test is mandatory for all pregnant women.

“I did not ask for the test, it is compulsory if you are pregnant. Whether you like it or not, you have to test for the child’s health.” (29 years, Soweto)

Others reported that they went along when offered an HIV test and believed that they were not infected until their results came back telling a different story.

It transpired during the discussions that the support groups take a bio-medical approach in discussing whether or not, HIV positive members of child-bearing age, who aspire to have children, can have them. The support group leaders, who were women of childbearing age themselves and aspired to have children, strongly discouraged the idea of conception in HIV positive women. They also asserted more knowledge and critically weighed their options in their responses, and then imposed their thoughts and values to the groups.

‘Things are not like before, help is there, but you get that fear that, what if I leave my child. Even now, we are going to see someone at Bara (hospital), she is pregnant, she wanted the child the way I do today, and she was positive. She is sick now, because of the pregnancy. The more the pregnancy, the more you get sick, because of HIV.’ (31 year old support group leader, Soweto)

Research has not shown that pregnancy speeds up HIV progression, therefore this leader was sharing her opinion of what she thinks lead to the sickness of the other member.

Another leader of a different group emphasised that conception for HIV infected women could compromise their immune system and speed up HIV progression.

‘Me... I really discourage them. We know we’ve got rights, but at the end of the day who is going to take care of the orphans? Definitely we know that we are going to die. And especially that when you have the child so much

(nutrients) will be drained from you, you will be left with nothing. Who is going to raise your child? At the end of the day we are going to have orphans in South Africa, and the doctors tell us that it is our right to have children, you understand? And at the end of the day, you won't know whether you are going or coming, especially with ARVs.' (33 year old support group leader, Soweto)

Although, this information is likely to be shared and discussed in most support groups, London et al. (2008) maintained that even though pregnancy is an immune-suppressed state associated with decreasing the CD4 count, there is no compelling evidence to suggest that pregnancy facilitates HIV progression. When asked whether, conception and reproductive health were discussed in the support group, this 33 year old leader said:

“We do discourage it (pregnancy), but sometimes you find that among ourselves; there are those who are pregnant knowing that they are HIV positive. Sometimes it feels like we are judging them, you see? But it becomes an opportunity if they are not around; we just discuss that, guys, especially when you have them(children) already, why do you want to go through this (pain and suffering) ?”

Throughout the interviews, there were great aspirations about motherhood, but different factors influenced intentions. Women, who were active members of the support group, were discouraged from considering pregnancy, based on all biological and medical reasons given to them. Likelihood is that women who fell pregnant felt ashamed of continuing with the support group. It is unfortunate that none of the options available for these women are discussed with them, and they miss an opportunity of minimising risk and managing the pregnancy well. Family planning, abortion and adoption did not form part of the support group discussions, because HIV positive women were not expected to have reproductive needs.

“Okay... the third one has a different father; I was also confused, again. The father of my second child was no longer interested in me, so I started dating this one, the last one. When I was still with him, I fell pregnant. I didn’t know that I was going to fall pregnant. I was not on contraception.”
(29 years, Soweto)

Structural barriers were also found by Cooper et al (2005) and remain a challenge. This clearly shows that intervention cannot only be focused at individuals and beneficiaries of health services, but speaks to the orientation of health staff and implementation of policies. ‘*Becoming*’ pregnant in these interviews suggests that it had not been actively planned. This is an important message for health care workers as it suggests that women with HIV should not be treated any differently from their un-infected peers when it comes to possibilities of having unexpected pregnancies. The point is that there are other things that clients do not tell their attendants and their fertility plans is one of them.

5.4 Reproductive rights, attitudes, perceptions and influence of others

Sometimes, moral values can create a conflict with reproductive rights, especially when they are imposed on individuals. Married women face more pressure from the expectations of their in-laws and significant others to have children, than single women. Even when this pressure is not pronounced and directed at them, they are likely to feel it. All women felt that in the ultimate end, it is their prerogative and reproductive call to decide whether or not they should have children when they are HIV positive, irrespective of what others think or say. With this said, there were still strands of societal expectations throughout the discussions. Women in discordant relationships expressed that their partners would like to have children, and they also aspire to have children, but they already had children from previous relationships. Two of them were engaged to their HIV negative partners at the time of the interviews.

“The other issue becomes the pressure, when you are married. Even if I tell them that I am positive, they will say they want a child. That is pressure, and

*I will probably do it because, of the pressure that they put me through.”
(FGD, Attridgeville)*

Women highlighted all the pros and cons, including immune suppression and orphan-hood but still maintained that it is an individual’s calling and no one has a right to violate it.

“Well... I don’t know. I will not say it is right or it is not (to have a child), because there are many reasons why people want to have children. But the main thing is to weigh your situation individually and pick up what is at stake and make informed decisions. At the moment, I can’t say ‘yes’ or ‘no’. It really depends on you and your husband” (25 years, Soweto).

Women were also asked about the attitudes and perceptions of their significant others including, family members, partners and friends. They were also asked if these attitudes and perceptions had an effect on their intentions. While others were supportive of the idea of pregnancy among HIV positive women, others discouraged it. All participants were confident that these attitudes and perceptions would not influence their intentions to have or not to have a child.

“My mother does not know (about my HIV status). But then when she asks, ‘you are older now, what about having a child’ my sister says ‘what is the child for? Who is she going to leave the child with?’ My mother asked her ‘what do you mean’. My sister said ‘I know what I know’” (25 years, Attridgeville)

“Actually, I had planned to have the first child only. The second one and the third one, she (mother) was not impressed at all. But still she is able to treat them well.” (24 years, Soweto)

Nduna (2008) pointed out that paternal grandmothers are especially vested with the powers to impose on young women who are daughter in-laws the importance of

childbearing in the lineage of a family and they are often left out in HIV messaging. This could cause a barrier for HIV infected couples who decide not to have a child. Comprehensive interventions should take this into account.

5.4.1 Planned and unplanned pregnancy

There sometimes is an inherent assumption in health service delivery that women are independently capable of making decisions around their reproductive lives. The WHO/UNAIDS (2004) policy statement recognises that the intersection of gender with other crucial social factors such as, age, marital status creates complex barriers for women who are living with HIV. Very few couples plan their pregnancies, and most couples and individuals intend to have a pregnancy at any stage of their relationships. Therefore it is important to note that timing a pregnancy is not always practical, and should therefore not be expected from HIV positive women either. Instead, a conducive environment that allows women to discuss their reproductive aspirations should be established from the onset. A woman's experiences of repeated illness and loss of a child did not influence her intentions about pregnancy and motherhood. She learned in 2003 that she was living with HIV. She recovered in 2004 and got pregnant in the same year. The child tested negative for HIV. In 2005 she got sick again and was bedridden.

"I fell pregnant, and got the child, but the child passed away. The child was a few months old. My mother knew that I had HIV. She was scared. She was scared. Because that time, what made me to sleep in hospital, was the seizures. They were scared for the baby. Sometimes they would call the ambulance thinking that when I fell I got hit hard on the stomach."

After recovering in 2006, she got pregnant and gave birth to a child who passed away after a few months. None of these pregnancies were planned. She intends to have a child when her CD4 count goes up, despite everything. She drew strength and courage from other people who live with HIV for many years, and she believed that God was going to see her through the pregnancy and life in general.

5.4.2 Termination of pregnancy

Women who decide to terminate un-intended pregnancies should be able to do so, without prejudice. However women should not be forced to terminate their pregnancies due to their positive HIV status. In practice there are varying challenges that hinder this choice of termination of pregnancy. Termination of unintended pregnancy could reduce the burden on an HIV infected woman. Two women were aware of the option of abortion for an unintended pregnancy, but their decisions about whether or not to do it were determined by their circumstances. These findings, further suggest that not all women living with HIV are not aware of their status when they get pregnant. A mother of two children conceived when she was already HIV positive, wanted to abort the third child, but was hindered by financial constraints. She was still not on contraceptives at the time of the interview. Although abortion is legal in South Africa, and freely available in some public hospitals, there are still women who may not access this service, due to affordability and other reasons. Again the decision to terminate a pregnancy does not always rest with the individual, as often desired and presumed.

“I decided that I will terminate the pregnancy. At home I was told that I am wrong.” (29 years, Soweto)

Though this woman’s reason for not wanting to have any more children was not related to her HIV status or perceptions of others, her financial circumstances hindered her. She drew her strength and courage from her family and to a certain extent, was influenced by their attitudes, such as that towards termination of pregnancy.

“I was going ahead with it (abortion) without their (parents & siblings) approval, but when I got to the clinic I was told that I am too advanced at the time. I had to go to the doctor who was going to cost me about R200 (US\$26), which I did not have, so I could not go ahead with it.”

