

**REPRODUCTIVE NEEDS OF MEN AND
WOMEN LIVING WITH HIV: IMPLICATIONS
FOR FAMILY PLANNING COUNSELLING**

by

CORNELIA VAN ZYL

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University of Pretoria

SUPERVISOR: Professor M.J. Visser

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Affidavit

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Angie

Written for this thesis by a friend

Angie could not concentrate in school today. This morning, on her way to school, she saw a team of men from the town council sweeping a dead owl and many dead baby turtles from the road. Angie's stomach turned when she saw this.

Uncle Tom was standing next to the fruit stall wearing his baggies, cane and funny hat. She asked him what happened.

"Na, nothing outa the ord'nary," Uncle Tom said. "Ev'ry year when the tournament comes during the hatch'n season them turtles get confused by them stadium lights. They reck'n them stadium lights must be the moon ashowing them the way to the sea an' them-all head to the tournament."

"Halfway across the road them turtles walk into a place where them wattles shade them stadium lights and them-all can see the real moon, so them-all turn back until they see them stadium lights again and turn. So them-all remain trapped in the road 'till the tournament ends. Then all them cars head home on the road atrampling them turtles."

"Owl was afeasting at the wrong place too. Always happens. Will happen again tonight with the final."

During short break Angie told her brother: "Sean, tonight we have to carry the baby turtles from their nests on the beach into the sea."

Sean laughed and said, for his mates to hear: "Silly girl, they will just drown if you throw them into the sea. They need to crawl from their nests to the waterline first to exercise their lungs and you will upset all their other programming too. No ways you can touch them and think they'll live another day. Don't you know anything at all?"

During second break Marge and Edwina and also Charles and Christian told her that they cannot help her this evening, because they are going to the tournament. So Angie could not concentrate in school today.

Now she has opened her pen box next to a lamp pole and she has taken out her scissors. She cuts the twine and removes the big tournament poster from the pole. It has a nice sturdy hardboard backing. She always carries her bag in her right hand, but today she straps it to her back and carries the poster with both hands. The wind tries to wrestle it away, slowing her pace. At home she tucks it into the space between the garden hut and the garage before she goes inside.

At seven when the stadium lights come on one by one, Angie is already on the beach. She has tied the loose end of one piece of twine to a loop on her shorts so that her moon shade cannot blow away. It is not a tournament poster any longer. The moon is up already and there is some activity on the beach with movements in the sand. Soon she notices a group of baby turtles freeing themselves from their sandy nest. The big brothers up front are already heading for the tournament. Angie blocks their way with the moon shade and delays them a bit until the others catch up. She nudges the last struggling baby along with a piece of bamboo.

Now she keeps the moon shade between her charges and the stadium lights and they all crawl in the direction of the moon and the sea. It is slow going and Angie must concentrate on guarding her troops despite noticing so many others heading in the wrong direction. Then she gets lucky when another batch of babies almost crosses paths with hers. She manoeuvres her moon shade to slow the leaders down and get the groups to join in the shadow of the moon shade. She guides them along and, after what feels like hours, lets out a huge sigh of relief as the last one steps into the backdraught of a far-reaching wave.

But there is no respite. Angie looks to see where the nearest concentration of endangered babies is. The babies are heading for death. She steps in with the moon shade and redirects them. Her back is starting to ache, but she has to keep going and concentrate.

Her third batch of babies is halfway to the sea, when the cars start roaring past and the stadium lights go out. Angie is no longer needed. She drags the moon shade to the ditch where she nudged the struggler out with the piece of bamboo.

She drops her tournament ticket into the ditch and pushes it below the surface with her toes. She pushes sand in to level the ditch out, but she takes the moon shade home. After all, it helped many babies to safety already.

Abstract

This research explored the reproductive needs of people of low socio-economic standing living with HIV/AIDS (PLWHA) and attending public health facilities in South Africa.

A qualitative research design based on the theoretical framework of critical realism using grounded theory was employed in revealing the dominant unobserved underlying mechanisms, powers and structures that influence their reproductive decision-making.

HIV-positive men, HIV positive pregnant women and HIV positive non-pregnant women were recruited by HIV counsellors from the Ante-Natal Clinic and the Voluntary Counselling and Testing Clinic at the Kalafong Hospital. Individual interviews were used to explore participants' reproductive needs. Focus group discussions were employed to holistically explore the HIV counsellors' attitudes and perceptions regarding their clients' reproductive needs and future family planning.

Parenthood was an important factor to all participants in establishing their gender identities. Different cultural norms existed for men and women realising their reproductive needs. Society expects of women to be mothers, yet at the same time negatively judges HIV-positive women who choose to become pregnant or refuse to abort an existing pregnancy. Consequently, most women choose not to disclose their status and continue to live as if they are not HIV-positive.

Having children is so important to these reproductive-aged PLWHA that they will risk their own health, the health of their partners and their babies. Emancipatory transformation of current HIV counselling services is needed and can be established by improving counsellor knowledge through training as well as giving PLWHA access to accredited HIV risk reducing services.

Keywords

Critical realism, grounded theory, HIV reproductive needs, HIV risk reducing interventions, HIV/AIDS family planning counselling.

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“The miracle is not to fly in the air ... or to walk on the water, but to walk on the EARTH...”

(Author unknown)

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List of Abbreviations

- AI: Artificial Insemination
- ANC: Ante-natal Clinic
- ART: Assisted Reproductive Techniques
- AZT: Azidothymidine (also known as Zidovudine)
- CD4: Cluster of Differentiation 4, one of the many cell surface molecules present on leukocytes
- CREAThE: Centres for Reproductive Assistance Techniques in hiv in Europe
- DNA: Deoxyribonucleic Acid
- ESHRE: European Society of Human Reproduction and Embryology
- FP: Family Planning
- FTC: Alternate descriptor for antiviral drug also known as Emtricitabine or Emtriva
- HAART: Highly Active Antiretroviral Therapy
- HIV/AIDS: Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
- HIV: Human Immunodeficiency Virus
- ICSI: Intracytoplasmic Sperm Injection
- IUI: Intra Uterine Insemination
- IVF: In Vitro Fertilisation
- MTCT: Mother to Child Transmission
- NNRTI: Non-Nucleoside Reverse Transcriptase Inhibitors
- NRTI: Nucleoside Reverse Transcriptase Inhibitors
- PCR: Polymerase Chain Reaction
- PI: Protease Inhibitors
- PLWHA: People Living With HIV/AIDS
- PMTCT: Prevention of Mother to Child Transmission
- RNA: Ribonucleic Acid
- RRI: Risk reducing interventions
- TDF: Tenofovir Disoproxil Fumarate
- VCT: Voluntary Counselling and Testing
- WHO: World Health Organisation

CHAPTER 1

CONTEXTUALISING THE STUDY

“long long way back...”

1.1 INTRODUCTION

South Africa is a country where HIV/AIDS prevalence numbers rank among the highest in the world. According to the latest survey done by the Human Research Council on the South African National HIV prevalence, incidence and behaviour, it was estimated that during 2012, 6.4 million people (12.2%) of the population were HIV-positive (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya, 2014). The survey indicated that overall females had a significantly higher HIV prevalence than males. The highest incidence of HIV among women was found in the age group 30-34 and among men in the age group 35-49.

There is an estimated 1 million births annually in South Africa of which an estimated 29% occur in women living with HIV between the ages of 15 and 49, using public health clinics in the country (Bekker, Black, Myer, Rees, Cooper, Mall, Mnyami, Conradie, Mahabeer, Gilbert & Schwartz, 2011; Cooper, Moore & Mantell, 2013). Phaweni, Peltzer, Mlambo and Phaswana-Mafuya (2010) pleaded for the promotion and improvement of post-natal family planning for HIV-infected women as 16.6% of the HIV-positive pregnant women in their study in Mpumalanga, South Africa, expressed a definite desire for future babies. The authors concluded that in this group, the younger the women were, the larger the probability was for them to fall pregnant again later on. The high HIV/AIDS prevalence among men and women of child-bearing age and the HIV-positive pregnancy rate are alarming facts because of the risk of transmission of HIV to the unborn infant. It must be kept in mind that the optimal reproductive age group is considered to be between 24 and 35 years (Bobak & Jensen, 1987; Te Velde & Pearson, 2002) – exactly the group with the high HIV prevalence.

In Africa, women are especially at risk of HIV. Young women in the reproductive age group were found to be particularly at risk and are four times more likely to be infected

than young men (Shisana, Rehle, Simbayi & Mbelle, 2005). There are various reasons for this high risk.

The first reason is the biological make-up of a woman. In order to infect a person the human immunodeficiency virus must be able to enter the body through cuts and sores to get into the bloodstream. The exposure of the body to the human immunodeficiency virus must be long enough and/or the concentration of the virus must be high enough. Women are more at risk of becoming infected with HIV during unprotected sexual intercourse, because they are exposed to infected semen for a couple of hours. In comparison, a man is exposed to the woman's bodily fluids for a short period of time. Additionally, the viral load is much higher in semen than in vaginal fluids (van Dyk, 2008). Many women are unaware that they have cervical sores or lesions that could give access to the human immunodeficiency virus. Many women are allergic to spermicidal products, which give rise to lesions or sores in the vagina and on the cervix. Additionally other sexual transmitted diseases cause women to be more susceptible to human immunodeficiency viral infection. Women are also more vulnerable to transmission when having unprotected sex before, during or after menstruation.

Various socio-economic and cultural factors increase women's risk of becoming HIV infected. Buseh, Glass and McElmurry (2010) reported that men often associate the practice of having more than one partner as having elevated status within their communities. In traditional African culture, a man who had more than one wife had more status. Nowadays, men do not necessarily marry more than one woman. This tradition continues in having multiple concurrent partners. A man acquires status for being able to maintain many relationships. During the 1990s 65% of Zambian married women considered themselves at risk of getting HIV/AIDS on account of the fact that their husbands or partners had multiple sex partners (Baylies, 2001). In a study conducted among 2016 men and women in Botswana (Visser, Jansen van Rensburg, Salo, Mohlahlane, Roodt, Ndala-Magoro, Lynch, van Rooyen & Cakata, 2010), 41% of the men reported having multiple sexual partners the past year and 50% of the women reported that they were aware that their partners were having other sexual partners as well. A similar pattern may be evident in South Africa where 20.1% of males reported having multiple sex partners in the past 12 months (Shisana et al., 2014).

Low gender status of women, lack of education, cultural attitudes towards sex, poverty and high levels of domestic violence further complicate matters for women. Reportedly, many women in polygamous marriages suffer emotional and financial burdens as the husband may in some cases not have enough money to support all the women and children. Research by Cooper et al. (2013) indicated that women living with HIV tend to renegotiate intimate relationships with men in terms of pursuing relationships and/or marriage with men living with HIV. They perceived men living with HIV to be different from other men and more likely to have life goals that are in line with their own. However, the desire to have children is strong among poor African women who do not have other sources of status, such as those related to a job or education (Oladapo, Daniel, Odusoga & Ayoola-Sotubo, 2005).

A study on prevention of mother to child transmission (PMTCT) by Goga, Dinh and Jackson (2011) in South Africa nevertheless found that 62% of pregnancies were unplanned. Unplanned pregnancies are associated with an increased risk of HIV transmission. Mother to child transmission (MTCT) of HIV is called vertical transmission. These authors estimated that 20% to 40% of children are born with HIV if no protection or prevention method is used. Babies are infected by the human immunodeficiency virus via the placenta during pregnancy, through blood contamination during birth and also during breast feeding. There is a very high likelihood of infecting her baby if the mother became infected shortly before she conceived, or if she has symptoms of HIV disease. In both these instances the mother's blood viral load will probably be high ($> 50\,000$ viral particles per ml), and her CD4 count will be much depleted (< 200 cells per mm^3).

Pregnancy in itself does not enhance HIV progression to AIDS if the woman is in the asymptomatic phase. However, the reverse is true for pregnant women with advanced HIV disease. For them, AIDS develops more rapidly during pregnancy. It is estimated that 23% of mother to child transmission takes place during the first trimester of pregnancy. HIV infections cause an increase of intra-uterine growth retardation, causing babies to be born prematurely, or causing still births as well as congenital infections (van Dyk, 2008). Besser (2007) reported the prevalence of HIV among pregnant women accepting HIV testing in Botswana to be 38.5% and soaring to 50% at clinics in KwaZulu-Natal.

The high prevalence of HIV/AIDS among men and women of child-bearing age is therefore a cause of great concern with regards to their reproductive needs. Considering the intersection between high HIV/AIDS prevalence and reproductive concerns among younger cohorts and pregnant women, intervention and prevention efforts can benefit from increased understanding of this cohort's reproductive needs. The current study focused on gaining an in-depth understanding of the reproductive needs of PLWHA amongst the poor in a developing country. It was found that people living in developing countries are often deprived of many preventative and curative health services that are available in developed countries (Bagratee, 2007).

Reproductive needs are driven by complex personal, inter-personal and cultural considerations and decision-making in this regard is equally complex. One determinant is that of basic human rights. In terms of the South African Constitution, all people are equal before the law (Bill of Rights: article 9.3) and as such, have the right to take decisions regarding their reproductive health (Bill of Rights article: 12.2 (a)). Article 27 refers to the general right to health-care, food, water and social security. Subsection 1(a) of this bill specifically refers to reproductive health-care; *inter alia*, everyone has the right to have access to health-care services, including reproductive health-care.

The rights in the Bill of Rights may be limited only in terms of law of general application (Article 36) to the extent that the limitation is reasonable and justifiable in an open and democratic society. These rights are based on human dignity, equality and freedom, taking into account all relevant factors (Currie & de Waal, 2005). Mantell, Smit and Stein (2009) reported that the sexual and reproductive health needs and desires of men and women living with HIV are not significantly different from those who are not infected. The authors contended that PLWHA have the same human rights as those who are not infected by HIV. They emphasised that the right to parenting among HIV-positive men and women remains neglected, as safer conception is seldom addressed in sexual and reproductive health policies. It is a matter of great concern that the South African public health sector as yet provides no assisted reproductive services to make it possible for PLWHA from lower economic standing to safely realise their reproductive needs.

Many researchers have expanded the focus on reproductive rights as human rights to include the broader scope of a reproductive justice framework acknowledging that

reproductive decision-making is rarely an individual issue. Luna (2009) describes such a reproductive justice framework that positions reproductive freedom within a broader social set of variables including gender, race, sexuality, socio-economic standing, ability/disability and sexual orientation. Reproductive justice also provides a lens for focussing on barriers and structural inequalities faced by marginalised women. These barriers may stem from cultural, social or legislative sources or may be imbedded in health-care systems, including those of psychology. It is valuable to explore the reproductive decision-making of HIV-positive individuals using a critical lens which is cognizant of this socially and institutionally embedded character.

1.2 PROBLEM STATEMENT

Despite the seemingly close link between HIV/AIDS status and reproductive concerns, reproductive needs were, until recently, mostly ignored in HIV studies. Sexual and reproductive health guidelines are not proactive in supporting HIV-positive people who desire more children (Mantell et al., 2009).

Considering that HIV-transmission from mother to child renders reproduction a high-risk behaviour, the search for effective treatment in South Africa currently focuses on the integration of PMTCT with primary health-care services. Additionally, because HIV is sexually transmitted, unprotected sex is a major risk for transmission. Therefore, women are discouraged to have unprotected sex or to plan a pregnancy with either/or both the parents being HIV-positive.

At this stage family planning counselling in South Africa to PLWHA is presented by health-care workers who give directive counselling, predominantly to women. Women are advised not to become pregnant again (Horizons Research Update, 2005). Couples are advised to rather consider adoption, if they find it necessary to realise their parenting needs. Within this framework, HIV-positive women are encouraged to use contraceptives and discouraged from having any further children (Horizons Research Update, 2005; Mantell et al., 2009).

However, the statistics quoted in 1.1 above show that many women living with HIV, even after the counselling, become pregnant. Oladapo et al. (2005) advised caregivers and counsellors to desist from the conventional advice against pregnancy and to rather provide information on practical ways of reproduction to PLWHA. Some women, who decide to become pregnant, do not disclose their status and live as if

they are not HIV-positive because their economic, social and psychological status hinge upon their ability to bear children (Semprini & Hollander, 2007). Research in Zambia examined the struggle women have in being pressured to have babies, fulfilling their own desire to have babies, but simultaneously wanting to protect themselves and their children against HIV transmission (Baylies, 2001). These findings indicate that a woman may have different needs in addition to protecting herself and others from HIV transmission. Intensive work and fortunes spent on HIV/AIDS prevention programs stand to be nullified by this compelling urge of men and women to continue having children, despite the risk of transmitting HIV.