Another woman who had an unintended pregnancy was encouraged by her partner to terminate the pregnancy, but she did not want to do it. The young woman was already HIV positive when she fell pregnant. Refusing to abort suggests that some unintended pregnancies can be wanted and welcome, particularly in instances where one does not have a living child.

“Yes, I had a relationship, then last year I fell pregnant and told him, and he told me to do abortion. We did not agree on that, so we broke up” (22 years, Soweto)

The two incidents, although different, are a strong indication of the control that these women asserted over their reproductive choices. It is also important to note that the twenty-nine year old woman who wanted to terminate the pregnancy already had two children and was already struggling financially to raise them, because the fathers were not contributing, while the twenty-two year old woman did not have a child at all. The latter, mentioned her intention to have another child, if she had a stable employment. Parity remains a factor for women, in making reproductive decisions. These experiences point out the complexity of motherhood, and pregnancy for young women who are living with HIV.

5.4.3 HIV positive role models

In some instances, all one needs is a good role model who will give them courage to live on in a future that seems to be bleak. For some, these role models are there but others see their friends deteriorating and dying on a regular basis and loose hope. A twenty five year old wife, wanted to have another child, even though her husband was also HIV positive and sick.

“I saw people who are living with HIV who are well. There is nothing that changes. The important thing is to accept”

Another woman who was also twenty-five years old felt that she did not compromise her health when she fell pregnant and believed that other people in her situation cope quite well with their status,

“I mean you can see that most people survive, I also put my hope in God. I wanted to have a child.”

It appears that HIV positive individuals who seemed to be healthy were seen as a source of strength and courage. One of the coordinators, while encouraged by these people who live for many years with HIV, also critically looked at the daily occurrences of people who die around her from the disease, even if they were not pregnant.

“Yes there are people, who live more than fifteen years or twenty years. Yes, those stories give you courage, but sometimes you are faced more with people who die than those who live long, and say ‘I have fifteen years living with HIV but I’m still alive.’ But with us, everyday, ours, we are faced with people who die, so you fear that, if I get a baby, it would be unfair to bring a child on earth, when you will leave him/her.” (31 year old support group leader, Soweto)

Again, with her being the coordinator and expected to live up to her teaching and information within the support group and make decisions accordingly.

5.5 Desire to have a child is not always a predictor of intention and behaviour

These findings show that desire and attitude cannot always result in behavior or intention. In this part we explore women who expressed desire to have children, but no intention due to various factors that hinder them.

“It’s a joy to have a child; I cannot even describe how it feels to have a child. But, again, I fear too much about my son, as I told you earlier that we live in fear everyday, if he is left alone. Yes there are people, who live more

than fifteen years or twenty years. Yes, those stories give you courage, but sometimes you are faced more with people who die than those who live long, and say 'I have fifteen years living with HIV but I'm still alive.' But with us, everyday, ours, we are faced with people who die, so you fear that, if I get a baby, it would be unfair to bring a child on earth, when you will leave him/her. I'm still in this dilemma because there is a lot that I think about. If it wasn't that I would have a baby, like today, but unfortunately, our situation is different" (29 years, Soweto)

Some women who desired children but had no intentions of having them were those who had lost a child previously to HIV, and those who do not have a support system such as a mother who would look after the children when they are no longer able to. These examples point out to the complexity of being a young woman in South Africa today, living with HIV and having to reconcile one's needs and wishes against those of significant other and the health system.

Table 1: Summary of findings

Perceptions of women intending to have Children	Perceptions of women not intending to have children or uncertain
Never had a child, a child gives joy, strength and courage to live on	Fear losing a second child, despite PMTCT intervention
Would like to leave an image of self when they die	Have enough children already
It is their reproductive right	Unemployed, cannot afford another child
Believe in PMTCT	Fear of leaving orphaned children behind
The partner does not have a child, and they would also like a second/third child	Pregnancy may speed up HIV progression
Have lost a child before and want to replace	

Chapter 6

Discussion

The findings of this study paint the complexity of HIV on women's reproductive lives and choices. Access to reproductive health services including family planning, termination of pregnancy, prevention of mother to child transmission, and antiretroviral treatment and management of HIV are all critical in ensuring safe motherhood.

From this review of literature, it appears that even researchers have differing information about whether or not, pregnancy speeds up HIV progression (London et al, 2008). When these issues are not clearly cut out to reach a common ground, health care workers who are providing direct services to the clients are may impose their own judgment about reproductive options of HIV positive women, and this could lead to violation of some sexual and reproductive rights of women. Even in the presence of programs and policy guidelines, for HIV infected women, pregnancy decisions are not clearly cut.

Most behavioural and human developmental theories originate from the Western and capitalist regions and often do not take into account the social context and constructions of communities. They often describe behaviour from an individual and bio-medical point and miss the role of the social networks that further shape behavior. Ajzen (1991) has at least included the influence of significant others in the analysis of intention and behavior.

Erikson on the other hand described human behaviour from a developmental point emphasizing that human beings go through various stages, which predict their expected behaviour. A sense of control over one's own life is very critical in general and in sexual behaviour. This is in line with the theory of reasoned action on the emphasis of the perceived behavioural control in predicting the likelihood of behaviour. Clearly, the significant others play a role in decisions that are often thought to be a private matter and this cannot be ignored.

The findings show that sometimes there is conflict between the desires of the individual and the perceptions and attitudes of others, but also that individual beliefs and attitudes are not independent from social norms and perceived behavioural control. Ajzen (1991) clearly articulates this in his theory of Planned Behavior. One of the complexities is family and partner involvement in decision-making (Cooper et al., 2005). In cases of newly wedded women the in-laws and in particular the paternal grandmothers have a time-honoured role. The finding resonates with those of Bezner, Dakishoni, Shumba, Msachi, Chirwa (2008) that grandmothers are highly recognised as powerful and influential in the role of fertility decisions and childbearing practices among women in African familial structures.

The motivation to behave in ways that gain approval from the people also came out in the form of pressure from the partners to have children, as indicated by Nduna & Jewkes (2008) and Cooper et al. (2005). Women who already had children mentioned that their partners wanted to have a child. Sometimes there is an inherent assumption in health service delivery that women are independently capable of making decisions around their reproductive lives. The WHO/UNAIDS (2004) policy statement recognises that the intersection of gender with other crucial social factors such as, age, marital status creates complex barriers for women who are living with HIV.

6.1 Are services reaching the women who need them?

Prevention of Mother to Child Transmission knowledge and the younger age of the mother (Peltzer et al., 2008); not being on HIV medication and higher current CD4 cell count (Stanwood et al., 2007) were associated with pregnancy desires and intentions. These came out again in these findings as critical in determining reproductive aspirations. Younger women, women who did not have a child and women whose partners did not have a child expressed the desire to have a child of their own. Some women referred to their CD4 cell count as a factor delaying them from having children. However another critical factor that emerged from these

findings was the number of live children and a previous loss of a child to HIV. HIV infected women are not a homogeneous and should not be treated as such.

Pre-conception counselling and information should be accessible to these women who are likely to get pregnant so that they can have successful pregnancies and prevent transmission of HIV while not compromising their health in the process. The question here is whether the current services provided to women in this category recognise and respond to these reproductive needs.

Information and services on family planning, including contraception to prevent unintended pregnancies and abortion for unwanted pregnancies should be readily available to all young women, irrespective of their HIV status.

6.2 Improved quality of life, reduced anxieties about dying and orphan-hood

Fear of infecting the partner or child and concerns about leaving current or future children as orphans (Cooper et al., 2005) also emerged strongly in this study. Women are often encouraged to communicate their pregnancy plans upfront with health care workers. Collaborative decision-making for women's fertility desires involves assessment of CD4 counts and viral load, establishing whether to put the woman on ARV during this period, or to change regimens. However, when the women are upfront with their aspirations related to fertility, they experience negative responses including interrogations about who will take care of their orphaned children when they die. This type of reaction from health care workers may dissuade women from discussing pregnancy plans.

The disapproving attitudes coming from the nurses have been reported in previous findings (Cooper et al., 2005) where women shared that this is a sentiment that is echoed at clinics and in support groups. The use of death as a threat to women does not assist in improving their quality of life. Often, individuals who know their HIV status are praised for being in control of the disease because they know what treatment to take, what to eat, how to keep their stress levels down and general healthy lifestyle. But, when it comes to making reproductive decisions, this control

is often taken away without exploring other bio-medical and socially acceptable alternatives.

6.3 Control beliefs and perceived behavioral control

In contrast with the assumption that behaviour is also dependant on the perceptions or approval of significant others; it was rarely the case in this study. All women felt that if they wanted to have children at any stage, it wouldn't matter what others think of it and whether they approve or not. The issue of human rights and reproductive rights of the women was emphasised. There was little mention of the child's rights, or future thereof. Women who had children after knowing their HIV status and those who had intentions of having a child spoke more about the chances of the child turning out to be HIV negative due to the Prevention of mother to child transmission (PMTCT) program. Beyond this, there was very little mention of concerns about the upbringing of the child, guardianship, education of the child or any other related issues, should the mother die, either as a result of HIV infection of any other form of death.

So much pressure can be put on individuals who know their HIV status (positive) to make provisions and think of death and future of the children, suggesting that other people do not necessarily have to concern themselves about such matters. All women felt that they had the control over whether or not they want to have children. Although the pressure in marriage in general was cited as a potential factor that could lead to women falling pregnant, no woman reported to be in that position personally.

6.4 Intention and behaviour

With regards to aspirations, women mentioned much about the image of themselves, joy, strength and hope that comes with being a mother. This complements Erick Erickson's theory of human development, particularly the seventh stage of generativity versus self-absorption discussed earlier. Also some women, who said they did not intend to have children, were not on contraceptives and had one or more unintended pregnancies.

According to the health belief model, individual's perceptions of the threat posed by a health problem (susceptibility, severity), the benefits of avoiding the threat, and factors influencing the decision to act (barriers, cues to action, and self-efficacy), are central to decisions that people make. While some women may say that they have no intentions of getting pregnant; not using contraceptives which are freely available and accessible, could be a sign of a low sense of susceptibility to pregnancy and absence of cues that motivate for action. The inability to take action and utilise contraceptives consistently when not intending to have a child, also happens to women who are HIV negative or whose status is unknown.

6.5. The role of Human development in predicting behaviour

According to Erick Erickson's developmental stages those women who strongly wanted to leave their image had resolved the stage of intimacy versus isolation and were keen to see a future generation which they have contributed to. Erickson's theory does not critically explore the context that women or individuals find themselves in and underlying factors that are critical in decision-making. Also this theory tends to focus more on the individual, and yet according to these findings the collective decides.

In these findings only one woman mentioned the possibility of her adopting a child at a later stage in life, depending on her financial status. This alone suggests that adoption is associated with having financial stability whereas biological motherhood is not necessarily tied to financial status. The concept of adoption does not fit well among average Black communities. However Erickson's interpretation of childbearing as a way for some parents to obtain 'return on their investment' was described in these findings where one woman in Soweto said that her older child will look after her and another one in Atteridgeville said that her children look after her more than her sister and give her strength.

On the other hand, there was a more pronounced ability of women to seek abortion when they need it, irrespective of the attitudes of significant others. A woman in

Soweto, who did not want to terminate her pregnancy, did not do it even though there were consequences of losing a partner in the process.

6.6 Public Health information on Reproductive health and rights

While a lot of information, including getting tested, is readily available to the general public, whether HIV positive or not, , disclosure, treatment, nutrition and management of opportunistic infections, information about conception and pregnancy in HIV infected individuals is not as easily and readily accessible. In most public clinics and hospitals there is information, education and communication material including posters and sometimes videos on positive living with HIV. There seems to be no expectation of HIV positive couples to want to be informed about conception and managing pregnancy. This does not help the HIV infected individuals not to fall pregnant, and it deprives them of a better managed pregnancy and wellbeing. Information about conception and pregnancy in HIV positive individuals should be made readily available and be accessible without having to consult with health professionals.

The health care workers need to respect the aspirations and intentions of women and couples who intend to conceive, by providing all the necessary information and guidance that will assist them to make informed decisions. Legislation and guidelines on pregnancy and HIV need to be presented clearly to the health care workers, who should in turn communicate well with clients. Because individual rights often override public health, it is not possible to deny women their right to reproductive health which for them means having a child if they aspire to have one. Much effort must be put into providing the correct information and once again, providing effective contraception for women who do not intend to conceive, as well as managing pregnancy for those women who choose to have children or who have unintended pregnancies that they do not want to terminate.

Relevant information about pregnancy is rarely shared with HIV positive clients, primarily due to health providers' concern about the physical health of the client and lack of sufficient information as well as their own attitudes and values. The

expectation is usually that clients should know better than engaging in unprotected sex and conceiving when living with HIV and that no other options should be explored. In fact, health providers need to have an unambiguous understanding of the interactions between pregnancy and HIV and how HIV-related immune suppression may contribute to undesirable pregnancy outcomes (Landers, Martinez de Tejadaand Coyne, 2006).

Lack of information can be limiting, as one may end up having to use one's discretion in making decisions. It is critical that health workers present all options and point out all pros and cons of conception to HIV positive women and couples on a case-by-case basis and let them make the decisions, rather than imposing on them what they should do. In some instances, the time to dwell on this may not be available due to patient load and issues of staff availability.

Some health workers, particularly in public health services, are overworked and understaffed. Still, this does not mean that health care workers should summarise by imposing their own attitudes and values. Rather, group sessions could be organised with clients of reproductive ages to explain the implications of conception on the immune system. Presently the information about the likelihood of HIV progression during pregnancy is not available to those who need it. The Centers for Disease Control did not take immediate steps to modify its recommendations on discouraging HIV infected women from pregnancy despite evidence from studies that pregnancy on its own does not increase the progression of HIV.

6.7 Legislation on paternal rights and responsibilities

Reproductive health matters cannot be seen and dealt with outside a gender framework. The responsibility of preventing unintended pregnancy lies with both partners and the burden should be shared fairly. In some instances, fathers get away with not taking responsibility for their children due to the absence of affordable and accessible paternity testing services. This can be a stressful encounter for the mothers and I imagine that the burden is more when the mother is also living with HIV. Taking care of one's health condition and having to worry about the wellbeing of a child can be distressing. At a primary level there are behavioural interventions

from Gender institutions such as EngenderHealth, Sonke Gender Justice, and South African Men's Forum. While these activists encourage responsible fatherhood and supportive partners, there continues to be a great proportion of men who do not take responsibility for their actions and advocacy should continue in these spheres to improve the lives of women.

Chapter 7

Strengths, limitations, recommendation and conclusion

This research adds some contemporary and new insights into the work done by many on this subject particularly in South Africa. However, conducting the research itself has proved to be a learning experience and produced some strengths and weaknesses, but certainly pointed out the needs for the focus of research and interventions to the improvement of quality of life of young women living with HIV.

7.1 Strengths

The study recruited participants who were both on ART and not on ART. This diversity enabled us to understand the needs of the two groups about fertility. Although the influence of ART on pregnancy intentions was not explored, this study really was inclusive and not biased towards any group of HIV infected women. The combination of women who had children and those who did not yielded more information about the dynamics of having and not having a child and the number of children.

7.2 Limitations

Participants for this study were recruited mainly from a support group with only three participants who were not actively involved. Due to the bio-medical information that is discussed in the support group sessions, participant's reflections may be influenced by this, and therefore findings of this research may not apply to women who are not influenced by a support group. This study was a qualitative design, and results may not be generalised to the entire HIV positive population of women. A few qualitative studies have been carried out in Soweto on the impact of ART on fertility and fertility desires. The period between HIV diagnosis or initiation of treatment and the interview about reproductive intentions was not measured in this research and this variable could have a significant effect on the emotional state of participants. For instance, it is possible that those women who

have known their status longer may have become comfortable and realised that they want to have children due to the improvement to their health over the years.

7.3 Recommendations

The findings from this research indicate that the reproductive health needs of young women who live with HIV cannot continue to be ignored. Fertility choices for HIV positive women should be contextualised within the framework of clinical disease staging, CD4 cell count, viral load and presenting AIDS defining illness, all of which have been shown to affect the outcome of pregnancy (Newel, 1995). Hope for an HIV negative child, previous loss of a child, firm belief in the efficacy of the ART and low parity should all be explored as possible predictors that women living with HIV wish to have children. Research into the ways of enabling women living with HIV to have babies with little anxieties around transmission, childbirth, recovery post-partum and long term family plans is needed to formulate conceptual frameworks that will better predict health promoting reproductive behaviours of women.