Currently risk reducing intervention strategies are available to people living with HIV in South Africa, but mostly to those who can afford such services in the private sector. Therefore, people living with HIV who can afford the services of private fertility specialists can be helped at specialised centres by means of assisted reproduction to have a baby in a safe way. However, these services are not affordable or accessible to men and women of low socio-economic standing living with HIV in the South African context. There are no assisted reproductive services available for the public health sector that provides alternative reproduction strategies to people from lower economic standing. It is therefore of great concern that there is no assistance for ordinary poor PLWHA to realise their parenting needs in a safe way.

This concern increasingly presented itself to the researcher. As an embryologist acting as counsellor to infertile patients pursuing assisted reproduction, she was repeatedly approached by HIV-positive couples wishing to have babies in a safe way. The private sector clinic where she works does not offer assisted reproductive treatment services to PLWHA, leaving her without answer for such couples, especially those of lower socio-economic standing. As the employee of a private firm, she regarded PLWHA as professionally “not *my* problem”, but still had to weigh her position from a moral viewpoint.

After much deliberation she took an opportunity to visit the Czech Republic in 2006 to attend the European Society for Human Reproduction and Embryology (ESHRE) workshop on safety and quality in Assisted Reproductive Techniques (ART¹). Her aim

¹ Please note that the acronym *ART* will consistently denote *Assisted Reproductive Techniques* in this thesis. *Anti-retroviral treatment* will be written out or taken up in *Highly Active Anti-retroviral Treatment (HAART)* (see section 1.4.1).

was to become better acquainted with the field and to ascertain whether a case could be made for the clinic employing her to indeed offer assisted reproductive treatment services to PLWHA.

During the workshop, many strategies were covered. These included treating HIV-positive sperm, harvesting of possibly HIV contaminated oocytes and employing various fertilisation procedures. The researcher was especially impressed by the well-oiled networks that existed between ART laboratories in Europe. Laboratories in Barcelona would treat and test HIV-positive sperm before returning it to requesting laboratories far afield. The researcher's technical questions were indeed answered in terms of procedures and laboratory safety conditions, but not regarding the economic and moral dilemmas. On her return she found that the plight of people living with HIV/AIDS indeed became "*my problem*". This was highlighted by a marked increase in such people approaching her for counselling regarding their options regarding risk reducing interventions and ART.

As HIV-positive couples visiting the private clinic are predominantly affluent people, she could refer most of them to private institutions that could offer them assisted reproduction services at considerable cost. This, however, highlighted the plight of those HIV-positive people who cannot afford these services and who also desperately want to have a baby in a safe way.

1.3 MOTIVATION FOR THE STUDY

The goal of this study is to develop an understanding of the reproductive needs of men and women using the public health system for HIV treatment. Ultimately, the results of this study should contribute to more comprehensive HIV/AIDS counselling, specifically relating to reproductive decision-making. This research will also aim to inform primary prevention and the introduction of risk reducing interventions at an early stage in situations where the individual has just been tested HIV-positive.

The study furthermore wishes to gather and present evidence that HIV/AIDS prevention and treatment programmes will retain glaring weaknesses as long as they approach the problem by addressing the immediate health concerns of individuals while ignoring the social and parenting needs of couples. Information is sought to motivate a more holistic approach to HIV/AIDS counselling, thereby boosting the national HIV/AIDS prevention programs. Such programmes may then aim to also

present safe parenthood options for HIV-positive men and women. PLWHA can benefit if the government extends its HIV/AIDS prevention programs to address reproductive needs among the HIV population.

It is envisaged, as will be motivated shortly, that the researcher will contribute by studying, within the paradigm of critical realism, the reproductive needs of PLWHA that attend public health services. In the process, the aim is to develop a theoretical framework, using grounded theory, to better understand the underlying unobservable reasons behind the desire for children in these men and women.

1.4 SETTING THE SCENE: THE DILEMMAS OF HIV AND REPRODUCTION

Like the ever-changing currents and waves of the sea, the face of the HIV/AIDS epidemic has constantly changed over the past three decades. The development of new medicine increasing life expectancy lead to more HIV-positive people wanting to have children (Mantell et al., 2009). Current literature emphasises the following aspects related to the dilemmas of HIV/AIDS and reproduction:

- Highly Active Anti-retroviral Treatment (HAART) and the implications for reproduction;
- PMTCT and the implications for reproduction;
- HIV/AIDS related stigma;
- The gendered aspects of parenthood and
- HIV risk reducing interventions and guidelines for counselling.

1.4.1 HAART and the implications for reproduction

Highly Active Anti-retroviral Treatment (HAART) was successfully introduced to the medical world in 1996. Through HAART, the plight of PLWHA was dramatically changed. What was considered a death sentence during the 1980's and 90's has changed to the management of a chronic illness. The development of HAART has presented a new lease on life to all PLWHA in developed countries who could afford the medication. Pomeroy, Green and Van Laningham (2002) have already reported a decline in HIV/AIDS cases and AIDS-related deaths. They stated that the numbers of HIV cases were relatively constant in 25 developed countries, since the advent of new medications. However, in South Africa HAART was only introduced into the public health system during 2004. Although HAART is not a cure for HIV/AIDS, the use of

HAART provides people the opportunity to live healthier and longer lives, and they have a second chance to redefine their future aspirations and relationships, such as the need to have a baby in a safe way.

Van Dyk (2005) describes the effectiveness of HAART drugs on the HIV virus as follows: HI viruses use two important enzymes to replicate in the CD4 host cells. These enzymes are called reverse transcriptase (essential in forming viral RNA into pro-viral DNA) and protease enzymes (essential to assemble all new viral RNA and proteins as well as the maturation of infectious new viruses). Anti-retroviral treatment drugs act by blocking the effectiveness of these enzymes.

Figure 1.1 demonstrates the action of the three main classes of the anti-retroviral drugs:

- Nucleoside reverse transcriptase inhibitors (NRTIs),
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs) and
- Protease inhibitors (PIs).

Reverse transcriptase inhibitors are effective in blocking early viral replication (A in figure below). Protease inhibitors block the release of newly formed H1 viruses from the infected host cells (B in the figure below). Fusion inhibitors (T20) and Integrase inhibitors are new developments in the search for effective drugs. Fusion inhibitors prevent the H1 virus from attaching to the host cell (C in figure below). Integrase inhibitors prevent the H1 virus from entering the core of the host cell (D in figure below) (van Dyk, 2005, p. 74).

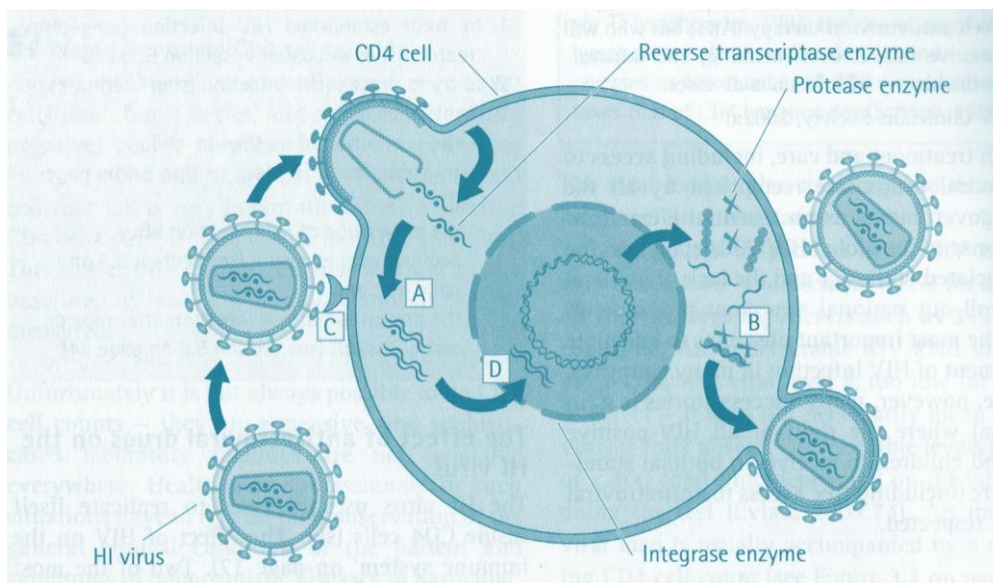


Figure 1.1: The effect of anti-retroviral drugs on the HI virus (van Dyk, 2005).

Mortality rates are reported to remain high in developing countries as a result of lack of access to HAART, or of getting HAART too late in the process of disease development when individuals are too ill already, or of non-adherence to prescriptions. The value of HAART is that it can slow down the progression of HIV to AIDS. It lowers the viral load in the blood and can reduce the transmission of the virus during sexual intercourse. The introduction of HAART helps PLWHA to stay healthy for longer. The probability of having a baby in a safe way is increased by applying HIV risk reducing interventions in terms of HAART. The viral load is lowered by HAART and this reduces the transmission risk of the virus during sexual intercourse.

1.4.2 PMTCT and the implications for reproduction

Women's knowledge and perception of the risk of vertical transmission of HIV vary widely. In four clinics in the United States of America it was found that women distrust health-care providers that discouraged them to have more children, as these women believed there is an overestimation of vertical transmission risk (Kirshenbaum, Hirky, Correale, Goldstein, Johnson, Rotheram-Borus & Ehrhardt, 2004). HIV transmission can be reduced with antiretroviral medication. In developed countries mother-to-child transmission was brought down to 1% by combining anti-retroviral treatment with avoidance of breastfeeding and caesarean section (Bertrand, 2006). Research results show that women who start taking prophylactic medication early in pregnancy, have a risk of vertical transmission of less than 2%. For women who start taking medication only late in pregnancy, or just before delivery or even after birth, the risk involved was between 12 to 13%. Where no preventative treatment was taken the risk was as high

as 25%. Women hold the argument that reproduction is not too risky, and that they should not be discouraged to have children (Kirshenbaum et al., 2004).

In developing countries, where access to medication is limited and no preventative measures are taken, it is estimated that 20% to 40% of babies born to HIV-positive mothers can become infected by the virus (Goga et al., 2011). However, the incidence of HIV transmission can be brought down drastically with correct medication administered during PMTCT programs (National Department of Health, 2010; Goga et al. 2012). In South Africa Hussain, Moodley, Naidoo and Esterhuizen (2011) reported the *in-utero* transmission of HIV to be much higher in women who did not receive HAART (8.5%) compared to women who did receive treatment (0.4%).

When the PMTCT program was introduced, a single dose of Nevirapine (Viramune) was given to the mother during the delivery and to the baby post-natally, complemented by avoidance of breastfeeding. Since 2010, South Africa complies with the recommendations set by the World Health Organisation with regards to PMTCT (National Department of Health: PMTCT, 2010). Currently, the recommendations of the WHO stipulate that anti-retroviral medication should be initiated from 14-week gestation, after the CD4 test was done. Patients with CD4 counts higher than 350 are given AZT twice daily with a single dose of Nevirapine (Viramune) during birth followed by single doses of TDF and FTC post-natally to prevent Nevirapine (Viramune) resistance. In cases where pregnant women have lower CD4 counts, they are started on HAART twice daily and are expected to continue with their medication indefinitely. Women who only received Nevirapine (Viramune) during labour are expected to re-determine their CD4 counts 6 weeks after the birth and 6 monthly thereafter, to decide when to start with HAART. Babies are given Nevirapine (Viramune) on a daily basis for a period of 6 weeks.

According to the guidelines for management of HIV in children in South Africa (National Department of Health, 2010), babies who are being breastfed have to continue with their daily Nevirapine (Viramune) until breast-feeding is stopped at 12 months. Various studies have shown that mothers who breastfeed their babies should not give their babies anything but breast milk to prevent digestive upsets that could increase the risk of HIV transmission to the baby (Coovadia, Rollins & Bland, 2007; Iliff, Piwoz, & Tavengwa, 2005; Kuhn, Sinkala, Kankasa, 2007). Previously, Newell, Coovadia and Cortina-Borja (2004) reported that one-third of HIV infected babies die

before their first birthday, as their health deteriorated very quickly. Since the advent of HAART, the PMTCT policy clearly states that babies should be tested by means of PCR (Polymerase chain reaction) at the age of six weeks and started on HAART before the age of three months (National Department of Health, 2010).

New treatment protocols decreased the risk of HIV transmission during unprotected sex and from mother to child. The desire for a family, therefore, became an important issue for patients who have benefited from HAART. It became especially important to sero-discordant couples (where one of the partners is HIV-positive), to realise parenthood desires without sero-conversion of the uninfected partner and in doing so assuring a healthy parent to the prospective child.

1.4.3 HIV/AIDS related stigma

Stigma related to HIV/AIDS is an important factor that influences reproductive decision-making of HIV-positive individuals. Stigma has been attached to HIV since the disease became known more than three decades ago. In Africa HIV related stigma is associated with the continued fear of casual transmission based upon a lack of in-depth knowledge and misinformation about HIV. In many traditional African cultures beliefs around spirits and the supernatural underlie these views of sickness and health. Kalichman and Simbayi (2004) reported that knowledge levels about HIV/AIDS in South Africa are relatively high. Despite this knowledge, 11% of participants still believed that HIV/AIDS were caused by spirits. It was also found that people who believed in spirits causing HIV/AIDS responded with strong repulsive attitudes towards people with HIV/AIDS. Similar results were found during a study in Tshwane, Gauteng, where people with traditional perspectives on HIV were more stigmatising towards people with HIV (Visser, Makin, Vandormael, Sikkema & Forsyth, 2009). HIV is associated with a moral dimension that creates a stigma through judgement, shame and blame. Stigma, in an African context, is built around a series of shared beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms, resulting in blame for contracting the disease (Nyblade & MacQuarrie, 2006; Ogden & Nyblade, 2005).

Kalichman et al. (2004) demonstrated the effect of stigmatisation by reporting the following statistics during a national household survey in South Africa: 26% of participants would not share a meal with PLWHA; 18% of participants would not be sleeping in a room with PLWHA and 6% of participants would not even speak to

PLWHA. Research done among women with HIV in Tshwane South Africa demonstrated that PLWHA observed their community to be highly stigmatising. They internalise some of the stigma they observe in the community which has a negative impact on their psychological well-being and willingness to disclose their HIV status to their partners (Visser, Kershaw, Makin & Forsyth, 2008).

Despite the opinion expressed by Jewkes (2006) that there is a process of normalising the reality of HIV/AIDS and that people from all walks of life begin to see HIV/AIDS as a normal misfortune in South Africa, there are still high levels of stigma observed in some communities (Visser et al., 2009). Discrimination against PLWHA, being an injustice, often results in lack of services, non-testing, non-disclosure of status and lack of adherence to treatment. The harmful effects of stigma threaten to undermine efforts to prevent the continued transmission of HIV and also play a prominent role in PLWHA's reproduction decision-making. This will be illustrated in the sections below.

1.4.4 Factors influencing fatherhood

The limited available literature and statistics on fatherhood and HIV/AIDS indicate that this is an unexplored research area. Sherr and Barry (2004) report that between 1990 and 2001, no papers could be found with the text word "fathers" compared to five papers with the text word "motherhood" and 251 papers with the text word "mothers." The reproductive needs of HIV-positive fathers thus require urgent consideration. The service provision in terms of fertility for HIV-positive men is still in its infancy. This is reflected in the finding that only 9.4% of men with HIV are given medical advice on reproduction (Sherr & Barry, 2004). This statement is further supported by the fact that only women took part in a study investigating South African community attitudes towards childbearing and PLWHA (Myer, Morroni & Cooper, 2006). With regards to the fact that mostly women attend prevention programs, Maharaj (2001) stated that men have an important role to play in protecting themselves and their partners, as a large percentage of women do not have control over their sexual lives in societies characterised by an unequal balance of power.

Brazil is a country known to have some of the most advanced and progressive HIV/AIDS programs. It is reported that 80% of HIV-positive men in Brazil were in sexual relationships, and that 43% still wanted to have children, or wanted biological children for the first time. These men found health-care workers to be very unsupportive of their parenting needs. They expressed that they did not receive

information about preventative treatment options (Paiva, Fillipe, Santos, Lima & Segurado, 2003).