7.3.1 Responding to sexual and reproductive needs of young women

Young women have emotional, physical, and psychological issues related to their sexual and reproductive development. The PMTCT program, while it starts before pregnancy in preventing HIV until post-natal care, it seems to focus more on the pregnant mothers and postnatal care, than those who still aspire or intend to have children. There is a need to:

- Popularise male and female condoms as reliable contraceptive methods from the health providers and community outreach programs.
- Interventions should transform the idea of contraception as a responsibility of women, and encourage men to take equal responsibility in preventing unintended pregnancies and HIV infections
- Experienced younger staff should be in clinics and organisations to provide information to new youth service users on SRHR issues. Information and services need to be relevant to young people who do not yet have children

- Establish clinical services that assist young women in psychosocial support (depression, anxiety, suicide, progression with infection).
- Increase access to emergency contraception. In South Africa, where contraceptive prevalence is quite high compared to other African countries, qualitative studies conducted among HIV and PMTCT clinic attendees showed that women and men living with HIV had little knowledge of emergency contraception or how to access it (Delvaux et al., 2007). Although emergency contraception, like other non-barrier contraception, does not protect against STI or HIV transmission, it should be more accessible, affordable and readily available to those who need it, not only in pharmacies
- Better access to affordable and reliable abortion services. Public health service needs to make this service attractive to those who need it and ensure that there are minimal inconveniences in accessing it.

7.3.2 Integration of family planning: Pre-conception counselling

A curriculum should be developed in direct consultation with PLHIV for new and existing health care workers. A review of any curriculum should be undertaken by credible groups. The curriculum must be specific to the reproductive needs and issues, including transgender people, youth and adults and should include sexual dysfunction relating to those on and off ARV therapy and other HIV-related

7.3.3 Addressing stigma and discrimination

It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. Across the world the global epidemic of HIV has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. Yet the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer countries of the south.

Many reports reveal the extent to which people are stigmatized and discriminated against by health care systems. Many studies reveal the reality of withheld treatment, non-attendance of hospital staff towards patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines. Also fuelling such responses are ignorance and lack of knowledge about HIV transmission.

A mechanism should be developed for the implementation and monitoring of guidelines and curricula that address stigma and discrimination for health care workers, school teachers, policy makers and programme staff on all SRHR issues that affect PLHIV, particularly for young people.

7.4 Further research

Future research needs to consider that individuals in Black communities in Africa live in a collective and communal manner, therefore decision-making about major life aspects such as whether or not to have children, are not as rational as presumed. While women may express that they have made the decisions, their social context may well be strong enough to prohibit this. For quantitative research, rigorous instruments to measure exactly what qualifies as intentions or desires should be utilised, including a depression scale, and a measure of the period between HIV diagnosis or initiation of ART.

This research and other research elsewhere (Delvaux and Nostlinger, 2007), show that contraceptive use is low even though pregnancy is not intended among women, irrespective of HIV status. Further research needs to rigorously examine the availability, accessibility and acceptability of contraceptives, to understand how to best ensure that women have access to the contraceptive method that they are most comfortable with. There is also a need for more research or review of literature on the interaction of hormonal contraceptives with ART, so that the correct information can be provided to service users and update all information that suggests that Intra-uterine contraceptive devices are contra-indicated in HIV positive women. More research on whether or not pregnancy speeds up HIV progression is needed.

7.5 Conclusion

The importance of having children cannot be underestimated and it seems that not even a life threatening condition will stop this. The findings point to the urgency to provide focused family planning counseling and services during consultations with women of reproductive ages. Young women who are sexually active and in their reproductive ages need to access information and family planning services, irrespective of their HIV status. Ideally from the initial consultations, information should be shared with HIV-positive women about the interaction of the drugs that they may be taking with the range of contraceptive methods that are available to them without prejudice or being judged. In addition information about termination of pregnancy and adoption as options should be as readily available as information on nutrition and HIV prevention.

Answers to women's questions should be put in the public arena and not reserved for a mother expressing intention to get pregnant. In agreement with findings from Cape Town (Cooper et al, 2005), this research suggests that young women who have had no child or who have lost a child will have aspirations to have children. The role of generativity especially as it relates to newly wedded young women was used as a reference to talk about the importance of the PMTCT program. Hope for an HIV negative child, previous loss of a child, firm belief in the efficacy of the ART and low parity should all be explored as possible predictors that women living with HIV wish to have children. Information about the risks and best timing of pregnancy for HIV positive women, who wish and intend to have children, should be made available publicly. Effort should be made to ensure that those women who do not intend to fall pregnant have access to quality and effective contraceptives.

Health care workers should not be left out of the equation in these efforts, as they are the first level of contact with clients and the information they provide is seen as credible. Simple guidelines about the kind of advice that should be given to clients based on the uniqueness of their circumstances should be made available to the most remote areas. In fact, information about pregnancy and HIV as well as options available to them should be routinely offered to all women of reproductive age who are living with HIV so that they can make informed decisions. Promoting pre-

conceptual management should not be confounded by normative unplanned pregnancy in the general population. Because a woman does not come and speak to the nurses about getting pregnant it does not indicate lack of fertility desire.

This research calls for more research into the ways of enabling women living with HIV to have babies with little anxieties around transmission, childbirth, recovery post-partum and long term family plans.

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Appendices

Appendix 1-Interview schedule for in-depth interviews

Introduction

- Moderator
 - Purpose of research
 - Consent and confidentiality
 - Permission for the use of a tape recorder
- Respondent
 - Name and location
 - Marital status
 - Parity

Reasons for participating in the focus group and experience

- How do you feel about being a mother?
- How do you feel about having more children now that you know your HIV status?
- Meaning of motherhood to the women?
- Whose opinions do you respect?
- Have you disclosed your status to him/her/them?
- How does your (mother, husband, boyfriend etc.) feel about you having child/more children now that he/she/they know your HIV status?
- What effect does this have on your attitudes and decision to have a child?

Questions from respondent and any other information she is interested in sharing.

End of interview!

Appendix 2-Interview schedule for focus group discussions

Introduction

- Moderator
- Respondent

Experience of being in a support group

- HIV testing and disclosure
- Pregnancy, HIV and motherhood- perceptions and attitudes
- Personal aspirations and intentions about motherhood
- Should women who know that they are living with HIV have children
- How do important people in your lives feel about women having children when they are living

with HIV

- Perceived control towards decision making on pregnancy and motherhood
- Role of support group in family planning and motherhood.

Questions from the participants!

Appendix 3-Information Document and Consent Form

I come from the University of KwaZulu-Natal and I'm currently pursuing my Masters in Health Promotion. One of the requirements for this program is a Thesis to qualify for the degree that I have registered. I will be doing my research on the reproductive health desires of young black women who are living with HIV. I am hoping that the outcomes of the study will contribute to scientific knowledge and inform health programs that target this group. Two focus group discussions will be conducted (1 in Atteridgeville-PTA and 1 in Mamelodi –JHB). In addition 6 to 8 in-depth interviews will be conducted with some of the participants in the focus groups.

The objectives of this study are:

- To explore the attitudes of women living with HIV in Atteridgeville towards having children.
- To understand factors that are associated with wishes to fall pregnant, continue with a pregnancy or not to want children altogether from the social context in which women live.
- To explore the control and power that these women have and can exercise in decisions related to pregnancy.

Confidentiality

Effort will be made at all times to keep the information received from you confidential. Your name will not be used in any part of the study. You have a right to withdraw from participating in this study at any stage when you feel a need to.

Data Collection Material

With your permission I would like to use a voice recorder to collect the information that we will discuss to make it easier for me to focus on our discussion. Also I may request you to allow me to use a video sometimes. This will help me as evidence that our discussion took place.

Consent

I will also request you to sign consent on the next page, just as proof that I explained the study to you and that you have agreed to participate.

Contact details: If you need any clarity or further details about this study please feel free to contact me, Lindiwe Farlane at: EngenderHealth (South Africa), 31 Quinn Street, Newtown, Johannesburg. Tel: 011 264 0184, Cell 078 338 9180, E-mail lfarlane@engenderhealth.org or lindiwefarlane@ yahoo.com.

Appendix 4- Informed consent form

To be filled in by the participant.

I agree that I have read the above information and have been informed by.....about my role in it. I understand that the information that I provide will be treated with confidentiality and that I have a right to withdraw at any stage during the study.

I therefore give my informed consent to participate in the study on reproductive desires of young black women living with HIV.

.....

Signature (Participant)

.....

Date

Appendix 5- In-depth Interview Transcript**IN-DEPTH INTERVIEW TRANSCRIPT**

Archival # OW5

Site: Shanty Clinic- Orlando

Interviewer: Lindiwe Farlane

Transcriber: Lindiwe Farlane

Date: 14/11/2007

I: Ok, you can start by telling me about yourself.

OW5: Ok, about me?

I: Yes, anything that you think is interesting.