These findings were supported by the research of Sherr and Barry (2004) in the United Kingdom stating that HIV-positive men are often overlooked and understudied. In this study, it was shown that 81% of HIV-positive men felt that children gave new meaning to life and was a reason to live. Only 6.3% of the men were aware of the fact that the vertical transmission risk in Europe was 20% before intervention, and that it could be brought down to 1% with ART treatment. The conclusion can therefore be made that greater awareness with regards to HIV treatment interventions could motivate more men to become active in HIV/AIDS prevention program activities.

From the above discussion it follows that parenthood is just as important to men and HIV-positive men should also be screened and counselled regarding their reproductive options (Sherr & Barry, 2004). According to research done among HIV-positive men and women attending HIV services in Durban, South Africa, women reported that their male partners desired the recent pregnancy despite their preference not to be pregnant (Matthews, Crankshaw, Giddy, Kaida, Smit, Ware & Bangsberg, 2013). Despite the efficiency of maternal screening in terms of cost-effectiveness and HIV/AIDS prevention, there are at this stage no corresponding services for fathers. It will be interesting to determine what differences there are in the needs of men. Do men have a need for more information and how motivated are they to actively partake in efforts to minimise the transmission risk of HIV/AIDS? Various obstacles were identified for men to attend clinics where they could receive such services (Koo, Makin & Forsythe, 2013). HIV-positive men were therefore included into this study to explore their reproductive needs and decision-making.

1.4.5 HIV risk reducing interventions (RRI)

According to Vernazza, Hollander, Semprini, Anderson and Duerr (2006) reproductive counselling for HIV-positive individuals should definitely include discussions on what is currently known through research about reproduction, prevention of HIV transmission, as well as the effectiveness of various risk reducing intervention therapies. HIV risk reducing interventions, involving reproductive counselling guidelines as well as techniques such as sperm wash, are promising developments in preventing HIV transmission between partners as well as from mother to child.

1.4.5.1 Counselling guidelines

Vernazza et al. (2006) proposed that counselling should be made more readily available to couples about strategies aimed at maximising protection from transmission, but also other risk reducing methods based on scientific advancements and by understanding the disease. Similarly, Bagratee (2007) confirmed the need for pre-conceptual counselling to all couples consisting of the following:

- A discussion of various assisted reproductive options;
- A discussion of the risk of partner sero-conversion;
- The risk of vertical transmission;
- The nature and risks of sperm washing;
- The success rate of treatment and counselling on coping with a child when one or both partners are HIV-positive.

This study explored two critical junctures where imparting of knowledge through counselling might influence the reproductive decision-making of HIV-positive men and women. Bearing in mind that the CD4 count results will determine the pathway to follow-up treatment; these junctures included the counselling interviews following HIV-testing and those concerning further family planning after giving birth. In the following section, some strategies of risk reducing interventions will be explained as background to the study.

During 2007 Bagratee proposed risk reducing interventions with special reference to couples where one of the partners was HIV-positive (sero-discordant). Couples where both partners are HIV-positive (sero-concordant) were also included. The following methods can be used to promote HIV risk-reduction to have a baby:

- For sero-discordant couples where the male is HIV-positive:
 - Donor insemination
 - Sperm wash with intra-uterine insemination (IUI)
 - Where IUI was unsuccessful after 3 to 6 attempts: Sperm wash with *in vitro* fertilisation (IVF) combined with intra cytoplasmic sperm injection (ICSI) into the egg to minimise the risk of virus transmission by the sperm sample
- For sero-discordant couples where the female is HIV-positive:

- Self-insemination with husband's sperm at time of ovulation
 - The use of HAART medication combined with elective caesarean section
 - Avoidance of breastfeeding can also reduce the risk of vertical transmission to the new-born baby
- For sero-concordant couples where both are HIV-positive:
- Sperm washing and IUI are recommended to decrease the risk of transmitting a mutated drug resistant viral strain to the female partner and the future baby

In South Africa, Bekker and co-workers (2011) described detailed intervention strategies needed in both resource-limited and resource-intensive settings by proposing guidelines on safer conception in fertile HIV-infected individuals and couples. Both the concepts of Treatment as Prevention (TasP) for the HIV-positive partner and oral pre- or post-exposure prophylaxis (PrEP/PEP) for the negative partner are included into these guidelines. By implication this means that any HIV-infected person wanting to conceive and thus contemplating unprotected sex should have an undetectable viral load before doing so. This would necessitate the use of HAART for at least 3-4months prior to the intended unprotected sexual intercourse. Bekker et al. (2011) emphasised that HIV acquisition was reduced by 96% in discordant heterosexual couples where HAART was initiated at CD4 counts >350. Combined with PrEP or PEP, male circumcision (46.4% South African male circumcision according to Shisana et al., 2014) at least two months prior to the intended unprotected intercourse, can protect the male partner against sero-conversion in cases where the female partner is HIV-positive. However, according to these guidelines, it should be noted that currently PrEP/PEP for discordant couples where sperm washing/insemination is not available (resource-limited settings) could have serious health implications to the man, the woman or the subsequent baby.

In terms of the financial and human resources of developing country public sector services, Mantell et al. (2009) referred to the various options for safer conception as being either "low-tech" (timed intercourse or self-insemination to minimize but not to eliminate HIV transmission), "medium-tech" (artificial insemination (AI)) or "high-tech" (intra-cytoplasmic sperm injection, ICSI) services. The following section will present a discussion regarding the sperm wash procedure that forms an integral part of medium and high-technology safer conception services (resource-intensive settings).

1.4.5.2 Sperm wash

The important work on successful HIV risk reducing interventions, *inter alia* artificial insemination or *in vitro* fertilisation with washed sperm, was presented in 2007 at the Congress of The International Federation of Fertility Studies (IFFS) in Durban, South Africa. Semprini and Hollander (2007) presented their statistics on the safety of risk reducing interventions from their pioneering work in Italy. In 1992, the births of 10 uninfected children were reported. None of the 29 women in their study had become infected, and the fathers were not taking anti-retroviral treatment medication. The fathers were only willing to refrain from unprotected sex. HAART became available in 1997, and the technology of PCR (polymerase chain reaction) was not available in Europe until 1995. No case of sero-conversion in HIV negative women have been reported in over 2500 inseminations in Italy.

According to Semprini and Hollander (2007, p. 424) sperm wash can be described “as a three-step procedure involving density gradient, centrifugation, wash and swim up”, see Figure 1.2 below. The liquefied semen is first filtered through the gradient. The resulting recovered sperm are washed to eliminate seminal plasma as well as the hyper osmotic gradient medium. Motile sperm free from any lymphocytes are recovered during the swim up stage. It is expected that the HIV titre is decreased to less than 0.1 % of that in the original semen sample.

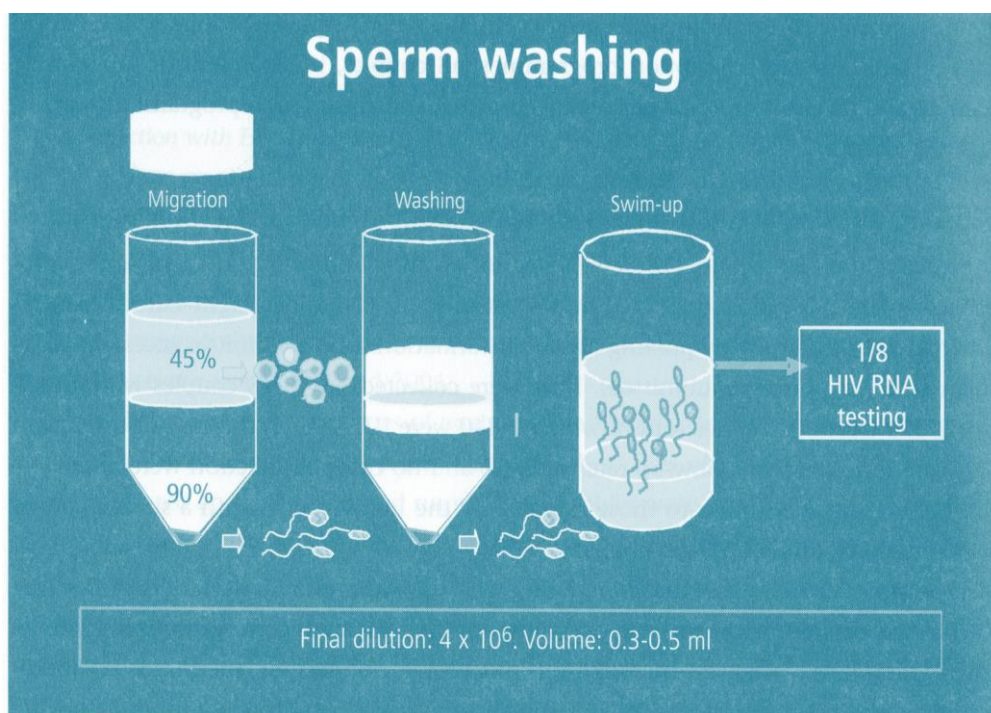


Figure 1.2: The sperm washing procedure (Semprini & Hollander, 2007).

The percentage of HIV-positive men with poor semen samples is on the increase as a result of the theoretical possibility of HAART being toxic to sperm mitochondria. This affects sperm motility. The nucleoside anti-retroviral-like inhibitors of reverse transcriptase are most likely to be blamed (Semprini & Hollander, 2007). Risk-reducing therapy can never be risk free as the sperm sample may still have the virus below PCR detection levels (Bagratee, 2007).

In terms of safety in the laboratory, the importance of complying with safety procedures and prevention of contamination to other patients are clearly described in the work of Englert, Van Vooren, Place, Liesnard, Laruelle, and Delbaere (2001). Gilling-Smith (2003) reported a single case in the United States of America of virus transmission through inappropriate sperm washing techniques and urge centres, who wish to establish a reproductive program to HIV/AIDS patients, to work according to published protocols.

It was concluded that where HAART resulted in reduced blood and seminal viral loads, sperm washing effectively reduced the infectiousness of semen. However, the two are not interdependent as sperm washing was shown to be effective in couples where the husband was not treated with anti-retroviral medication as well (Semprini & Hollander, 2007). Access to techniques such as sperm wash is thus a medium technology strategy with the possibility of eliminating HIV compared to the low-technology strategies of timed intercourse and condom use which at best can only minimise HIV transmission (Mantell et al., 2009).

1.5 RESEARCH QUESTION, AIM AND OBJECTIVES

A research question “is a statement that identifies the phenomenon to be studied” (Strauss & Corbin, 1990, p. 38). Based on the literature review the research questions for this research are:

- Why is the pregnancy rate high among HIV-positive people despite the risk of HIV transmission?
- What are the reproductive needs of a group of South African men and women living with HIV/AIDS attending public health services?
- What are the implications of such needs for family planning counselling contributing to HIV prevention?

Following from the research questions the objectives of this grounded theory study is firstly, to explore the reproductive needs of both men and women living with HIV/AIDS who attend the public health services. Secondly, to explore the perception of such needs by the HIV counsellors. Thirdly, to establish the implication of these needs to comprehensive HIV counselling and family planning. The impact of such needs on HIV counselling and future family planning by the integration of risk reducing intervention will be explicated during the process of theory building.

1.6 RESEARCH DESIGN AND METHODS

Critical realism is a philosophy of science that focuses on a mind-independent reality (Bhaskar, 1978). The assumption is that there is a reality that exists out there, independent of people's interpretation. There are also unobservable things like structures, powers and mechanisms that are worth discovering and investigating. The researcher is cognizant of the fact that according to the principles of critical realism, our understanding and explanation of reality are constructed by our interpretation of our own and other's experiences. Our interpretation of reality can therefore never be equated to reality as humans are fallible and can make mistakes. As new information comes to light our interpretations always stand to be rectified. Critical realism further offers an explanation of the structural impediment to human development by facilitating programs that lead to the emancipatory transformation of those structures (Houston, 2001, Maree, 1990). The researcher was therefore convinced that critical realism was the most appropriate theoretical framework to the study in order to identify the underlying unobservable reasons or motivations for the prevalence of a high pregnancy rate among reproductive aged PLWHA.

The study will therefore involve HIV-positive men and women attending public health services where interventions at the two aforementioned junctures can affect their future health regarding their reproductive decision-making. The researcher will conduct interviews with men and women as well as with their HIV counsellors in order to holistically establish any reproductive needs pertaining to PLWHA and the implications of such needs for family planning counselling. The researcher will attempt to "look" through the eyes of HIV-positive women, HIV-positive men as well as those of the HIV counsellors that advise them. In order to learn what the reproductive needs of people living with HIV are, the study will focus on how people in this setting interpret and understands reality, what their reported perceptions, truths, beliefs and

explanations about their world views are. The consequences of their interpretations and behaviours and their effect on those with whom they interact, will also be investigated.

The systematic analytic methodology of grounded theory will be used to create a substantive theory describing the phenomena studied as “a theory can alter your viewpoint and change your consciousness. Through it you can see the world from a different vantage point and create new meanings of it” (Charmaz, 2000, p. 128). In order to contribute to the scientific body of knowledge theory building will be used to describe the phenomena studied in order to develop contextualised theory (substantial theory) for practical applications. Substantive theory further serves the purpose of bringing research to practice more safely. According to Oliver (2011) “while the final theory is rooted in the participants’ experiences, it is constructed by the researcher and contains the researcher’s words and thoughts, not those of participants” (p. 14).

1.7 OUTLINE OF THE THESIS

The research report will be structured in terms of the following chapters:

- **Chapter 1** gives the background and motivation to the study. The available research highlighting the problem area and results from other parts around the world is discussed as motivation for this study.
- **Chapter 2** provides the theoretical framework used for the study, and the research methodology followed to investigate the problem area. This chapter describes the principles of qualitative research based on the theoretical framework of critical realism using grounded theory as the research methodology of choice.
- **Chapter 3** gives the research results in terms of open coding. Open Coding describes the actions and processes necessary for getting started in interpreting the vast amounts of qualitative research data. Text is therefore taken “apart” and different codes are assigned to the “deconstructed” text in order to be able to find meaning and the real issues at heart of the phenomenon being studied. The principles of the critical realist paradigm guide the interpretation process of the deconstructed text.
- **Chapter 4** gives the results of the axial and selective coding process. During the process of axial coding, the fragmented data obtained from the open coding

process is “reconstructed” by means of interpretation, compared and visually represented in terms of similarities, differences and subtle variations among the groups studied. Constant comparisons between the study groups, demanded by grounded theory, highlighting the similarities, differences and subtle variations guided the research process during the interviews and group discussions. Selective coding is the next step where all the new insights gained during axial coding are interpreted and conceptually organised around one or more integrated themes. In this chapter, all similarities, differences and subtle variations between the study groups are brought into focus within the critical realism paradigm revealing unobservable and deeper levels of reality as seen through the eyes of the HIV-positive participants.

- **Chapter 5** is a review and discussion to integrate the emerging themes obtained from the axial and selective coding processes in terms of the latest literature.
- **Chapter 6** concludes the research by presenting the substantive theory explaining the phenomenon studied. The chapter will also include the implications, limitations and recommendations to the study.

CHAPTER 2

RESEARCH METHODOLOGY

“deep water cold black...”

2.1 INTRODUCTION

In a thorough exposition of the application of quantitative versus qualitative research Patton (2002) quoted Albert Einstein saying: “Not everything that can be counted counts and not everything that counts can be counted” (p. 12). Qualitative research involves a naturalistic inquiry based on a process orientation documenting actual operations in comparison to the fixed treatment/outcome emphasis of the controlled experiment in quantitative research (Patton, 2002). In other words, the controlled experimental designs of quantitative research predominately aim for statistical analysis of data compared to the opposite scenario of qualitative research. In qualitative research, the researcher focuses on data which describes and communicates someone else’s experience of the world, using his or her own words.

The development of qualitative research began during the early 1900s, and the development went through various phases up to World War II. During this period, the researchers were seen as larger than life figures returning to their people with stories about fieldwork done amongst strange cultures and with the power to tell the subject’s story. During the modernist phase and the development of interpretive theories (1940’s to the 1960’s), the role of the researcher doing qualitative research changed to that of giving a voice to society’s underclass. Then again, during the developmental phase of blurred genres (1970’s to 1986), the researcher was seen as having no privileged voice in the interpretations that are written. According to Denzin and Lincoln (2000), it is currently believed that the role of the researcher is to blend his/her own observations with *inter alia* self-reports from participants obtained through interviews; life histories; case studies and other documents.