OW5: Okay, I am Blue*, at the moment I am a coordinator at WoM*. Before that... er... actually where I am now, I think it's a calling for me. I like to work with people. That's my passion. And... there is a lot about me. I have been through hell, but that is what made me the person that I am today. And then, all my experiences... I don't know if I can go into details about my life, but just briefly, I have been through rape, I've been neglecting, I've been through emotional abuse, physical abuse, I've been through it all. Suicide, I've been through it all. And at first I thought that this is... something like a curse. That God doesn't love me, but looking back where I come from and where I am today, I think that each and every situation, no matter how bad the situation is, there's a lesson there, and then there's something good that will come out of that situation. These situations made me the person that I am today, because... I don't know... to a point where... my experiences changed me, to be where I am... because I remember when I left school I liked engineering, but through my experiences, I ended up with people, helping people because I have endured difficulties. I realize that when you talk to people about my experience, somebody would say, 'I've been through that'. Because you tell me about your problem, it's easy. But for me I felt that... that's why I say I'm here because it's a calling for me. Basically, I am still struggling with confidence,

but I'm getting there. I know that I was born to be something. I'm here for a purpose. So, that's me.

I: In a nutshell. So how did you meet WoM?

OW5: Okay, how did I meet WoM? I was at MoW* doing counseling there. I'm a person who likes to research about things. I like volunteering. So, I went to WoM. At MoW, I used to go on certain days for counseling, so I had many free days at my disposal, so I decided to do voluntary work, because I had been doing voluntary work for a long time, before I even joined MoW. So I went to WoM and said I want to do something, but I don't know what, but something that has to do with people. So I went to WoM and said I want to do voluntary work. When I got there I met a woman who told me that 'we have many programs, what do you want to do?' I told her that I want to work with youth more, because I can reach the youth, you see? Okay, she told that, 'you know what, we will call you when there is voluntary work available, so bring your CV, there is work here, but you need to start by volunteering'. Unfortunately, the second time I went there to bring my CV, I didn't find this woman. I found our boss, who is the site manager. I found her and gave her my CV. She looked at it. I remember that my CV was a mess because I took advantage of the fact that she (the first woman) is a child and this is just voluntary work, nothing much. My CV was upside down and I just carried it as it was in my hands (no envelope). So she grilled me about that and showed me my mistakes, she didn't judge me. She set me down and showed me my mistakes in the CV and told me that 'you don't have to write this in a CV, you have to give full information, full details, everything about CV'. After that she came to me and asked who I am and what I want. I told her what I want, I remember I said confusing things but at the end of the day she managed to sift out that I have a passion and I have a heart. That's what attracted her about me. She groomed me, she told me many things. I don't know what to say. She told me that 'this is how it works, here you have to start by volunteering and then you get a job, but for now we don't have anything'. The next day... we had a chat to a point that she invited me for coffee, you know? There was a lot that she found from me. The next day... I knew that they will tell me

about voluntary work after some months or so, the next day she asked me to come for an interview at 10. I was in Kagiso by then. I said it's ok.

I: Ok, so the following day they called for an interview?

OW5: Yes, they called me for an interview. I was interviewed by somebody different, and this woman also interviewed me. And they were impressed at that time. Two months passed by, and they didn't call me. I even forgot about it and continued with my MoW, applying to other places. After two months they called me to come for an interview. I went. I was interviewed by the national manager. This guy, they call him Green. He interviewed me for five minutes and that was it. That's how I entered WoM. I entered permanently. I did not struggle, like other people who start with voluntary work, to an extent that my colleagues were complaining that some people have been volunteers for seven years, three years. So, that woman for me, I don't now what to say, the way it happened, this woman saw something in me. Even today she calls me 'you are my diamond in the rough'. You know, like... for a girl like me, who is not used to getting someone who believes in me, it was wonderful. It boosted my confidence a lot. That's why I try a lot to do my work properly. I work hard. Now I have confidence, and people see how special I am, you know! It is something for me. It felt good, because I grew up without anyone who says 'you can make it.' 'You are good.' I was told that I am a failure, I was told negative things. So, it was wonderful to hear good things about me. So that's how I got to work at WoM.

I: Alright. Tell me about your parents.

OW5: Okay, my mother is around and my father is around. My father comes from Zimbabwe; he lives with my step-mother. The step-mother has a house in Central. My mother does not have a house. She lives at my grandmother's. I look after my mother and my grandmother, actually all my family. I'm the breadwinner at home. My father does not live with us.

I: okay, he lives with the stepmother?

OW5: Yes

I: Alright, how many are you?

OW5: With my mother, we are three.

I: Alright that's nice to hear, your other siblings... you said you are three, what do they do?

OW5: The other one is not working, she is sick, and the other one works at Y.

I: Okay... you mentioned that you went through a lot of traumatic ordeals in your life. Did you receive any counseling relating to those?

OW5: Actually I did... but I didn't feel like they have helped me at all, like even today I still feel that I have a problem somewhere. I don't know if it was caused by the experiences that I have or what. I went for counseling at MoW. For me to get involved with MoW, I went for my problem. Like... I was raped and I got hurt because this thing was bothering me.

I: Did your mother know about this incident?

OW5: Eish you know... it's a long story, because my mother knew but... Eish... what can I say... she didn't care about me. I raised myself in a way, I can say that. People don't believe me, but I raised myself in a way. My mother was there... my grandmother chased us away time and again, so I would stay here, sometimes with friends, sometimes I would get a boyfriend and live with him. You see! That's how life was for me. I was raped by my step-mother's son who was older than me.

I: So... you basically got your own healing from the inner you? Do you think you have healed?

OW5: I think I have, but not completely, because, especially the second rape. I don't have its memory even today. I really think hard trying to remember about what happened that day. So it has not passed although the person came to me and said 'I'm sorry'. I have not yet found peace. At that time I told him that 'forgive yourself, before I can forgive you' and then he said 'I will'. And then I said 'I am forgiving you', but surprisingly enough, I didn't. Because when I see him sometimes I will be angry. I don't know if this makes sense. You know this person, I liked so much, we were very close and if you didn't know you would think we are siblings. But he was crazy about the fact that I was a virgin at that age. I was 19 and still a virgin. So... I don't know. I didn't get angry. I was just hurt, I was hurting. In fact most of the time I don't experience anger too much, I experience hurt. I would feel hurt, than being angry to someone. So, he came to me, and I remember I got sick. I lost my mind. I lost my mind (in another language). I lost it. And then when he found me, he came and began to visit me and then he told me that 'I did this to you'. I said 'Okay'. I thought that I was at piece. But when he got out of me, he told me that he loves me. He wanted a relationship with me, but I didn't want it. But that really... it did something for me. I don't know if this makes sense. I was happy that he loves me, but when he started having interest in other people, I started having a problem, I started being angry about what he did to me. I started going through emotions, 'why'. Have you noticed, I don't know if it makes sense to you? So, that's why today I'm still angry at him because I felt that this thing was going to tie me for a long time, was going to love me forever. So, but now it's not like that. Now I need answers from him. I need to know 'why did he do it'. I thought that he raped me because he loved me, and I refused to sleep with him. You see? Like, he said he wanted a relationship with me. So... (sigh) I don't know if it makes sense.

I: It does. And then tell me about your relationship. Do you have a relationship?

OW5: Yes, there is someone that I'm with currently. I can actually say he is my fiancé because he has paid Lobola but he has not yet finished.

I: Okay. How did you meet?

OW5: Mhhh (laughing) details? I was coming from town. I can't remember what I went to do in town. And then I was standing in the queue on my way to KG. When I was still on the line, I saw him, wearing a cute cap. I remember I had recently loosened my hair (removed hair piece), so my hair was dry. So as I stood on the line I saw him, and I thought to myself 'this guy is handsome' but I thought that he wouldn't be interested in me, because of the way I looked facially. I was taking glimpses of him, bit by bit, but he noticed. After I entered into the taxi, he winked at me. And then, he said to me 'come out' and I said 'no'. I was shy of getting out in front of the mothers. He said 'come out', and I said 'Hawu'. I left him like that and the taxi left. I don't know... I think we were meant to be together me and him, because the very same day, I found him, standing, not knowing where he is going, in town. The very same day, in KG, I was coming from the salon to book. As I approached, I was walking with two other kids, I saw him. I saw the shirt that he was wearing; he was walking with his friend. I don't know if it was a coincidence or what, because, that person I was flirting with in town, was wearing the same shirt. When we got closer it was like, 'Wow, this is a small world'. Things like this don't usually happen. It's rare, you see? So, we spoke and exchanged numbers because we couldn't earlier on, so, that was that.

I: Okay... when was this?

OW05: Last of last year. In March 2005.

I: Were you in a relationship when you met him?

OW05: I was... sort of. Because I was involved with the father of the child. I have a child, who is 5 now. The relationship was on and off, if I may. I felt that I had

enough in this relationship. I had enough. I just can't take it anymore. By the time I met this one, and with him also, I was not looking for a serious relationship. I was just flirting with him and I was looking for attention. Because with the status, with HIV, we have this mentality that it is hard to find someone. So, for me I was just flirting with him. So I was with the both of them. You see, it was not nice.

I: So how is your relationship going with the new guy?

OW05: With the guy, it's wonderful. I've never felt... in my life I've never been loved the way he loves me. He has his mistakes, because he is struggling with self confidence, self esteem. He is struggling. He was raised by the mother, so he is still having difficulties with being independent, personally. He is working, but at a personal level, he is too emotionally dependent on me, but he is a wonderful person.

I: Alright. When did you know your HIV status?

OW05: I knew about my status when I was... I think it was 2003 around June. I can't remember the date well, but it was cold. I remember I locked myself for almost a month. I am generally an active person; I do a lot of voluntary work and other things.

I: How did you get to know your status?

OW05: Oh, ok... what happened is that I was at Bara, there is a study that they are doing on Microbicides. Before I got my baby, I was enrolled in the study. So you know that when you are pregnant, you stop for a while, and continue after delivery. At that time, it was a study for people who were negative, so I was negative. So I wanted to go back, because I was struggling at that time, so the ZAR 150 that they gave us, in fact it was not ZAR 150 then, it was ZAR50. The money came in handy because the father of the child was not helping me with the child. I was struggling with the child. So I decided that he is giving me a difficult time, so it is better for me to go back there. It was a long time since I went, so I decided to go back to the

study. They took the test, the screening test, then that's how I found out that I was positive. I couldn't believe, because I was enrolled in the study, because even when I tested when I was pregnant, I was negative. I couldn't believe that I'm positive. I remember, I went to the clinic to check again. I checked for several times, to be sure. If there is something that shook me in my life, it's that. I felt that it's not fair. I felt, that when I began to feel that now I have a break from the bad things, and the last thing that I expected. Do you understand what I'm saying? (I: Mm) I felt that this is not fair at all. I felt like... somehow, I didn't blame him (the father of the child), I didn't blame me. I took it to God. I just said 'God, I hate you for this, I hate you so much. Why me? What have I done in this world to deserve this kind of punishment? '. I took it hard.

I: How long did it take you to come into terms with it?

OW05: Yoh! It took a very long time, to really... earnestly, like... even today I still think I have accepted, but at that moment, when I woke up, I realized that HIV is like this. You can sleep alone and tomorrow when you have to wake up, it is difficult to wake up. Your body is refusing and it will pull you down, you know? With HIV you don't know, no matter how well you look after yourself. I usually say to people 'do you think it is easy to live with HIV, or is it hard?' You know I get this thing, with people say 'no, I've accepted.' It's not like that. I'm not saying... I have accepted it, but it's not like that, you live in constant fear. When you hear somebody, you see how big that woman is? She was well. Tomorrow you hear that he is in hospital, the next thing... you know? It's something that you live with, that something like that could happen. So people get scared... it is not easy as people. Yes, you can live with it, you can manage HIV, but you come across things that you wouldn't have experienced if you were well. I fell like that about my child. My child is jolly, and active. He likes to play. Sometimes he wants to play with me, he wants to kick the ball, but my body is refusing. It's a everyday battle. You can no longer do things that you want to do. And again, it is psychologically damaging, until you find a way to live with it. Maybe when you live with it, and deciding that 'you know what? I will live with it and I'm gonna manage it to my best ability, the

best way I can' you see? Because the minute to find out that you are positive, you think your dreams have been shattered. You think you cannot achieve. And you neglect yourself physically, emotionally, you see? That's why even in hospitals they treat us as if we are illiterate, we are not learned, we don't know our rights. I wish you can go to a hospital and see the way we are treated. And maybe you are refused a grant and told that you are fit for work. How can you be fit for work when I have to be here every three months for treatment, I have to come here. I am not working. I need that money. You see? And they think being positive is a disability. We are not disabled. We are not disabled. But they think like that. They don't take us seriously. They treat us... I don't know. Unless you are dressed well and... That's why I make sure, that I dress well, because HIV defines the person that you are now, they don't see who you are. If you can see... I disclosed right?... and they began to say 'but... you...' But if I was OW01, they could just diagnose her from a distance. So, it's hard everyday.

I: Okay... have you been able to disclose to your parents or boyfriend?

OW05: Yes, I have.

I: How was that?

OW05: Whew! It was a challenge. Whew! But then the reason I disclosed was that, I grew up without being loved and when I grew up, they abused me, people came into my life and abused me and everything. I didn't love myself, but I remember somebody saying, 'you gotta live your life'. Then I started loving myself, I started teaching myself. Remember, I grew up without being loved. That's why even people don't love me, because I don't love myself. So I had to learn to love myself regardless of my status, regardless of what I have or don't have, regardless of poverty, I learnt to love myself. When you love yourself unconditionally, everything starts falling into place. You know what is best for you, you know what is not best for you. Before, I started loving myself I was focusing on the things that people did to me, thinking that no one will love me. But when I began to love

myself everything changed. I said whoever comes into my life I will tell them that this is who I am, this is what I have, it's either you take it or you don't take it. And if you don't take it, it's not because I was not good enough, I was just not for you. I'm good enough. I am good despite my HIV status. I am gold, if you can't see that I am gold, it's your loss. Yes, I know that there is rejection. You get rejected when you are HIV positive. It's not my loss, it's his loss, because he couldn't see what I am, he saw HIV. So before that I was scared of dating and, people find me attractive like this. Then, I would go out with you, when it is time for sex I would disappear because I was scared of rejection, but when I started loving myself, that changed.

I: What made you reach that level of saying, this is you, you are an unpolished diamond?

OW05: I don't really know how I got there but, I remember a talk, in *3talk*, talking about teenage pregnancy, saying that teenagers fall pregnant with so much...(tape cut off)... through loving yourself (inaudible), nobody will change you or shake you on that. So I kept wondering, when somebody says value your life, how do I value my life. But when they emphasized love, I thought let me try this because I had tried lots of things in my life. So I thought, let me try and see if it will work for me. Believe me, slowly but surely, I started loving myself bit by bit. Do you know, I got rid of friends who used me, making fun of me because I was poor? It was hard for me to get rid of my son's father even though he infected me; it was hard for me to leave him. I felt that I need him, because I was not going to cope while not working, if I leave him. But, through loving me despite what he was doing for me, that was not enough for me anymore. So that's how I found myself in that position, where I can say, 'I am gold'.

I: Okay. How did he take the news?... About the status?

OW05: The status, he did not believe (inaudible). At first he did not take it serious, but I told him that 'you should go and get tested'. So, because myself and him, we

have always used condoms, that's why I got a child late, I have always used a condom.

I: How old were you when you got the child?

OW05: 27. So I used a condom too much me and him, so it was easy for me to say 'let's stick to condom until you go for a test'. So he did not believe and yet he knew. Because we used to use the method of seven days after periods, but not often. That's why I tested for several times. It was hard for me to believe how did it happen, because we slept for a short period of time (*without a condom*), and now I'm infected. Can you imagine? It was hard for me. But for him, it took a long time before he could believe and accept, until he started getting sick on his feet. That's when he decided to go for a test. When he tested, he found that he is positive, and then he came back to me, and told me that 'I decided to go and test'. Because he was also an open-minded person, he had knowledge of lots of things. So it wasn't that hard, I don't know, I can't speak for him and say it was easy for him, but when I told him it was fine.

I: And your current boyfriend, how did he receive it?