Working as an embryologist within the context of reproductive biology the researcher continually relies on quantitative approaches and strictly controlled/pre-determined methods of investigation. In planning this research, the ultimate personal nature of in depth inquiry to the reproductive needs of people living with HIV, necessitated the

researcher to consider alternative research approaches. This study needed a research approach enabling the researcher to be truly able to understand how people think, feel and act regarding a subject that might easily cause them to feel stigmatised. Consequently, the attention of the researcher was drawn to the philosophical responses of social science to the observation that social science cannot be developed in the same way as natural science (Bhaskar, 1978). In this chapter the researcher motivates qualitative research within the paradigm of critical realism, using grounded theory, as methodology of choice for this study.

2.2 RESEARCH APPROACH

Selecting a research approach for this study required the identification of a suitable research framework. Selecting a research approach requires at least the cursory consideration of all established research options followed by a more detailed inspection of the established approaches most promising to yield good results in the specific study. A single approach can then be identified and its theoretical bases, its strengths and weaknesses and eventual suitability for the task can be documented to validate the choice. This follows in section 2.2.1.

Following the selection of a research approach, the research process can then be planned by formulating an epistemology of research questions and methods within the selected research framework. This is done in section 2.2.2.

2.2.1 Ontology: how reality is described

The critical realism paradigm assumes a mind independent reality consisting of different levels and that there are multiple underlying unobservable structures and processes that influence reality (Denzin & Lincoln, 2005). Critical realism is a philosophy of science and was established during the 1970s by Roy Bhaskar. He envisaged reality as a complex, multi-layered, multi-causal web of interacting forces. Lopez and Potter (2001) described the development of critical realism as a sustained and vigorous critique of positivism in natural science. They state that:

- It is both possible and desirable to study social phenomena scientifically, but not in the same way as either positivism or constructionism, and
- that critical realism accepts the fallibility of human knowledge and its sociologic nature.

Critical realism “presupposes an objective reality which exists independently of our thoughts and its discovery is one purpose of knowledge acquisition” (Oliver, 2011, p. 4). Critical realism thus views reality as independent from the human mind and the interpretation of reality as fallible and provisional (Maree, 1990). Bhaskar emphasised that we will only be able to understand and change the social world if we identify the structures at work that generate those special interests (Corson, 1991).

The multi-layered character of reality as proposed by Bhaskar (1978) consists of the following three levels:

- The empirical domain where science and what is real is restricted to what can be observed and/or measured.
 - (In anticipation of applying this background information to the current research, it can be deduced that good examples of empirical facts would include the measurable HIV-positive test results of men and women, as well as their CD4 counts.)
- The actual domain consists of the actual observable events that take place, whether we experience them or not. The actual domain can be measured empirically.
 - (The prevalence of a high pregnancy rate among men and women within their reproductive years living with HIV/AIDS can be an example of the actual domain related to the current research.)
- The underlying real domain of mechanisms, powers and structures generating events. Oliver (2011) describes a structure “as the inner composition making each object what it is and not something else” (p. 4). The real domain is therefore, the deepest level of reality where causal mechanisms are at work, and as such it is unobservable. According to Bhaskar (1978), these mechanisms, structures and powers can be unobserved but at the same time be experienced as real by individuals. The process of science is to reveal these deeper levels of reality in an effort to understand it. Although it cannot be directly observed the real domain can be inferred from experiences and interpretations of individuals.

- (From the current research the discovery of the underlying, unobservable reasons or motivation for the reproductive needs of men and women within their reproductive years living with HIV/AIDS can serve as an example of the real domain.)

According to Bhaskar (1978), the social reality is different from the natural reality. For example, enduring structures form part of the characteristics of natural reality, compared to social science having relatively enduring structures. Social reality is also concept dependent in a way that natural reality is not. Concept dependence implies that individuals create social reality, which then becomes an object of knowledge. Critical realism declares both an intransitive and transitive dimension to reality. The intransitive dimension of reality is stable and means that things are what they are, irrespective of what we believe. However, despite affirming the existence of a stable mind independent reality, the transitive domain consists of our interpretations, understanding, explanations and theories about reality.

In efforts to understand or interpret reality, people can always be wrong, and therefore need to constantly revise theories in the light of new evidence. Because our knowledge claims are transitive, our interpretations, understanding, explanations and theories can never be equated to what is to be interpreted, understood or described about reality (Lopez & Potter, 2001). Our knowledge claims always stand to be tested, revised and criticised. Therefore, the transitive dimension of reality can constantly be changing. However, the intransitive dimension of the real is relatively stable due to structures that endure flux and change. Epistemological mistakes occur when the intransitive and transitive dimensions of reality are conflated; meaning that what we can know about reality is conflated with the way reality is (Maree, 1990).

A natural or a social situation can best be described as an open system “where a number of mechanisms are responsible for a number of potential and actual events” (Maree, 1990, p. 52). Critical realism draws heavily upon the ontological difference between open and closed theoretical systems. Open systems include cause and effect mechanisms, but due to the fact that it is an open system, the events can never be linear or simple. In an open system, events are always hindered or confounded by other interfering mechanisms. Single linear cause and effect relationships can only be found in closed systems, such as laboratory experiments. However, reality is never a

closed system. By rejecting linear causality (as suggested by positivism), critical realism describes the social world with multiple opportunities where intervention and change can take place all the time.

Critical realism posits that mechanisms produce tendencies and in doing so it directs attention to an understanding and explanation of those tendencies. However, Bhaskar postulated that the person is not at the mercy of these mechanisms as the person can actively transform his or her social world and is in turn transformed by it (Houston, 2001). Therefore, a social system can be seen as an example of such an open system. (Applying this to the current research, it may be deduced that, by analysing the experiences of PLWHA, we can learn what it feels like to be HIV-positive and to want a baby regardless of being accepted or rejected by the community.)

The realist part of critical realism refers to the reality under investigation, meaning that what we can see and touch as well as that which is unobservable. Critical realists, therefore, believe that there are unobservable things “such as structures, powers and mechanisms that are worth discovering and investigating” (Maree, 1990, p. 50). (Identifying these underlying structures, powers and mechanisms may, in the current research, explain, “why the pregnancy rate is high among HIV-positive people despite the risk of HIV transmission”.)

In explaining the critical dimension of critical realism Lopez and Potter (2001) state that the fallibilism of realist epistemology posits the possibility not only of error in general, but it also represents the possibility of ideological error. The social distortion of knowledge is therefore represented as to be examined as an object of knowledge (Lopez & Potter, 2001). As we can rationally choose between competing explanations of either physical or social reality, we can diagnose errors in the explanation. However, we can go further and locate the source of these errors in reality itself. “That is, the possibility of social scientific examination and explanation of social inequality, for example, give rise to a further possibility; the social scientific explanation to the effect of social inequality upon explanations (including explanations of inequality)” (Lopez & Potter, 2001, p. 14).

Critical realism is thus open for the possibility of distorted perception. This is so because the human subject, including the social researcher, can never fully gain a totally accurate picture of the world (Houston, 2001). Science, therefore, is not pure

and can contain ideological distorted elements in both explanations, and the methods used to arrive at them. Truth is relative and knowledge is culturally and historically situated. Any attempt to describe reality will be influenced by language and meaning-making nuances as well as the social context within which the event is taking place. There will always be a gap between one's own perspective and the real world. Reality, therefore, becomes an interpretation of the interpretations of other individuals (like constructionism) (Maree, 1990). In order to understand reality, the researcher can only interpret the experiences of the participants given during the individual interviews.

The results of such a study can, therefore, only be the researcher's interpretation of how the participants in this study interpreted reality. It can never be equated to reality. Critical realists seek to find vertical explanations linking events and experiences to their underlying generative mechanisms instead of looking for their antecedent events and experiences (Oliver, 2011). In contrast to the strict empiricism of positivism and post-modernist writings which celebrate ambiguity and complexity, realism struggles for clarity and simplicity (Lopez & Potter, 2001).

In his writings "what science is and what reality is" Maree (1990) explained the theoretical principles of critical realism as proposed by Bhaskar. He stated that "critical realism negotiates the line between empiricism, on the one hand, and idealism, on the other" (p. 49). Maree (1990) described the theoretical perspective of critical realism as a meaningful way to negotiate empirical work (research) between the problems posed by positivism as an example of empiricism and constructionism as an example of idealism. Positivism can be defined as the strict empiricist enterprise that scientific knowledge can be based only on observable events. This implies that all concepts which cannot be observed cannot be spoken about within scientific language and should therefore be seen as nonsense or not meaningful. Positivists reduce real things only to the one dimension where observable actual events are experienced, namely the empirical. In contrast, Bhaskar (1978) states that the second level or domain of reality is the actual, and the third level is the "real" where causal mechanisms are operative and as such are unobservable.

Positivists have a great problem with unobservable events or things. For them "forces such as cause or concepts, such as truth, cannot be observed and thus cannot be meaningfully spoken about within a scientific context" (Maree, 1990, p. 50). Critical

realism describes positivism as having an ontological problem. Ontological views of what reality is, depends on what we can know about it. Positivism and empiricism ask and answer these questions only implicitly. Their implied ontology is philosophically incoherent, and as such they commit the fallacy of actualisation. Actualism implies that reality is seen to consist of two domains, namely the actual and the empirical. The domain of the empirical is seen as a subset of the former and directly or indirectly forms the basis of all knowledge (Lopez & Potter, 2001).

In contrast to positivism, Lopez and Potter (2001) stated that constructionism understands science and the production of knowledge as a process of social construction. Constructionism developed within the social sciences during the beginning of the previous century as a reaction against the influence of positivism. Constructionism claimed that there is no method that can lead to truth or certain knowledge.

According to Lopez and Potter (2001) observation, (which is the basis of empiricism and considered the absolute truth), was turned inside out by post-positivist thinking showing that observation is always theory laden. Scientific work is done in social contexts because observation takes place through the lens of theories, background knowledge, assumptions and perspectives. Knowledge is thus socially constructed and substantively subjective rather than objective.

It is possible to believe that “knowledge” is whatever human beings socially agree upon, and theories are therefore considered as constructions. The alleged discovery of the irreducible complexity of the natural and social world of language and meaning is central to constructionism. Patton (2002) describes constructionism as the collective generation and transmission of meaning within a culture or community. It thus illustrates the influence culture or the community has on the individual. In other words, the way an individual perceives (sees and feels) things around him/her is shaped or influenced by the shared meanings within a group or community that can be described as the culture in which a person lives or grows up. This is in accordance to the principles of critical realism; however, constructionism equates reality and interpretation. Thereby constructionism also commits an epistemic fallacy by conflating that what we can know about reality with the way reality is (Maree, 1990).

Oliver (2011) further states that critical realism shares an emancipatory agenda in social science. This kind of research can offer the best chance to emotionally engage practitioners and build relationships between researchers, policy makers and service providers to re-enforce the theory-practice connection. (The current research, for example, may eventually have an influence on policy-making regarding safer reproductive strategies for PLWHA). Exactly why critical realism is considered to have an emancipatory agenda stems from the centrepiece of Bhaskar's work: "Social sciences should not be value-free. The role of critical realism is not only to uncover psychological and structural mechanisms but to challenge their existence where they lead to human oppression" (Houston, 2001, p. 851).

Houston continued by stating that social researchers should therefore adopt a critical, methodical and systematic approach whereby they can identify patterns of unmet need in the society or in a person; develop hypotheses about any underlying mechanisms generating these patterns; analyse whether the phenomenon under study is adequately described by these formed hypotheses and test the new hypothesis where necessary. Where it appears that oppressive mechanisms have been identified the researcher then has to attempt to have their influence exposed. Corson (1991) stated that once postulated hypotheses were shown to be real, they become available as evidence for interpreting the world and action to replace unwanted with wanted forms of determinism. This provides the critical concluding phase in this emancipatory process of discovery.

Corson (1991) further describes the emancipatory process, proposed by Bhaskar, as the reclaiming of reality "through eliminating prejudice, errors, unsupported claims and philosophical false trails, which have covered or disguised reality for us and that emancipation occurs when we make the move from unwanted to wanted sources of determination" (p. 232). (The possible identification of any oppression related to the reproductive needs of PLWHA should therefore be exposed to policy makers and society at large.)

As social realities are not always accessible to empirical testing and observations, it can therefore be concluded that the perspective of critical realism "provides a way of avoiding the epistemic fallacies and problems of both positivism and idealism" (Maree, 1990, p. 58). Critical realism provides a theoretical framework that "allows the theorising to go beyond what is immediately knowable but maintains an obligation to

test that theorising in the crucible of real-world experience and against competing theories” (Oliver, 2011, p. 5).

Studying the social world according to the principles of critical realism could therefore ultimately contribute to a better understanding of the high pregnancy rate among men and women living with HIV/AIDS regardless of their status. Inferring the experiences, perceptions and meaning of reproductive age men and women living with HIV will help the researcher to interpret and understand the unobserved underlying structures and mechanisms influencing their reproductive needs. (Emerging themes from the current research, as will be discussed in Chapter 5, may be generated through applying grounded theory principles and will then explicate the underlying real domain of mechanisms, powers and structures playing a role in the reproductive behaviour of PLWHA).

Lastly, by philosophical standards, critical realism is seen as a relative new approach to ontological, epistemological and axiological issues. Easton (2008) writes that as with all philosophical approaches, critical realism cannot be proven to be the “right answer” as acceptance of a critical realist approach depends on whether one agrees with its basic assumptions.

The researcher in this study concurs with Easton (2008) stating:

In my own case, I accept critical realism as a suitable vantage point for this study, because:

- I think that this is how the world is.
- Even if it is not like that, I behave as if it is like that.
- I think that critical realism is more suited to the study than the alternatives and
- It is a well thought through and relatively coherent perspective on the world (p. 128).

2.2.2 Epistemology: how reality is studied

Subjectivist epistemology implies that the researcher and the respondent interact to discover the unobservable and underlying processes that influence events as proposed by critical realism (Denzin & Lincoln, 2005). Grounded theory was developed by Glaser and Strauss during the 1960s at a time when quantitative

researchers saw qualitative research as impressionistic, anecdotal, unsystematic and biased (Charmaz, 2006). Historically grounded theory therefore represented a revolt against the dominance of a quantitative ideology pervading social science research during the 60's (Dunne, 2011). Glaser and Strauss recognised a lack of systematic guidelines within the qualitative inquiry which would improve the quality of research and also counter the critique of quantitative thinkers. They, therefore, defined grounded theory as a method of discovery consisting of systematic yet flexible guidelines for collecting and analysing qualitative data in order to construct theories that are "grounded" in the data itself (Charmaz, 2006). They explicitly stated that "their perspective was phenomenological, and that they presented grounded theory as a method that aimed at generating theory" (Hallberg, 2006, p. 142). By providing "practical guidelines that would enable the rigorous construction of theories relating to social processes from raw data" grounded theory represents an attempt to bridge the gap between theory and empirical research (Dunne, 2011, p. 112).

Hallberg (2006) suspected that there is a difference between the two authors regarding the meaning of theory generation. He deduced this because according to Glaser, a grounded theory study can result in an empirically grounded hypothesis that can be further tested and verified with new data using quantitative or qualitative methodology. In contrast (in the view of Hallberg), Strauss argued that an empirically grounded theory is both generated and verified in the data. Strauss contended that the developed theory can be applied and used in practice without further testing. Substantive and formal theory is developed through the processes of grounded theory. Substantive theory refers to a delimited specific area under study, e.g. the high incidence of pregnancy among women within their reproductive years living with HIV/AIDS. This is compared to formal theory concerning a general phenomenon with a wider application such as male dominant societies and stigmatisation (Hallberg, 2006).

Strauss and Corbin (1990) stated that in using grounded theory "one does not begin with a theory and then prove it. Rather, one begins in an area of study and what is relevant to that area is allowed to emerge" (p. 23). Grounded theory is therefore a specific way of doing qualitative research with the purpose of systematic theory development. It is based on the foundational question asking "what theory emerges from systematic comparative analysis and is grounded in fieldwork so as to explain what has been and is observed" (Patton, 2002, p. 125). Grounded theory aims at

developing new theory inductively through a process of concurrent data collection and analysis.