OW05: That one thought I was joking (laughing). He was living in Leon, so I did this thing of disappearing; by with him I decided that this is it. This is it. If he rejects me, so be it. The other day, he was going to a party with his friend, and he wanted to come with me and I said I can't. He asked 'what will you be doing during the week?' I said, I will be around. He said fine. Er... I want to come to see you. When I got there I did not know what he was up to. When we got there, you know guys, he made us food, in his mind he wants to sleep with me. Okay, when I saw where this was getting I told him, 'there is something very important I want to tell you'. He said 'what' and I told him 'you will know, let's get in the other room and talk'. We went into the room and talked. I said 'I need to show you something', at that time my skin was peeling off, all over the body. I took off the t-shirt and showed him, 'do you see what I have'. He said 'yoh, you have AIDS?' I said 'yes, I

have AIDS'. He laughed. After that I said 'I want you to be serious this time, something that I want to talk about, is related to HIV'. He then became serious. I told him that 'I don't know how you will take this, but you have a right to react as you wish, it's your choice, but as for me, I am positive.' He said 'are you serious, serious that you are positive?' I said 'yes'. He did not believe me, because although I was not fatter than this, I had a body. I said 'but I showed you how my skin looks like'. He said that it happens sometimes a person gets a skin problem. He said 'I had a skin problem (showing me the dots) but I was not positive, so how come you say you are positive, you are lying'. Unfortunately, at that time I did not think of coming with something that will prove that I am positive. I told him that 'okay fine, because you need proof, I will come with proof'. But still, although I told him that I'm positive, he wanted to sleep with me'. I told him that 'I know that you want what you want, but I want you to do so when you are sure about my status. If you want it, you can do so after seeing the papers'. We agreed about that. He kept calling me to come, and I kept coming and the other time I came with proof, that I'm positive and he saw them and was like, 'well'. I could sense that rejection was there, but not complete. Not really rejection, but shock about how he is going to handle it. Because he told me that 'I have never come across this kind of a situation, but I heard about HIV, my friends are positive, but for it to be this close is the first time'. He told me that 'a part of me wants to run, but another part of me loves this woman, there's something special about you, so I don't know what to do at the present moment'. I told him that 'what you can do is to give yourself time, I will understand. If you feel that you can have a relationship with me, I'm a phone call away, if you feel that you can't, still it's fine.' He said 'even if I can't, can I be your friend, even if I can't have a relationship with you'. I said 'It's fine, I don't have a problem.' Okay the time went by. He kept calling me, he did not stop calling. He kept calling, checking up on me on how I was keeping. You know people, when you say you are positive they think that you are sick. It went on like that he kept calling but surprisingly enough, he would ask me to visit and I would. I saw that he is pushing me away, because he started telling me about his girlfriends. He had two girlfriends at that time. I asked him 'why, two girlfriends?' I irritated him about HIV and found that he has the knowledge and he protects himself. As time went by,

he got to know me better, the person that I am, bit by bit, he fell in love with me, until one day he came, and I remember I was in Pimville. He told me 'I have a problem.' I asked 'what is it?' He said 'I have a problem at work'. He came to talk to me and told me 'I have never been open to someone, the way I'm open to you.' Me and him, we had a lot in common, and then he was happy because he felt that he has never met a woman that he clicks with like this. Through that, he told me that 'I don't know how you will take this because you know people that I'm involved with.' He told me that 'I feel like you are my soul mate, I can't stop thinking about you.' 'How do discordant people live? How do they go about, because I really love you, I don't know what to do. I cannot love you there; I want you in my life. Right now I can see we are friends, but I want more.' It just... bit by bit... I was also scared, I was really scared that this person is negative, I had fears that when a person is negative and you are positive and you infect that person and so on. So, it was... it went on like that until, I remember we went to seek information about HIV, how we can move forward. They told us that the condom is 99% safe; the remaining 1% is about how you use it. So that's how the relationship started. At the moment we forget sometimes that there is HIV. That was that, so we communicated and shared. And then the person who spoke to us about discordant couples introduced us to other people in the same situation, some their situation slightly different. So we continued.

I: And then, have you spoken about children?

OW05: Eish...we do. It's a problem, it's a problem. Sometimes I fear that I might lose him because of that, you see? I remember, I have another friend, Melody*, we share a lot. She understands about being positive, because she has the same situation, like her partner wants a child and she already has two children of her own. Now she fears that she might re-infect herself, because she will sleep with him, she will re-infect herself. Also it will be difficult for her to carry a child for a long time. So, basically in my case it's hard. He doesn't have a child. He doesn't have a child, it's me who has a child.

I: Do *you* want to have a child?

OW05: Too much.

I: why do you want to have a child?

OW05: Eish... maybe if I didn't know the experience of having a child, I wouldn't want one, but I know the experience of having a child. How it is. It's a joy to have a child, I cannot even describe how it feels to have a child. But, again, I fear too much about my son, as I told you earlier that we live in fear everyday, if he is left alone. Yes there are people, who live more than fifteen years or twenty years. Yes, those stories give you courage, but sometimes you are faced more with people who die than those who live long, and say 'I have fifteen years living with HIV but I'm still alive.' But with us, everyday, ours, we are faced with people who die, so you fear that, if I get a baby, it would be unfair to bring a child on earth, when you will leave him/her. It's worse for me, I've been through a lot, I've been through neglecting, I know how damaging it is inside and killing. So I'm thinking I will leave my son, and my son might go through the things I went through, because his father is not the kind of a father I can rely on. If I am away...because even now, things are not like before, help is there, but you get that fear that, what if I leave my child. Even now, we are going to see someone at Bara, she is pregnant, she wanted the child the way I do today, and she was positive. She is sick now, because of the pregnancy. The more the pregnancy, the more you get sick, because of HIV. HIV is (sigh) something else.

I: So have you decided what to do?

OW05: No, I'm still in this dilemma because there is a lot that I think about. If it wasn't that I would have a baby, like today, but unfortunately, our situation is different, and again, in my part the partner is negative, how do we think we can have a child?

I: Yeah, it's quite a situation. Why don't we pause here, and not necessarily close this conversation. I think we need to continue with it. I will keep in touch, maybe in the next week or two we would probably meet and talk further. Thank you very much for your time and your honesty. I appreciate. End!

Appendix 7- FGD Interview Transcript

FGD INTERVIEW TRANSCRIPT

Archival # FGD2

Site: Itereleg Clinic

Interviewer: Lindiwe Farlane

Date: 23/03/2007

I: Okay... so you found this support group already in process.

ALL: Yes

I: Okay... so P1 when did you join the support group.

P1: I joined the support group in August.

I: Why did you join the support group?

P1: I joined so that I can meet people like me. I thought that if I meet people like me, I would be able to accept my status.

I: Okay... do you think you have accepted now?

P1: Yes, I have.

I: Okay, thank you. And P2, when did you get to know about your status?

P2: I knew it in 2005 (inaudible) I was stressed.

I: Okay... please do bear with me because some of the questions that I will ask you, may have come up in the support group so you may feel bored of going through a

similar process again. Alright... I hear this word 'stress' a lot. What is it all about? What happens when one has stress?

P3: Sometimes you seem confused.

P4: There are many questions that you ask yourself but you don't have answers to the questions, like she said. You ask yourself 'why me?'

P5: When you have that thing, you do not have strength. When you get home you feel down, you do not have the energy to do anything. As a result you feel like sleeping all the time. You tell yourself that you are sick. And when you tell yourself that you are sick, you find that psychologically, you have stress. You keep asking yourself, 'why me?'

I: Alright, thanks. Some people cope in different ways with stress. For example, P1 joined the support group to deal with it. P6, how did you cope with the news of finding out your status? Have you ever been stressed by your status?

P6: Yes. I got stressed, because, I did not understand. I was pregnant and thinking that I will give birth to a child, who will be positive, and then I will die and the child will die as well. So, my problem was mainly there.

I: So... how did you cope? What did you do to deal with the stress... or are you still stressed?

P6: No, I am not. I met these ladies, but before then I got support in the hospital. They taught me how to live with the virus. So I realized that I can also live a normal life.

I: Alright... before coming here, I went to Wits in a seminar, and I listened to one person presenting her findings on the stressors that affect young people who live with HIV. Some resorted to alcohol, some go to church and hope that it will help. I want us to talk about all of us, what things we can do apart from the support group? Sometimes we join the support group at a later stage, so, apart from a support group, what can we do?

P7: I think we need to accept the status first. In another language, I can say, being positive.

I: Okay

P8: Well, you need to do something and not just sit there feeling sorry for yourself. You will get sick worse. You need to bath and be beautiful.

I: Okay... thank you P8. I want us to talk about children, because more often than not, females would want to get married one day and have children. That's what some females desire. But now when one is diagnosed with HIV we think about a long of things. If we are working we think about what will happen to our jobs, and then sometimes we think about issues to do with children. Now I want us to talk about having children. Are there any people who have children in here? Apart from you P9, yours is obvious because you are carrying the child at your back?

All: The child is not hers.

I: Okay... I thought it's hers. Okay who has a child?

All: All of us except P3

I: Okay... do you want to have a child P3?

P3: Yes, I would love to have a child, but not now. When I am financially stable, I would probably adopt a child or raise my siblings' children than having one of my own.

I: Why would you want to adopt as opposed to having a child of your own?

P3: because of my HIV positive status, I feel that I will stress myself by having a child. A child takes a lot from your body, and personally I am still weak. Now having a child would... I don't know how to put it. A child will drain me. My CD4 count is not at a point where I can afford to have a child.

I: Okay... so you have both biological and financial reasons for not wanting to have a child?

P3: Yes

I: Okay... for argument sake, let's say your CD4 count was a thousand and you were working, would that make a difference? Would you want a child?

P3: I would have a child.

I: Okay... P4 do you have a child?

P4: Yes, I have two boys but unfortunately the father died because of AIDS. And after that, I told myself that I no longer want relationships, until I got somebody who understood my status. The relationship is moving forward and now we have a problem about where to start because he wants a child. But I checked and my CD4 count doesn't allow me. They say Nevirapine can help, but right now there is nothing I can do.

I: Okay... the Nevirapine... does it help you or the child?

P4: They tell us that it helps both of us

I: When you say that your CD4 count does not allow... what CD4 count allows one to have a child?

P4: When I checked, mine was 308 and the doctor said that if it can be above 400 I can take chances, but it's 50/50. So, with 308 he wouldn't encourage me to have a child, because as much as a healthy person wants a child, when they fall pregnant, so much from her goes to the child. So when I fall pregnant a lot will go to the child and I will be left with nothing. I am on the ARV treatment so I will strive for my CD4 to go above 400 and start from there.

I: Okay... how old are you P4?

P4: I'm 33

I: And you P3?

P3: I'm 25

P10: Well, for me I'm really confused. I want to have a child, but I'm scared. I had a child, my second born, I got sick. The child got all those things and drops, but

they did not help. Sometimes I think about having a child, but I get scared that what if the same thing that happened with the second child happens again. So I am not sure about having a child.

I: So your fear is about the child... not you?

All (laughter)

I: Alright... generally, generally when we are no longer speaking about us... is it okay for anyone who knows that they are HIV positive to have a child?

P4: Me... I really discourage them that... we know we've got rights, but at the end of the day who is going to take care of the orphans. Definitely we know that we are going to die. And especially that when you have the child so much will be drained from you, you will be left with nothing. Who is going to raise your child?

I: So for you... it's also about raising the child?

P4: Yes, at the end of the day we are going to have orphans and orphans in South Africa, and the doctors tell us that it is our right to have children, you understand? And at the end of the day, you won't know whether you are going or coming, especially with ARVs. What about the next partner? Re-infection and everything, you understand?

I: So... it's not only about you and your rights?

P4: It's not only about you. Many people are involved. Maybe I didn't even tell him, it's only known to me (all...nodding) then I infect him, and then I die, he will be left with the child.

I: Mm... disclosing? Is it an easy thing, especially to your partner?

P11: It is difficult. It is more difficult than Matric. It is difficult, especially a person... let's say, you knew that you are together for almost four to five years. You ask yourself where you are going to start. Where you will say, this thing comes

from. You have lived for a long time with this person and he was your only partner. Where are you going to start telling him that you tested HIV positive?

I: So... are you saying that you have not disclosed?

P11: I have disclosed, but he told me that he is clean. He says he is fine.

I: Did he test?

P11: He says he is fine, he tested when he got injured a while back and he healed, which shows that he is clean because people who have HIV do not heal. (All laughing)

I: So how did you go about with disclosing... as you say that it is difficult more than Matric?

P11: Firstly, I came with my results and put them under the bed. I then took them out because I forget a lot, because he likes putting money there, so he would find them. They went missing, I was stressed that he found them. I decided that it is better for me to sit down with him. I set down with him and told hi that, 'Hey... it's like this' where I realized that he knows his status is when he said 'they are mad. Can't you see how chubby you are?' It ended there; he left and went to drink with friends.

P8: I wanted to say that it depends on what kind of a person you are dealing with. Whether it is your partner and you know him well or the people you live with. Their understanding of HIV and the way that they talk. For instance, for me it was not difficult. I just told my friend that there is this thing that I heard. It started there and then I began to tell more people freely. It depends what kind people they are.

I: Okay... P2, you said you don't want to have a child. Why?

P2: I have two children already, so I don't need any more kids.

I: Okay... for argument sake... if you didn't have a single child at the time of discovering your status, would it be different?

P2: I would at least have one child

I: Why?

P2: I would want to at least leave behind a picture of me behind. So that when I die, at least it could be said that I leave a child behind.

I: Okay... you could get a cat, and leave him or her behind? (laughter). P5, would you want to have a child?

P5: I am undecided. Because I also lost a child. So, there is always this thing at the back of my mind that this thing once happened. And then, apart from that, my CD4 count doesn't allow. It is too low, for me to have a child. I wish for a child when I see others, but I don't have the energy.

I: Okay... you talk about CD4 count. Do you think if your CD4 count was different, you would feel different?

P5: No, I don't think so.

I: Alright... you talk about finding out your status when you were 5 months pregnant. Is it compulsory to test when you are pregnant?

All: (Discussion, others saying yes other no)

P4: Not, it is not.

I: Sometimes, I hear people say that they were pregnant and had to test. As if it is compulsory.

P10: What happens is that you become curious, you think that if you do not test, what if? The child could have got Nevirapine and be protected, such things. You end up going for the sake of the baby.

P6: Sometimes, the reason why we test when we are pregnant is that after the counseling we test, thinking we have nothing, The first thing that happens when you enter is that you tell yourself that "I do not have it." That is why we agree that they can test us. And then, the results come back.

P11: I am one of those people who tested. I was number three in the queue and my blood does not come out easily under normal conditions. On that day, the blood came out very fast and I joked by saying that this one (the blood) is the one, only to find out that indeed the blood has the virus.

I: Okay... is there anybody, who just tested, who was not pregnant?

P3: It's me.

I: What made you want to test? Did you say you were sick at the time?

P3: When I got sick, I already knew my status. There were stories that the person I was involved with is infected. I would receive text messages that a person that he was in love with is HIV positive. I decided that instead of just sitting, maybe I should get tested.

I: Okay

P4: In my case, when the father of my children passed away, rumors were there, about him being killed by AIDS. I did not want to admit until, I met an HIV and AIDS counselor who sat me down and said, to be on a safer side, it's better... You know the denial was also there and the pressure. I went to the hospital, you know you just lose weight, and the stress within two weeks. Then at the hospital we looked for his file and they asked, 'do you know the ID number?' They came with the file and said, 'no, he died because of AIDS, so we have to test you now.' Then they found out that I was also positive.

I: okay... in general what do you think are the attitudes of people out there? People talk, sometimes when you are in a taxi. What do you think they would say about someone who is HIV positive falling pregnant?

P10: People will definitely say 'how can she have a child when she knows that she will die?' There are lots of things that people are likely to say, and put pressure on you at the same time.

I: Okay... I have a last question. As a support group, do you guys talk about issues of pregnancy and having children?

P4: We do discourage it, but sometimes you find that among ourselves, there are those who are pregnant knowing that they are HIV positive. Sometimes it feels like we are judging them, you see? But it becomes an opportunity if they are not around, we just discuss that, 'guys, especially when you have them already, why do you want to go through this?'

I: What about when you do not have even one?

P4: Well, you can go and take a chance, but it's 50/50.

I: Okay... now in clinics generally, is there a time when these issues get talked about? When you are already pregnant, you normally get enrolled in the PMTCT program. But now, what if I am not pregnant and I am HIV positive? Where do I get the information and the support around pregnancy and having children?

P8: I think having a child is not really something that we do not plan. If we are sleeping with a man and we do not use a condom, you cannot say you did not know. That one is clear. The other issue, becomes the pressure, when you are married. Even if I tell them that I am positive, they will say they want a child. That is pressure, and I will probably do it because, of the pressure that they put me through. I may not be able to exercise my autonomy. For others it is like that, but for others, it is plain naughtiness. Some people would already be having a child, and then get the second child, without checking the CD4 count. Maybe a person did not disclose, that is being naughty.

P10: It happens that an HIV positive person gets a child who is negative.

I: Okay... thank you very much for all your input. I will write up everything, and come back to you if I have any queries. I also wish to have a feedback with you. Any other questions?

P9: I still have a problem around this issue of CD4 count. In my case, I discovered my status when I was already pregnant. Now, having to wait for the CD4 count to go up, how is it possible for me.

P4: Well, they are just protecting me, so that my CD4 count can go up. I'm also under pressure though, because I need to do the right thing. But I discourage the issue of the CD4 count because we rely too much on the CD4 count and forget the viral load. But you find that the CD4 can pick up any bacteria in the body and go down, because it detected a flu bacteria in your immune system. We rely a lot on the CD4 count sometimes.

END!

Appendix 8- MAP of Gauteng province