The flexibility of qualitative research allows the researcher to follow leads as they emerge from data and thus new pieces of information can continually be added to the body of knowledge pertaining to the study up to the very end in the research project (Charmaz, 2006). This supports Houston's (2001) opinion that through the process of constant coding and simultaneous comparison of data, mini hypotheses are created by the researcher during interpretation of such data. Grounded theory methods therefore enable the researcher to shape and reshape the data collection and thereby refine the collected data (Charmaz, 2006).

The emphasis in grounded theory is on steps and procedures for connecting induction and deduction by constant comparison of research sites, theoretical sampling and testing of emerging concepts by additional fieldwork. The flexibility to the process holds that, should the researcher need more data on a specific aspect, the researcher then develops a hypothesis about it. He or she goes back and does more interviews regarding that specific aspect. It is thus meant to build theory rather than to test theory and serves as an analytic tool to the researcher in handling huge amounts of raw data.

Strauss and Corbin (1990) described the framework offered by grounded theory as a set of coding procedures to help provide some standardisation and rigor to the analytic process. Charmaz (2006) describes coding as attaching labels concerning actions to segments of data that depicts conceptually exactly what each segment is about, and it gives us a handle to make comparisons with other segments of data.

Coding consist of two phases: initial coding and focused coding. The process of coding starts off with initial coding where fragments of data, words and lines are studied for their analytic importance. During focused coding we select what seems to be the most useful initial codes and test them against extensive data. According to Strauss and Corbin (1990), the grounded theory methods of simultaneous data collection, data analysis as well as constant comparison is designed to push the understanding of the researcher beyond any previous understanding.

Constant comparative analysis and theoretical sampling uniquely differentiate grounded theory from other research methodologies. It also makes grounded theory

difficult to use, as it has been the subject of multiple definitions and interpretations. Dunne (2011) states the most problematic issue relates to how and when existing literature should be used during a grounded theory study. Initially, Glaser and Strauss explicitly argued against the use of existing literature prior to primary data collection, characteristic of most strategies of inquiry. An early literature review was seen as “potentially stifling the process of developing a grounded theory and thus something that could detract from the quality and originality of the research” (Dunne, 2011, p. 114).

Strauss later deflected from the strict initial outset of grounded theory. In his collaboration with Corbin, he showed a more pragmatic view of grounded theory. He rejected Glaser’s view as being closer to positivism (Hallberg, 2006). Glaser staunchly retained that grounded theorists must learn **not** to know, which implies the avoidance of engaging with literature before entering the field of study. He believed *inter alia* that “delaying the review encourages you to articulate your ideas.” From this purist’s perspective, it is therefore argued that a literature review at a later stage ensuing from the emergent grounded theory is essential to demonstrate how the study builds on and contributes to existing knowledge (Dunne, 2011).

However, the notion that no literature must be studied prior to coding of the data is one of the most widespread reasons behind the lack of use of grounded theory. Contrastingly the focus should rather be on how to make proper use of existing/previous knowledge. Postponing a literature review until the process of data collection and analysis is almost finished is an impossible situation to PhD students who need to submit detailed proposals to research and ethics committees. The rationale behind an early literature review, therefore, is (Dunne, 2011):

- To provide a cogent rationale for the study
- To ensure the study has not been done before
- To contextualise the study
- To help the researcher gain theoretical sensitivity
- To promote clarity in thinking about concepts and theory development
- To be reflexive regarding existing literature.

However, Dunne (2011) writes that a middle ground can be successfully reached through the processes of reflexivity and memo writing as it is already incorporated into the guidelines underpinning grounded theory.

Over the years, the principles of grounded theory evolved from strictly discovery to the construction of grounded theories. Charmaz (2006) stated that because we are part of the world we study and the data we collect, we, therefore, construct our grounded theories through our past and present involvements with people and research practices. The researcher's interpretive understanding rather than the researcher's explanation of how the participant creates his or her understanding and meaning of reality is the result from the study (Hallberg, 2006). Any theoretical proposition thus offers an interpretive portrayal of the studied world and can never be an exact picture of it. This statement corresponds with the principles of critical realism stating that our data can only be an interpretation of reality and thus stand to be rectified as new information emerges. Thus, any knowledge produced by people can be interpreted differently and from various perspectives. Mistakes can be made by information being misinterpreted or due to personal biases. Knowledge, therefore, always stands to be rectified by any new information (Maree, 1990).

Hallberg (2006) writes that over the years grounded theory has developed and was modified during each era during its development. Ontological and epistemological standpoints regarding our assumptions about what reality is and how it can be known are thus embedded in different modes of grounded theory. In the classical mode, data is treated by the researcher as objective facts to discover theory from and to be analysed using qualitative or quantitative methods. This has some positivist accents. In contrast, the constructivist grounded theory is positioned within the interpretive tradition and data, and analysis is thus seen as social constructions between the researcher and the participant presented as narratives or as a story depicting all categories, conditions conceptual relationships and consequences (Charmaz, 2006).

It can be concluded that grounded theory can be used from different theoretical perspectives as "it can adopt any epistemological perspective appropriate for the data and the ontological stance of the researcher" (Bryant & Charmaz, 2007, p. 269). The researcher's reflected standpoint coincides with the idea that grounded theory allows for an interpretive view.

Studying the compatibility of critical realism and grounded theory Oliver (2011) argued that together they offer an accessible and congruent research approach of particular relevance to social science. Grounded theory can provide critical realism a method and in doing so tie research more firmly to practice. The key feature of critical realism is the rejection of the epistemic fallacy which conflates reality to only one level of knowledge. Due to a shared focus on abduction and a commitment to fallibilism and the interconnectedness of practice and theory, critical realism and grounded theory become highly compatible. Bhaskar's proposition of the three levels of reality (section 2.2.1) being the empirical, the actual and the underlying real domain now comes into focus in explaining the phenomena studied.

Grounded theory can thus be described as the notion to start with what people say and then develop abstract theory from what was said (Oliver, 2011). As the reproductive needs of men and women living with HIV/AIDS and cultural expectations are "non-observable" and a very sensitive topic, the principles of grounded theory within the critical realist perspective is ideal and well suited for this study. By interviewing men and women within their reproductive years living with HIV/AIDS about their reproductive needs, the researcher can begin to develop abstract theory regarding the prevalence of the high pregnancy rate among the younger population living with HIV.

Theory is therefore developed from where the people are and not from within an ivory tower. It is a way to bring research to practice. Although the final theory is rooted in the participants' experience, it is written in the words and thoughts of the researcher. The identities of the HIV-positive participants are protected in that the process does not demand revealing descriptions or any focus on a few individuals. Subsequent endangering of individuals in unsafe and HIV stigmatising communities is avoided. Therefore, grounded theory offers protection to participants in the study by "distancing them from the research conclusions, aggregating contributions to enhance anonymity and encourage the critical analysis so important in the field" (Oliver, 2011, p. 14).

As caveats the researcher must remain aware of the possibility of being influenced by previous knowledge:

- apply constant reflexive thinking in comparing and evaluating data;
- apply constant reflexive thinking in documenting the research in memos;

- apply constant reflexive thinking on how existing knowledge and collected data can be integrated into formulating the emerging substantive theory;
- stay abreast with external developments in the field of study in order to take own informed and defensible positions on how to apply new knowledge.

2.2.3 The theoretical framework: specific research methods

In line with the nature of qualitative research Neuman (1994) describes the researcher's efforts understanding people in the social world as getting to know "how they feel inside, how they create meaning and how their personal reasons or motivations can be used to understand them" (p. 61). To learn how people perceive reality the researcher has to see it through the eyes of the individuals being studied. Individuals perceive reality in their own way. Every individual is constantly influenced by underlying unobservable processes. People's interpretations, understandings and theories can never be equated to reality and always stand to be rectified as new information becomes known.

Based on the sensitivity of the topic of the current study, as well as the requirement that the research methods should match the purpose of the study, the researcher decided that the theoretical perspective of critical realist grounded theory within the qualitative research approach was the most fitting choice to the study. The methodology which included the specific methods of conducting the research, e.g. individual interviews and focus group discussions (sections 2.3.3.1 & 2.3.3.2) were conducted at the clinics that the HIV-positive participants attended and where they received counselling.

2.3 RESEARCH DESIGN

As grounded theory embraces the critical realist methodology requirement of epistemic relativism, grounded theory acknowledges "the idea that there are many ways of knowing" (Oliver, 2011, p. 9). As part of grounded theory, simultaneous and multiple data sources, data collection methods and analyses are used within its framework. The concept of "many ways of knowing" can also be related to the fact that no single method ever adequately solves the problem of equally plausible causal factors. Multiple methods should therefore be used to strengthen the study in terms of triangulation. Triangulation implies the use of a combination of methods or data (Patton, 2002).

In applying the principle of triangulation to the study, the researcher decided to collect data from various sources including HIV-positive men, HIV-positive pregnant women, HIV-positive non-pregnant women and also HIV counsellors. The researcher furthermore decided to make use of individual interviews when interviewing the HIV-positive participants, but focus group discussions when interviewing the HIV counsellors. In this way, the researcher made an attempt to strengthen the study by the use of a combination of data sources and different methods during data collection to explore “many ways of knowing.” Patton (2002) stated that “qualitative inquiry is not a single monolithic approach to research and evaluation. There is a rich menu of alternative possibilities within qualitative research by focussing on different theoretical perspectives, and the various theoretical traditions are emphasised by their different foundational questions” (p. 76).

2.3.1 Research Setting

“Qualitative designs are naturalistic to the extent that the research takes place in real-world settings, and the researcher does not attempt to manipulate the phenomenon of interest (e.g. a group, event, program, community, relationship or interaction)” (Patton, 2002, p. 39).

The study focused on two junctures where access to and knowledge about HIV risk reducing interventions can be critical in contributing towards the success of HIV prevention programs. At these junctures counselling on future reproductive options may be of critical importance to all participants whether they are male or female, pregnant or not pregnant. The two junctures are:

- when a person tests HIV-positive for the first time and
- when an HIV-positive woman is pregnant or has just given birth.

The Kalafong Hospital was chosen as the research setting, being both an academic and public hospital that represents a typical area where services are rendered to a community ranging from low to middle class. On average the socio-economic status of the community is below average and is characterised by high levels of unemployment. The hospital is situated in the Tshwane metropolitan area, and provides services to a predominately African community, representing various cultural groups.

Patients are tested and counselled on HIV at the Voluntary Counselling and Testing (VCT²) Clinic, while follow-up care to people living with HIV, is given at the Immunology clinic. The VCT clinic is attended by approximately 200 patients per month. The Ante-natal Clinic (ANC) at the Kalafong Hospital offers pre-natal and ante-natal care to pregnant women and new mothers. As part of the national prevention of mother to child transmission programs (PMTCT) offered to pregnant HIV-positive women at ante-natal clinics in South Africa, all pregnant women are tested for HIV (National Department of Health, 2010). When they are diagnosed as HIV-positive, they are referred to (or enrolled in) the PMTCT program. The ANC is attended by approximately 1200 pregnant female patients per month of which one out of three are diagnosed HIV-positive (the heads of the clinics were only willing to give estimated numbers of patients to the researcher). The researcher recruited the HIV-positive men as well as the HIV-positive non-pregnant women from the VCT and Immunology clinics, while the HIV-positive pregnant women were recruited from the Ante-natal Clinic (ANC) at the Kalafong Hospital.

Access to the research sites was obtained from the authorities at Kalafong Hospital, namely; Kalafong Chief Executive Officer; Head of the Immunology clinic where HIV-testing is done and HIV-positive people receive their medication and the Head of the Ante-natal Clinic where pregnant women receive care (See Addendum A: Research Institution Informed Consent).

2.3.2 Participants

As public sector HIV-positive individuals may be unlikely to afford assisted reproduction in the private sector, the study specifically focuses on HIV-positive men and women in their reproductive years who attend public health facilities. The HIV-positive participants were recruited according to the concept of purposeful sampling as described by the principles of grounded theory. Purposeful sampling is very important for the research design as qualitative inquiry focus on small samples, which are purposefully selected to allow in depth inquiry and understanding of a specific phenomenon of central interest and importance to the researcher. The primary focus with “information rich” purposefully selected samples are therefore useful insights about the phenomenon under study and not an empirical generalisation from a sample

² Currently the correct term used for “HIV Counselling and Testing” is HCT, but the researcher preferred to use the old term, because when the study was done in 2009, the terminology used was VCT (before it was changed to HCT),

to a population. Gaskell (2000) stated, “the real purpose of qualitative research is not counting opinions or people but rather exploring the range of opinions, the different representations of the issue” (p. 41). It was therefore decided to sample HIV-positive men, HIV-positive pregnant women and HIV-positive non-pregnant women to determine the extent of reproductive needs from various angles among people within their reproductive years living with HIV/AIDS in South Africa. HIV counsellors were included in the research as they interview many people with HIV and have specific knowledge about the needs of many people living with HIV. They are also the providers of counselling regarding family planning to HIV-positive individuals and they know the current practices of HIV counselling.

The criterion of saturation applied to the sample size. This means that the researcher continued to interview HIV-positive participants and held group discussions with the HIV counsellors until no more new information was gathered. Kempster and Parry (2011) state that “theoretical sampling helps the researcher to engage in several iterations of data gathering and analysis such that the emerging explanation is as valid and reliable as possible” (p.108). Strauss and Corbin (1990) described the relationship of research design to theoretical sampling needed in grounded theory as follows: “Unlike the sampling done in quantitative investigations, theoretical sampling cannot be planned before embarking on a grounded theory study as specific sampling decisions evolve during the research process itself” (p.192). This statement will be further explicated during the discussions on coding procedures.

The heads of both clinics introduced the researcher to the HIV counsellors who assisted in the recruitment of the participants. With reference to the two junctures discussed in section 2.3.1, the HIV-positive participants as well as the HIV counsellors were recruited for the study from both the Immunology and the Ante-natal Clinics at Kalafong Hospital in Tshwane.

2.3.2.1 The HIV-positive participants

In recruiting the participants, the researcher first arranged an introductory meeting with the HIV counsellors to explain the aim and motives of the study. The researcher explained to the counsellors their dual role in the study in terms of both recruiting HIV-positive participants as well as their own participation in focus group discussions. The researcher also requested the presence of a counsellor acting as an interpreter to be present during interviews to make participants feel more comfortable and to help with

any language barriers, should they occur. The study group comprising the HIV-positive participants consisted of the following 3 subgroups:

- HIV-positive men: being part of the group of people who tested HIV-positive;
- HIV-positive pregnant women or woman who have recently delivered babies: being part of the group of people who tested HIV-positive, but also in need of family planning counselling with regards to their reproductive future; as well as
- HIV-positive non-pregnant women: being part of the group of people who tested HIV-positive, but not burdened by the direct consequences of a current pregnancy and probably with different reproductive needs than the other subgroups.

The HIV counsellors were requested to recruit eligible and willing participants from the HIV-positive attendees at the various clinics and bring them into contact with the researcher. The following criteria applied:

- Eligible participants must have known their HIV positive status for at least 6 months, in order for them to be more used to their status and therefore more open to talk about it;
- Eligible participants must have received post HIV/AIDS test counselling;
- Eligible participants must be within their reproductive years (15 to 49 years);
- Eligible female participants could be pregnant or not;
- Eligible participants could have previous children or not.

The recruitment of HIV-positive male participants was problematic as 2 out of 3 patients at the VCT clinic are women and the men seemed to be more inclined to be in a hurry to complete their business at the clinic as quickly as possible. The counsellors succeeded in recruiting 10 male participants out of a cohort of 33 nevertheless. A summary of the recruited participants (obtained from Addendum B: Participant information) is given in Table 2.1:

Table 2.1: The HIV-positive participants

	Age	ANC participants	VCT participants
HIV + men	29 to 46 years		n = 10
HIV+ pregnant women	19 to 32 years	n =12	
HIV+ non-pregnant women	22 to 38 years		n = 11
Number of participants		12	21

Although HIV is present in all population groups, all HIV-positive participants taking part in the study were Black. The absence of participants from other racial groups is regrettable, as they could have contributed different perspectives. Participants reported their home languages as follows: Sepedi, Setswana, isiZulu, isiNdebele, Xitsonga, Northern Sotho, Shangana, Shona, SiSwati and isiXhosa.

To minimise any inconvenience to the participants in terms of time, travelling and costs, the interviews were scheduled to coincide with their existing appointments at the respective clinics. A time table was set up in conjunction with HIV counsellors in order to optimise attendance of all participants at the Ante-natal and Immunology clinics.

Each participant was interviewed only once. In order to ensure a rich variety of responses on each of the explored topics, interviews were therefore continued until the flow of new information dwindled significantly. A total of 33 HIV-positive participants were therefore interviewed. As a token of appreciation for the time and information shared with the researcher, the researcher presented the HIV-positive participants with a food parcel. A small gift for the baby was given to all participating pregnant women and new mothers.

2.3.2.2 The HIV counsellors

The researcher considered the HIV counsellors important in the study, as they could give perspective on the perceived needs of their HIV-positive clients. They also provided key information about the counselling they provide to their HIV-positive

clients. The counsellors reported to the researcher that they each had daily contact with an average of between 15 and 20 HIV-positive clients, indicating their significant sphere of influence. They are therefore in an influential position as they give guidance and can influence the opinions of HIV-positive people.

The researcher recruited a group of willing HIV counsellors from the respected clinics to take part in a focus group discussion. Some participating counsellors did not attend the scheduled discussion due to nurses and medical staff being on strike for higher wages at the time. They took part in a rescheduled focus group discussion that took place at a later date. The travel expenses of counsellors were borne by the researcher.

During these sessions, the researcher informed the HIV counsellors about the importance of their taking part in the focus group discussions. Their perspective of the reproductive needs of men and women living with HIV/AIDS could provide a more holistic view on the phenomenon and the consequent implications to family planning. All the participants in this group described themselves as black and reported Northern Sotho, Venda and Ndebele as their home languages. Table 2.2 is a summary pertaining to the characteristics of the HIV counsellors being mostly lay persons with short periods of training:

Table 2.2: The HIV counsellors

Age	23 to 40 years
Males	2
Females	10
Counselling experience	Between 4 months and nine years
ANC counsellors	n = 4
VCT clinic counsellors	n = 8

The relationship of the various study groups to each other within the study is represented in Figure 2.1 and can best be demonstrated as a tetrahedron where the various participant groups formed the lateral sides with the group of HIV counsellors at the base.

Relationship of study groups

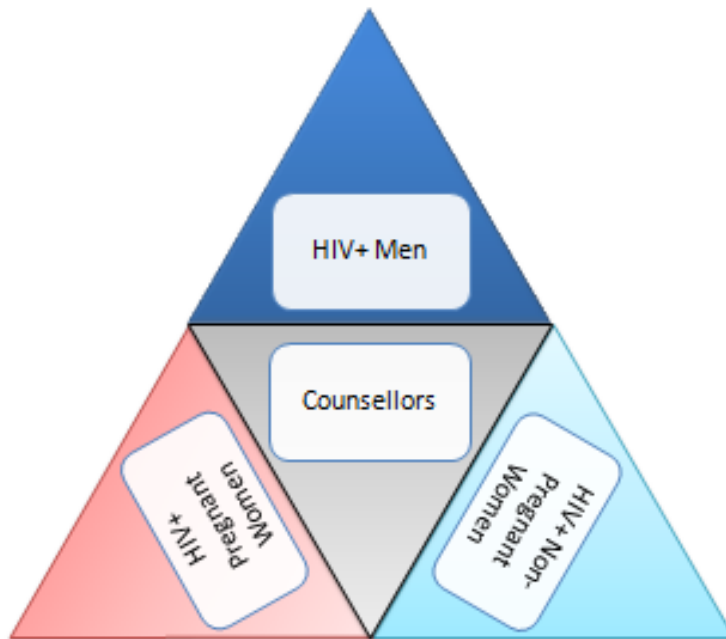


Figure 2.1: Relationship of study groups.

In the diagram of the unfolded tetrahedron (Figure 2.1):

- **the top triangle** represents the HIV-positive male participants attending the Immunology Clinic at Kalafong Hospital.
- **the bottom left triangle** represents the pregnant HIV-positive female participants in their reproductive years attending the Ante-natal Clinic at Kalafong Hospital.
- **the bottom right triangle** represents the non-pregnant HIV-positive female participants in their reproductive years attending the VCT clinic at Kalafong Hospital.
- **the centre triangle** represents the counsellors at both the VCT clinic and Ante-natal Clinics at the Kalafong Hospital. The HIV counsellors in their counselling capacity were central to all three groups of HIV-positive participants in that they have contact with all groups of participants and can influence the decisions made by HIV-positive men and women.

2.3.3 Data collection

The discovery-orientated naturalistic inquiry minimise investigator manipulation of the study settings, as no prior constraints are placed on any possible outcomes. Open-ended conversation-like interviews are good examples of naturalistic inquiry and allow participants to freely express themselves on sensitive topics that might provoke anxiety in them. The application of questionnaires with pre-determined categories, classic to quantitative research, would have seriously impacted and restricted the richness of information obtained from people living with HIV and their reproductive needs. The raw data of qualitative inquiry is, therefore, descriptions and quotations free of judgments about whether what occurred was good or bad. The data simply describes what happened or the people's opinions (Patton, 2002).

According to the principles of grounded theory the process of data collection focuses on sampling broad enough and interviewing deep enough to give a full account of all variations of the phenomenon studied (Strauss & Corbin, 1990). The data obtained through qualitative research relies on linguistic data and meaning-based analyses by using grounded theory. The data collection of this study was done by applying the principles of triangulation (section 2.3). The semi-structured individual interviews and focus group discussions combined with various participant groups as data sources formed part of the process of data collection.

The researcher was aware of the importance of choosing a suitable research design and the recruitment of enough participants in order not to waste the valuable time of the participants. Napier (2005) described respect for the individual as key to ethical conduct and states the importance of consent, confidentiality, competence and conduct. At the start of the semi-structured individual interviews as well as the focus group discussions, written consent was obtained from each participant (Addendum C: Participant informed consent). The researcher clearly explained to each participant the purpose of the study, what was expected of them as participants, what the likely outcomes were, as well as the possible risks involved.

The researcher assured participants that their identity as participants to the study would never be made public and that all information would be dealt with confidentiality, and all records be kept securely. Further assurance was given that the researcher will not disclose any information in cases where the one partner did not disclose his or her HIV status to the other partner. The participants were also assured to be able to

withdraw from the study at any time without having to give any reasons. The participant informed consent form (Addendum C) also contained the name and address of the supervisor (see addendum), should a participant have any complaints about the conduct of the study. The study was approved by the Ethics Committee of the Faculty of Humanities of the University of Pretoria.

The presence of the interpreter, recruited at the outset of the study, contributed to make the participants feel at ease during the discussions knowing that they could speak their own language when it was difficult to express them. The counsellors acting as interpreters were known to the participants. It seemed as if it was comforting to the participant to have a familiar face in the room, reducing the concern of a familiar face being an inhibiting factor in similar settings. It seemed that the previous open relationships between participants and counsellors at VCT precluded this.

All interviews and focus group discussions were conducted in English, as most of the HIV-positive participants, and the HIV counsellors, spoke the language fluently. To ensure that the respondent truly understood what was discussed during the individual interviews as well as during the focus group discussions, it was important that the interpreter was an HIV counsellor who knew the context of HIV and was fluent in most of the African languages. In most cases, the participants understood and spoke English fairly well, but the services of the counsellor acting as an interpreter did come in handy when there was a language problem.

With the consent from all participants, responses to exploratory open-ended questions were recorded during the individual interviews and focus group discussions. This was done in order to transcribe responses of participants to ensure clear and accurate data for interpretation. All participants were debriefed at the end of the semi-structured interviews as well as the focus group discussions. The researcher gave a summary of everything that was discussed. Participants were put in touch with clinics offering "HIV risk reducing interventions" to men and women living with HIV/AIDS, should they have the need approach them after the conclusion of their participation. The researcher strived to comply with the standards and codes of conduct as stipulated by the guidelines from the Health Professions Council of South Africa. In the following section, the two data collection tools will be discussed briefly.

2.3.3.1 Individual interviews

Individual interviewing is preferred in academic research situations where “the research objective is to either explore the life world of the individual in-depth; ...when the topic concerned issues of particular sensitivity, which may provoke anxiety” (Gaskell, 2000, p. 48).

Charmaz (2006) described interviewing as fitting in with grounded theory principles, as researchers are required to take control of their data collection and analysis. The interview allows researchers the necessary control over their material to be able to follow up on situations where the researcher needed more data on certain aspects under study. In this study semi-structured interviews allowed an appropriate format to discuss sensitive topics in a confidential way, e.g. being HIV-positive and discussing reproductive needs. It was a very important tool for the researcher to gain the trust of the participants, as they were initially very hesitant to talk about their HIV-positive status. The researcher asked the HIV-positive participants questions “to describe and reflect on their experiences in ways that seldom occur in everyday life” (Charmaz, 2006, p. 25). The presence of the HIV counsellor acting as the interpreter helped to gain the trust of the participants and to make them feel more at ease. The comfort level of the participants was more important for the researcher than getting sensitive bits of information. The researcher tried to understand, in a non-judgmental way, what was said from the participants’ point of view.

As no dedicated office was assigned to conducting the interviews, the researcher with the assistance of counsellors had to find a suitable space every time in order to interview the participants in private. Even though inconvenient, conducting the interviews in no specific room or office had an advantage in the study. Initially, the participants feared that they might be recognised by somebody they knew from their own communities who might label them as HIV-positive because of being interviewed “officially” by the researcher. With the interviews being conducted in locker rooms, baby rooms, side-rooms, counselling rooms, general consulting rooms and general offices according to daily availability, the “official” aspect disappeared. The participants could therefore, not be stigmatised based upon the location of the interviews.

The schedules of the individual interviews were semi-structured. A discussion guide consisting of broad questions was used to give some structure to the interview. The

questions provided flexible guidelines for the interview according to the principles of grounded theory. This allowed the interviewer to explore themes in order to understand the meaning the respondent attached to issues and also allowed personal answers outside that of the set framework. The discussion guide provided areas to be explored by all participants (See Addendum D, E and F for details on slight variations in discussion guides used between various study groups). As an example, broad questions explored HIV-positive men in terms of what they think; how they feel and what their responses are regarding:

- The improvement of male attendance at HIV clinics;
- The motivation of men to actively combat the transmission of HIV/AIDS.

As another example, the following broad questions to HIV-positive pregnant women explored what they think; how they feel and what their responses are with regards to:

- The influences on her decision to become pregnant with this child;
- Her perception of good timing to have this baby.

The following broad questions to HIV-positive non-pregnant women explored what they think; how they feel and what their responses are with regards to:

- The importance of parenthood;
- The effect of not having children on her position in the family.

These questions only served as guidelines or prompts to expose sensitive issues and were arranged in a logical order, to flow naturally during the interview or focus group discussions. Typically of interviewing in a grounded theory research study, the questions evolved over time to suit theory development.

2.3.3.2 Focus group discussions

In order to study the reproductive needs of men and women living with HIV from a wider perspective it was thought necessary to include the HIV counsellors in the study. The HIV counsellors have interviews with almost all people tested positive in the hospital. The focus group discussion, where a number of people meet to discuss issues of mutual concern led by the researcher, was selected as the method to

interview the counsellors. The researcher wanted to explore whether the counsellors perceived any reproductive needs among their HIV clients. Gaskell (2000) stated that people in groups are more willing to entertain novel ideas as well as explore their implications. Groups have also been found to take risks and show attitude polarization through which the researcher wanted to explore whether any biases or prejudice exist in terms of the reproductive needs of people living with HIV.

The focus group discussion is therefore a naturalistic setting where participants take note of the views of others in formulating their responses as well as commented on their own and others' experiences (Gaskell, 2000). The researcher compiled a discussion guide (Addendum G) to invite the HIV counsellors during the focus group discussion to talk at length in their own terms on what their responses are to various aspects of interest, for example:

- Their perceptions of the reproductive needs of their HIV positive clients;
- Their need for training regarding counselling on HIV risk reducing interventions.

Due to a limited number of counsellors who could attend the first meeting, the researcher arranged a second focus group discussion. More counsellors attended the second meeting and greater clarity could be obtained with regards to aspects such as their attitudes towards counselling people living with HIV having babies, their perceptions of their clients' reproductive needs, their knowledge regarding HIV risk reducing interventions as well as whether they had any training needs regarding counselling on future HIV family planning. Similar to the interviews the focus group discussions were tape recorded and transcribed to enable the researcher to interpret the data.

2.4 DATA ANALYSIS

Denzin and Lincoln (2000) stated that "there is no correct telling of an event as each telling, like the light hitting a crystal, reflects a different perspective of the incident" (p. 6). The best way of reflecting these different perspectives will be achieved through the framework of grounded theory consisting of the following:

- Simultaneous collection of data and analyses,
- two step coding of data,

- constant comparisons between previous and current concepts and ideas,
- writing of memos to construct the concepts analysed,
- constant refining of emerging theory and
- integration of the theoretical framework (Charmaz, 2000; Elliot & Timulak, 2005).

The qualitative naturalistic approach largely allows for an inductive design. The strategy of inductive design allows the important analysis dimensions to emerge from the patterns found among the cases under study, without presupposing in advance what the important dimensions will be (Patton, 2002). Patton further states that all theories about what is happening in a setting are grounded in, and emerge from, direct field experience. It is not imposed *a priori* like in the case of formal hypothesis and theory testing. Inductive analysis and creative synthesis can therefore be described as the immersion of the researcher into the details and specifics of the data to be able to discover important themes, patterns and relationships hidden in text. The process begins as a simultaneous gathering and exploration of data obtained during the interviews and observations by the researcher. The analytical principles of grounded theory then flexibly guide and confirm emerging themes, patterns and relationships that were found. The process ends with a creative synthesis towards a substantive theory.

The purpose of the analyses is to build a theory, as was described by Strauss and Corbin (1990). One way of doing this, is to move from the specific situation to the more general. The researcher, therefore, used a specific case to open her mind to the range of different meanings. She could then move on to other cases with her mind being sensitised to all the possibilities. By comparing incident to incident, the researcher was more likely to recognise sameness, variations and differences between cases. For example, the researcher learned the importance of supporting relationships in coping with HIV status. The HIV-positive men disclosed their status to their partners as they all were in supportive relationships, compared to most of the HIV pregnant women who did not disclose their status for fear that they might be deserted by their partners as many of them did not have supportive relationships.

Comparisons are a major tool of grounded theory. It involves the constant comparison of views, situations and meanings at various levels of the research process both

between men and women living with HIV/AIDS and between women who were pregnant and the other groups. This data was ultimately compared to that of the counsellors. Underlying patterns or phenomena became clearer as more comparisons were made between the inputs of various role-players at different levels of the study.

2.4.1 Data interpretation

According to Elliot and Timulak (2005), the first step in the data preparation is to transcribe all notes and verbatim recordings. The researcher captured the interviews and focus groups discussions in text form by verbatim typed transcription of conversations from recordings following careful listening during the interviews. This was done on a same-day basis. As the researcher conducted the interviews and focus group discussions herself, she felt that she could better understand what the participants were saying. In this way, the researcher's theoretical sensitivity to the data was also better developed.

The simultaneous process of data collection and coding allowed the researcher to ask questions on aspects that were unclear or to explore certain issues better, based on previous data collected (Addendum H). For example, as the researcher became more familiar with the community of people living with HIV during the interviews, she could recognise some irrelevance in the guiding questions and could adapt that. She realised that asking participants about taking part in prevention programs was not part of the experience of HIV-positive men, as these programs were mostly presented at the clinics which the men did not attend. Instead, the researcher then focused on asking men how situations at the clinics could be improved so that many more men will attend the clinics.

Better understanding of the research questions was achieved by in depth interviewing and following the participants' subtle directives in exploring issues that were important to them from their specific frames of reference. Conducting interviews in this manner, allowed the researcher to review the formulation of the problem (Bryman, 1988) dynamically.

As more information became clear, the researcher became more adapt at adjusting questions to better understand the phenomenon under study. A distinction was made between the participant's spoken words, and the notes made by the researcher.

During the interviews and the group discussions “rambling” sometimes occurred where the interviewee moved away from the designated areas in the researcher’s mind, towards areas most important to the participant. From one perspective, it may seem that the researcher lost some control over the interview, but this was done to explore the issues central to the participants’ point of view. The researcher revisited “rambling” transcripts to hone in on any detail overlooked during the interview. Notes were made on the researcher’s question guide if that was the easiest or least disruptive way of securing valuable transient data. All notes in transcribing recorded data were interwoven by the researcher using italics (Bryman, 1988).

Some of the dialogue was very soft, as women were scared to be overheard or simply shy. During transcription on the same day the researcher could still mentally see them sitting in front of her and this recollection bolstered the notes that she made during the interviews. If the research assistant, who was not present during the interviews, had to transcribe the interviews, some of the information and nuances might have been lost. It was, however, the research assistant’s task to confirm the consistency and trustworthiness of the data that was captured in the transcriptions made by the researcher.

The researcher clarified her picture of the phenomenon being studied, by re-reading the data set. Emerging insights and understandings were written as memos (see Addendum I: Memo of Initial Interpretation). By writing memos the researcher was kept in contact with the raw data during the process of linking analytic interpretation with empirical reality. The writing of memos was especially helpful for the researcher during the early interpretation of the transcribed interviews, as it helped the researcher to look at the data differently and to spark new leads for continued data collection. Charmaz (2000) describes memo writing as the intermediate step between coding and the first draft of the final analysis.

The researcher was always conscious of the fact that the nature of grounded theory is not about the accuracy of descriptive units, nor is it an act of interpreting meaning as ascribed by the participants during the study. It is much rather an act of conceptual abstraction where it must explain and not describe what is happening in a social setting (Bryant & Charmaz, 2007). Strauss and Corbin (1990) described coding as the process where data is “broken down, conceptualised, and put back together in new ways” (p. 57). These authors summarised the analytic procedure involved with coding

as building rather than to only test theory. Coding gives the research process the rigour necessary to make “good” science. It helps the analyst to break through the biases and assumptions brought into the research process. Coding also provides the grounding, builds the density and develops the sensitivity and integration needed to generate a rich, tightly woven, explanatory theory that closely approximates the reality it represents (Strauss & Corbin, 1990).

Data collection and analysis by means of coding are thus concurrent processes of grounded theory which enables the researcher to continue data collection until no new insights are obtained. In this study, codes were created as data was studied line-by-line by the researcher. Through interacting with the data new questions were formulated in order to determine the theoretical categories these statements might indicate (Charmaz, 2006). Strauss and Corbin (1990) contended that concepts are thus created in describing the phenomenon that is studied. Bryant and Charmaz (2007) describe the skill needed by grounded theorist as being able to leave the empirical detail behind in order to lift the concepts above the empirical data and to “integrate the concepts into a theory that explains the latent social pattern underlying the behaviour in a substantive area” (p. 273).

Categories are created by the grouping together of similar concepts and naming them on a higher order of abstraction. Categories and concepts are developed in terms of their properties and dimensions. This is accomplished by asking questions about the data, make comparisons for similarities, differences and variation between each incident, event and other instances of the phenomenon studied. The properties of a category can be described as the characteristics of a phenomenon (category) and can give you the full range of dimensions over which a category might vary. The dimension of a category is the continuum of variation as can be seen from table 2.3:

Table 2.3: Category dimension variation

Category	Properties	Dimension
Yearning to have (another) child	Frequency	never.....often
	Extent	less.....more
	Intensity	low.....high
	Duration	short.....long

Generating categories early are important because categories also become the basis of the theoretical sampling during the process of constant comparison.

In order to establish categories and the conceptual relationships to other categories the researcher used the following analytical tools during the analytical process of coding (Strauss & Corbin, 1990):

➤ **Questions**

Good questions helped the theory to evolve. Such questions were built on the simple constructs of *who*, *when*, *why*, *where*, *what*, *how*, *how much* and *with which results*? Whenever the researcher experience a researcher's block, such questions were most helpful in reenergising her thought processes. Revitalised thought patterns improved theoretical sampling and yielded important further questions to participants.

➤ **Analysis of a word, phrase or sentence**

The researcher scanned the document for at least a couple of pages and then returned to a word or phrase that stood out as having particular meaning or significance. The researcher made a list of possible alternative meanings to the word or phrase in question and then returned to the document in search of incidents that will point to meaning.

➤ **Further analysis through comparisons**

To make comparisons is essential for identifying categories. Firstly, the researcher compared incidents to each other by looking for concrete properties that formed similarities and differences to classify them by. The making of theoretical comparisons based on more abstract properties followed. This construed the classification of properties that were not easily seen by the researcher. It also helped in expanding theoretical sampling.

There are two types of theoretical comparisons, namely: the flip-flop technique where the concept is turned "upside down" or "inside up" by looking at extremes or complete opposites thereof; and systematic comparison of two or more phenomena where an incident in the data was compared to one recalled from literature or from the experience of the researcher. The focus was not on how many individuals exhibited this concept, but rather on how often this concept emerged and what it looked like under different circumstances.

➤ **Waving the red flag**

Lastly, the tool of “waving the red flag” sensitised the researcher to the possibility of her own or the participants’ biases confounding the analysis. The researcher can never be truly free from biases, but whenever the face value acceptance of participants’ explanations or the complete rejection thereof took place without questioning; a red flag should wave in the mind of the researchers. The words “never”, “always”, “everyone”, “no other way”, “sometimes” and “occasionally” were all red flags compelling a closer look at data and the asking of more questions, as stated earlier.

The researcher looked for simple ways in terms of figures to illustrate her interpretative understandings regarding the difference, similarities and subtle variations between participants of the various study groups creating their understanding and meaning of reality (Hallberg, 2006). Chapter 4 will therefore give all the details pertaining to the relevant figures with regards to coding procedures in terms of difference, similarity and subtle variation, as well as story telling leading to the formulation of the substantive theory based on grounded theory principles within the paradigm of critical realism.

2.4.2 Substantive theory

A substantive theory is formulated by the systematic abstraction and conceptualization of empirical data that constitute the theory generating process in a grounded theory study (Hallberg, 2006). Hallberg (2006) reported that Glaser and Strauss differentiated between substantive and formal theory. Substantive theory relates to a specific area under study, for example “the reproductive needs of men and women within their reproductive years living with HIV/AIDS”. In contrast formal theory concerns a more general or broader application area, for example “stigmatization.” Glaser (in Bryant & Charmaz, 2007) stated that a formal theory exists in terms of the study of data from many substantive areas during which the substantive theories are broadened and generalised into a formal grounded theory. However, most grounded theories are substantive theories as grounded theorists more often address specific substantive areas (Hallberg, 2006).

In this study, the focus will be specifically on the area of the reproductive needs of men and women within their reproductive years living with HIV/AIDS. The substantive grounded theory pertaining to this specific area of study will be generated by the researcher through the factual writing of the storyline by conceptually interacting with

the data during selective coding, integrating the various categories and themes into a core category ultimately leading to the substantive theory. In the process, the underlying unobservable generative mechanisms pursuing emancipatory, rather than merely descriptive goals as such will be exposed by the substantive theory describing critical realism as the theoretical framework (Oliver, 2011). The significance of the underlying unobservable generative mechanisms emerging as themes, pertaining to the reproductive needs of men and women will be discussed within the context of existing literature during Chapter 5.

2.4.3 Reporting a qualitative research study

“The result of a grounded theory study is not the reporting of facts but the generation of probability statements regarding the relationships between concepts: a set of conceptual hypotheses developed from empirical data” (Bryant & Charmaz, 2007, p. 273).

The findings of a qualitative research study can be communicated to the reader in the form of graphs, diagrams, figures, tables and narratives. This process can be seen as “marketing” of the results where the reader can make their own judgments. The main findings are abstracted from the category structure and follow the rule of essential sufficiency. Charmaz (2006) stated that grounded theory should focus on meaning, action and process. According to Bryant and Charmaz (2007), a grounded theory must offer a conceptually abstract explanation for a latent pattern of behaviour in a social setting under study. It must explain, not merely describe, what is happening in a social setting. Consequently, from a critical realist point of view, the researcher chose to reflect the interpretive tradition as proposed by Charmaz (2006) assuming a position between positivism (the observable facts) and constructionism, where data and analysis are seen as social constructions between researcher and participant. The results from the study will therefore be presented as a story told by the researcher depicting the interpretation of categories, conceptual relationships and consequences.

It must be mentioned that the researcher is aware of various computer packages aimed at assisting researchers in qualitative data analyses. These packages are designed to sort and organise mountains of coded data and to do multiple concurrent searches on various topics (Charmaz, 2000). However, the researcher decided to conduct all analysis manually in an attempt to stay in narrow contact with “the deepest part of human existence” (Charmaz, 2000, p. 520).

The criteria of internal and external validity and reliability are replaced in the paradigm of qualitative research by terms such as trustworthiness and consistency of interpretation (Denzin & Lincoln, 2005). The researcher assessed the trustworthiness of the analysis throughout the study by presenting a summary of all areas discussed during each semi-structured interview or focus group discussion to the participants involved as part of the debriefing phase. The participants, as original informants, gave feedback and correction to the researcher about interpretations the researcher has made (Elliot & Timulak, 2005).

The researcher's conceptual interpretation of the data shaped the emerging codes. Consistency throughout the process was enhanced by the genesis of data during the transcription process in such a way that it was possible to check and distinguish statements made by the participant and interpretations made by the researcher. The research assistant, trained in transcribing as well as coding of the text, verified the consistency and trustworthiness of data interpretations by choosing recordings at random and comparing it to the transcriptions made by the researcher. Following directives of Flick (2005) and Neuman (1994), constant rechecking improved the comparability of researcher's and assistant's conduct and all values emerging from the interpretations were made explicit, while no value was deemed superior to any other.

2.5 CONCLUSION

In this chapter, the researcher metaphorically "prepared her moon shade" by explaining the research process from the theoretical framework of critical realism as a philosophy of science using grounded theory as the approach most suitable to study the very sensitive issue of HIV-positive reproductive needs and counselling in South Africa. Chapter 3 will give an exposition of the all-important task of theory going into action where the processes of simultaneous coding and interpretation will be described.

CHAPTER 3

RESULTS: OPEN CODING

“mind shut muddy down...”

3.1 INTRODUCTION

“Grounded theory coding generates the bones of your analysis. The theoretical integration will assemble these bones into a working skeleton. Thus, coding is more than a beginning; it shapes an analytic frame from which you build the analysis” (Charmaz, 2006, p. 45).

According to Strauss and Corbin (1990) open coding can be described as the process where data is fractured and this allows one to identify some categories, their properties as well as their dimensions. In line with the principles of critical realism, coding gets the researcher off the empirical level by fracturing (i.e. dissecting) the data, then conceptualising the underlying pattern of a set of empirical indicators within the data as a theory that explains what is happening in the data (Bryant & Charmaz, 2007).

Chapter 3, therefore, describes the process where data was divided into distinctive units of meaning or action. These snippets of language had to be large enough to still communicate sufficient information to the researcher, yet concise, and therefore varied enough to allow a focus on a large number of concepts bearing meaning in the context. The researcher had to determine this optimal length by repeated adjustment until a balance could be found. Initially, the researcher coded the data line by line in order to get started on the coding process. In order to lift the data from the empirical level to interpretation and conceptualisation, the researcher proceeded to code phrase by phrase and paragraph by paragraph. Open coding in grounded theory (Strauss and Corbin, 1990) is therefore defined as the analytic process where concepts are identified and developed in terms of their properties and dimensions. All of this is done by the constant asking of questions about the data such as those suggested by Bryant & Charmaz (2007):

- What is this data a study of?
- What category does this incident indicate?
- What is actually happening in the data?
- What is the main concern being faced by the participants?
- What accounts for the continual resolving of this concern?

Comparisons are made for similarities, differences and variations between each incident or other instances of the phenomena under study.

3.2 OPEN CODING: INDIVIDUAL INTERVIEWS

According to Strauss and Corbin (1990) codes or concepts are seen as the building blocks of grounded theory. The authors explain that initial names for codes or concepts are often written on the transcribed interviews or group discussion documents. Categories and concepts pertaining to them are then taken from these pages and written as code notes, which can be seen as a type of memo to be used later by the researcher. The process of open coding can also be described as “deconstructing” the text in order to find the real issues at heart.

After all the transcriptions were done, the data was re-read by the researcher. The following questions who; why; what and under which circumstances, (true to the tradition of grounded theory), directed the process of interpretation. Strauss and Corbin (1990) explain the necessity of asking questions about data as “your theoretical explanations will be far more dense because your questions took you away from the standard ways of thinking and allowed exploration of other avenues of thought and hopefully gave new insight to the problem” (p. 90).

The researcher then went back to the original text in the transcriptions and applied the techniques described in section 2.4.1 in coding the text. The researcher wrote memos on the initial interpretation of the data. In most cases, codes were substantiated by direct citations from participants. To identify participants in a non-revealing way, each participant got a number generated by the voice recorder. This number appears as the participant’s number in brackets next to their citations. All interviews were done and numbered as the participants presented themselves to the researcher on a specific clinic day.

The following is an exposition of all the emerging codes/concepts in breaking down text per individual interview group: HIV-positive men; HIV-positive pregnant women and HIV-positive non-pregnant women. Table 3.1 is an overview of all the codes organised according to themes and sub-themes obtained during the individual interviews with HIV-positive participants:

Table 3.1: Codes and themes: Individual interviews

<p>Code: (3.2.1) Background info</p> <p>Themes:</p> <ul style="list-style-type: none"> - Knowledge level - Reproductive counselling - Perception of counselling 	<p>Code: (3.2.2) Value of having children</p> <p>Themes:</p> <ul style="list-style-type: none"> - Personal importance responsibility value as a woman feelings of guilt - Cultural importance gender identity approval mechanisms - Future support cont. of families marital dispute gender inequality 	<p>Code: (3.2.3) Effect of not having children</p> <p>Themes:</p> <ul style="list-style-type: none"> - Personal effect unhappy loneliness no future support - Position in family family pressure pressure on women to retain relationships - Cultural effect establish identity 	<p>Code: (3.2.4) Cultural acceptance/rejection</p> <p>Themes:</p> <ul style="list-style-type: none"> - Community support - Personal desire - Fear of transmission - Stigma
<p>Code: (3.2.5) Involvement in prevention programs</p> <p>Themes:</p> <ul style="list-style-type: none"> - Participation - Suggestions to increase men's attendance 	<p>Code: (3.2.6) Effect of HIV on life and relationships</p> <p>Themes:</p> <ul style="list-style-type: none"> - Quality of life positive effect negative effect - Quality of relationships support partners need for baby - HIV disclosure partner's rejection - Effect on sexual relationship strained loss of trust loss of spontaneity 	<p>Code: (3.2.7) Awareness of risk reduction</p> <p>Themes:</p> <ul style="list-style-type: none"> - Lack of knowledge - Need for improved services - Need for access to services 	

3.2.1 Emerging code: Background information

The following strong themes emerged from the text obtained from the different study groups, as participants reflected on their HIV status and the counselling sessions they received:

- Knowledge level
- Counselling on future babies
- Perception of counselling experience

All participants reported that they received counselling on viral transmission and the use of condoms. Most participants were cautioned not to have any more children. Some were advised to consult the doctor at the clinic should they wish to have babies in the future. The conceptual interpretation of the interviews within different groups showed the following:

The **HIV-positive men** interviewed were tested HIV-positive between 1999 and 2008 (interviews were done during 2009). All the men had accurate knowledge on viral transmission. Most HIV-positive men were counselled not to have children and to always use condoms when having sex. The following citations from the participants illustrate the counselling men received:

- “You must stop having children; you must use condoms” (respondent 20) – (Knowledge).
- “They said we must rather not have children otherwise it is going to cost us a lot of money” (respondent 22) – (Counselling on future babies).
- “They treated me in a nice way... I am doing what they say” (respondent 21) – (Quality of counselling experience).

The **HIV-positive pregnant women** interviewed were tested HIV-positive during 2002 up to 2008 (interviews were done during 2009). Some of them knew their status before the current pregnancy. Most of the pregnant women interviewed had accurate knowledge about viral transmission. Some were counselled not to have any future children. Others did not receive any counselling about future family planning. Some were advised to abort the current foetus. A few HIV-positive pregnant women

reported that they had used condoms sometimes before their pregnancies. The following citations illustrate the women's point of view:

- “They told me about the disease, they said I must use condoms... they did not tell me about another baby” (Respondent 16) – (Knowledge; Reproductive counselling).
- “They said you must use condoms... you must not have another baby” (Respondent 17) – (Knowledge; Reproductive counselling).

The **HIV-positive non-pregnant women** interviewed were tested HIV-positive between 1997 and 2008 (interviews were done during 2009). Most HIV-positive non-pregnant women had accurate knowledge on viral transmission. Some were counselled to consult the doctor at the clinic if they wanted another baby. All were counselled to always use condoms. For example:

- “They said to me, I must speak with the doctor if I want another baby” (Respondent 39) – (Reproductive counselling).

3.2.2 Emerging code: Value of having children

The following themes and sub-themes emerged from the text obtained from the different study groups as participants reflected on the issue of having children:

- Personal importance:
 - responsibility
 - value as a woman
 - feelings of guilt
 - future support
- Cultural importance:
 - gender identity
 - approval and acceptance
 - mechanisms

Having children was personally important to all **HIV-positive men** interviewed. The main reason for the importance was that children give one responsibility and give one support when you are old. One participant summarised this as follows:

- “To be a parent... it is very important, I want to see my babies grow older, get to school... college, grow up strong to be happy, so that when I grow old they will be there for me” (Respondent 47) – (Future support).

Culturally, parenthood is important to all the men, mainly because it gives a man a sense of identity. Individual participants from the various ethnic groups mutually agreed to the huge importance of parenthood by using different terminology. For example, a Zulu participant said without children: “*you are not a man*”; the Ndebele participant said without children “you are not seen as a human being”, while a Tswana participant said: “A child for one family is a child for the whole society” – (cultural approval).

There is so much cultural pressure on men to have children that various procedures, like having a second wife or adoption, are culturally accepted to enable men to realise parenthood. This inevitably put pressure on their partners to give them children. The following citations illustrate this:

- “The time will come for me to be old, and my children will buy me food. If you have no children, you are not seen as a human being... you are respected if you have a child” (Respondent 48) – (Identity).
- “I want to take care of them; they are my future” (Respondent 21) – (Future support).
- “They want us to have children; the male child is very important; the surname must grow... with a girl child our surname dies” (Respondent 21) – (continuation of families).
- “It is so important that I will adopt a baby... If you adopt, then they look at you differently; you are responsible, then” (Respondent 47) – (Cultural acceptance).
- “The elders in his culture will put pressure on a man and will arrange his youngest sister in law to test his fertility” (Respondent 23) – (Cultural mechanisms).

Most of the **HIV-positive pregnant women** reported having children as being important. To most women having children was culturally important. It is especially important in cases of customary marriages where a woman is expected to have a child before the marriage in order to prove her fertility. The pregnancy is also stressful for

HIV-positive women, as it will be culturally unacceptable if the baby is not healthy. Some women reported that their cultures would accept it as God's Will if she cannot have children. Then it will be expected of her to adopt a baby in order to have a child.

The reasons HIV-positive women gave for them being pregnant were that the pregnancy gave them a reason to live, for some the child is seen as an ally in marital disputes, to nurture and love the family, not to be alone, future security and to establish her value as a woman. Some women expressed themselves as follows:

- “It shows how much woman you are” (Participants 11) – (value as a woman).
- “I have always loved the role of nurturing... it is how we measure your value and your being as a woman... it is a stamp of approval” (Respondent 14) – (Cultural approval).
- “Maybe you fight with your husband; the baby can destroy that fight” (Respondent 13) – (solve a marital dispute; future support).

Although they felt they should not be pregnant because of their HIV-positive status, most pregnant women wanted their current babies very much. A few women, however, described their pregnancies as a “mistake.” The reasons they gave for being pregnant without them wanting to be pregnant, were that their partners would not use condoms, and that they were consequently violently forced into submission to unprotected sex by their partners. Due to cultural gender inequality, women do not have control over their relationships. A few of the women were still at school and therefore did not want this pregnancy. Some participants voiced their regret as follows:

- “The baby was not planned... was a mistake... because I am HIV-positive” (Respondent 17) – (Feelings of guilt).
- “This one was a mistake... eish, I was using condoms with my partner, and then one day he was drunk and said he wanted to sleep with me without using condoms, and I said no...Then we started fighting... and then it was...” Participant started to cry (Respondent 25) – (Marital dispute; feelings of guilt).

Most of the **HIV-positive non-pregnant women** interviewed, reported that having children is personally important to them. The reasons given varied between the facts

that they needed a baby as it will give them responsibility; that they did not want to be alone; that their mothers wanted a grandchild; that they themselves wanted a baby before they die, and that they wanted to prove that they can be mothers. The women expressed these needs as follows:

- “I want to be a mother; I do not want to die; I want a baby first” (Respondent 35) – (value as a woman).

The majority of HIV-positive non-pregnant women reported that they perceived parenthood as culturally important to married couples in saying:

“People will treat you like something is wrong with you if you don’t have a baby, so you MUST have a baby” (Respondent 43) – (Cultural acceptance).

- “His family would want you to have a baby; you must have a husband and a big family, and they will disrespect you for not having a baby” (Respondent 32) – (Cultural mechanisms).
- “They say you have to have a husband and a big family” (Respondent 35) – (Cultural approval).

3.2.3 Emerging code: Effect of not having children

The following themes and sub-themes emerged from the text obtained from the different study groups as participants expressed themselves about the effect upon their lives should they not have children:

- Personal effect:
 - unhappy
 - loneliness
 - no future support
- Position in the family:
 - family pressure
 - pressure on women to retain their relationships
- Cultural effect:
 - establish identity

The **HIV-positive men** interviewed expressed that not having children would be personally very painful, unhappy, alone, difficult and stressful. This will force them to adopt otherwise they will actually kill the family. With regards to their position within the family, they said that without having their own children they would not be considered an adult in their families:

- “I stay my mother’s child; I must get another woman; I must marry another wife, or I stay with my wife and adopt or divorce and remarry” (Respondent 20) – (identity within the family).
- “There is nobody to call you Baba, you are not man enough, and you are disregarded as a man. You are being pressured once you are 21 to have children. They look at you differently. You will be expected to take care of your brothers’ children” (Respondent 20) – (masculinity; community pressure).
- “Personally not having children will be difficult because I will be alone. In my family, I will be disregarded” (Respondent 52) – (identity within the family).
- “You are not seen as a man if you do not have children... they do not regard you. You do not know what you are talking about” (Respondent 22) – (masculinity; acceptance into the community).
- “Personally not having children is going to be difficult. His position within the family will not change; his focus will shift towards the children in the community. He will maintain his role as a man in the community but the elders in his culture will put pressure on him and will arrange for his youngest sister in law to test his fertility”(Respondent 23) – (Cultural pressure; mechanisms).
- “Personally not having children will be stressful to me. My position within the family will not change because I do not have to divorce my wife, but I can take another girlfriend to have a baby. Culturally, I will be disregarded as a man and in the community I am not allowed to speak about children because I do not have any myself. They will laugh at you... they will tease you... they will tell you must make a baby” (Respondent 45) – (Cultural strategies to enable parenthood; masculinity).

Most of the **HIV-positive pregnant women** described their feelings about not having children as sad and painful. They said it will be difficult for them as they are scared to be alone and without support in old age. Some women described not having children

as devastating and having a baby was seen as her right. Most women reported not having children will seriously impact on their role as women. A woman's position in her family will be different if she does not have children. There will be pressure from the family in-laws and she will be divorced by the husband. Within the family there would be great pressure on her to have a baby. Having a baby was crucial to her to retain her relationships. She will be disrespected and excluded from cultural affairs, as can be seen from the following quotes:

- “Even my grandma will tell me. It is totally unacceptable if you cannot have a baby... they will laugh at you” (Respondent 14) – (Acceptance in the community; pressure).
- “The behaviour of black people... if you are married they give one year and if you do not have babies you have to divorce” (Respondent 27) – (Cultural pressure; rejection).
- “If you do not have kids you do not survive in life” (Respondent 25) – (no future support).
- “If you do not have a baby you are nothing” (Respondent 26) – (Identity).
- “There are the others who become divorced because they cannot have babies, they become the prostitutes... they work for themselves... they stay alone... it is not good” (Respondent 29) – (Lack of community acceptance).

Most **HIV-positive non-pregnant women** also reported not having children as sad, painful, very bad, heart-breaking and stressful as everybody would ask why. They will be alone, and it will be difficult because people will be calling them names (verbal abuse). They are of the opinion that they will not get married because most men want babies. They feel that if a woman does not have a child, she will be lost. People look down at them and that changes everything. Their social status thus depends on having children. There is heavy pressure on HIV-positive women who feel they will be culturally rejected, should their babies not be healthy; they will not be respected and be called hurtful names like “rubbish.” The following citations from the interviews illustrate the pressure on women, and specifically HIV-positive women:

- “If you cannot have a baby, they take you back to your family, and they take another woman” (Respondent 39) – (Family pressure; no future support).

- “People look down on you, and it changes everything. Because of pressure by the in-laws, it will ultimately cause your husband to turn against you. Your value as a woman is determined by your ability to have children” (Respondent 43) – (Pressure to retain relationships; value as a woman).

Most women reported that their position within their families depends on their fertility. The family will put pressure on a woman to have a baby. Ultimately, that will turn her husband against her, and he may divorce her and re-marry. Alternatively, a husband may take a second wife or a girlfriend whom he does not marry. Most women reported that not having children is culturally unacceptable, as she is expected to have many children. Her value as a woman is determined by her ability to have children. However, the children must be healthy as one woman reported:

- “It makes it better for me if there is a healthy baby” (Respondent 27).

3.2.4 Emerging code: Cultural acceptance/rejection

The following themes emerged from the text obtained from the different study groups regarding the participants’ perception of cultural norms towards people living with HIV that had babies:

- Community support
- Personal desire
- Fear of transmission
- Stigmas

All **HIV-positive men** interviewed were very scared of transmitting the virus. They experienced their communities were not supportive of HIV-positive people having babies. More than half the men wanted another baby regardless of their HIV status. Some participants are quoted as saying:

- “They do not like you, because you spread disease” (Respondent 50) – (Fear of spreading disease; stigma).
- “It is bad... because if you are sick that baby is going to be sick. I am scared... I want the baby to be healthy” (Respondent 20) – (Fear of spreading disease).

- “They think it is bad because they are going to die soon. I do not want to be responsible if the baby is sick” (Respondent 47) – (Fear of spreading disease; stigma).
- “If you are HIV-positive... they condemn it completely that you have children” (Respondent 24) – (Community rejection).

Most **HIV-positive pregnant women** were also very concerned about the health of their babies. The majority of women reported that the baby came at a good time in their lives. The researcher got the impression that some women had planned their pregnancies as it is a very important way to secure their relationships within the family, while a few others reported the baby was a mistake, because their partners did not want to use condoms. Most of the women were very anxious about the health of their babies as they were scared of rejection by their communities, should their babies be HIV infected. They observe the community to expect women to have babies but consider HIV-positive women having babies as irresponsible. HIV-infected women experience this as a double bind situation and become very anxious in internalising their motherhood roles. The following examples illustrate the conflict created through this double bind for women living with HIV/AIDS:

- “I felt I was ready to have a baby. The baby came at a good time. My community does not support HIV-positive people having babies. I am very concerned about the baby’s health” (Respondent 13) – (personal desire; community rejection).
- “The baby is very important to me because of my boyfriend’s marriage proposal. I had some pressure from my boyfriend to get pregnant. The baby came at a good time. My community does not support HIV-positive people having babies. They think you are sick, and you are dying and you are better left alone. I am very concerned about the health of my baby” (Respondent 14) – (Pressure to retain relationship; future support; community rejection).

The **HIV-positive non-pregnant women** reported they were also very scared of transmitting the virus to their babies. Only one woman trusted the effectiveness of ARV medication and was not scared of transmitting the virus. These women also suffered the consequences of the observed double bind created by the conflicts discussed in the above paragraph:

- “My community does not support HIV-positive people having babies. They say it is a risk... they say you must stay without a child. I badly want another child but am very scared of transmitting the virus to my baby” (Respondent 32) – (Community rejection; personal desire; fear of virus transmission).
- “My community does not support HIV-positive people having babies. They still have that stigma... you are sick, and you are going to die... if you want a child even if you know you are HIV-positive, you will not disclose it. I am concerned about transmitting the virus but takes courage from medical advances” (Respondent 43) – (Community rejection; stigma; fear of transmitting the virus).
- “The community where I live does not support HIV-positive people having babies. They say it is bad, and once they know your status, they do not come into your house, because they are scared you might infect them. I am very scared of transmitting the virus. I feel very helpless” (Respondent 42) – (Community rejection; stigma; fear of transmitting the virus).

3.2.5 Emerging code: Involvement in prevention programmes

The following themes emerged from the text obtained from the different study groups regarding the participants’ participation in existing HIV prevention programs:

- Participation
- Suggestions to increase men’s attendance

None of the **HIV-positive men** took part in prevention programs, compared to the women taking part in many HIV prevention programs. Most men reported that they were not attending any clinics. It is frustrating for them to wait all day at the clinic to see a health-care provider. However, the HIV-positive men agreed to always use condoms, and they were motivated to combat viral transmission. They made valuable suggestions to improve men’s attendance at the clinics. They suggested that they want appointments instead of waiting in line. They preferred more male staff, men's focus groups to enhance communication, programs to convince men to test and the ability to visit the clinic anonymously. They suggested mobile clinics that come to the people and they want clinics to be open over weekends. The men also wanted information on how to get a long life, to have a baby in a safe way, how to manage the disease, how parents should disclose to children and how to have a healthy

relationship after knowing their partners' status. They also need information on what to expect and how to manage their futures. The HIV-positive men expressed their suggestions as follows:

- “I feel that men need to be treated at the same level as the ladies. Men also need to be given more information. I want communication to be enhanced amongst partners. I want more information on reproductive cycles, disclosure of our status to our children and having a healthy relationship after knowing our partner's status” (Respondent 24) – (Need for communication; need for improved services; need for information).
- “I did not take part in prevention programs, but I want services to be speeded up at the clinics. They must get more staff, and they must give you an appointment. I also want more information on staying healthy” (Respondent 47) – (Need for improved services; need for information).
- “I did not take part in prevention programs. I would like programs at the clinic to convince men to know their status. I want to attend the clinic anonymously, because I am scared of people recognising me. I also want more information on the disease and the future” (Respondent 50) – (Need for information; need for improved services; fear of stigma).

PMTCT is designed specifically for pregnant women and nurturing mothers. In contrast to **HIV-positive pregnant women** who were all taking part in PMTCT programs because of their pregnancies, most **HIV-positive non-pregnant women** did not take part in prevention programs. One non-pregnant woman reported to have consulted a sangoma (a traditional healer, often associated with supernatural powers). The difference in response between the HIV-positive women can be seen in the following quotes:

- “I took part in prevention programs, because I have seen the effect of HIV deaths on the family and child headed households in my community” (Respondent 14) – (pregnant woman).
- “I did not lose any babies due to HIV. I did not take part in prevention programs because I have consulted a sangoma” (Respondent 39) – (non-pregnant woman).

3.2.6 Emerging code: Effect of HIV on life and relationships

The following themes and sub-themes emerged from the text obtained from the different study groups regarding the way the participants experienced the effect HIV had on life and their relationships:

- Quality of life:
 - positive effect
 - negative effect
- Quality of relationships:
 - support
 - partner's need for a child
 - HIV disclosure
 - partner rejection
- Effect on sexual relationship:
 - strained
 - loss of trust
 - loss of spontaneity

Most **HIV-positive men** reported that they were taking better care of themselves since their diagnosis with HIV. The extents to which the quality of the lives of men is affected by their diagnosis are clear from the following quotes:

- “My life became more difficult because of my HIV status. I have skin lesions and lost an eye. I am lying to people about my status” (Respondent 21) – (Negative).
- “I value life more and I am taking good care of myself” (Respondent 23) – (Positive).
- “I am taking better care of myself in terms of my diet” (Respondent 22) – (Positive).
- “I am living a healthier life than before” (Respondent 45) – (Positive).

The majority of the HIV-positive men reported that their partners wanted to have another baby regardless of their HIV status. All the men were in supportive

relationships. In most couples, both parties were HIV-positive. The value of supportive relationships to the men is explained in the following quotes:

- “My girlfriend very much wants another baby, having just lost our baby due to liver failure. She puts lots of pressure on me not to use condoms. We are both HIV-positive; we have a supportive relationship” (Respondent 21) – (Partner’s need for a child; supportive relationship).
- “My girlfriend is very keen on having another baby. She is HIV negative and knows about my status. We have a very supportive relationship” (Respondent 51) – (Supportive relationship; partner’s need for a child).
- “My wife very much wants another baby. We planned for a long time. We are both HIV-positive. We are very supportive of each other in our relationship. She is always on my side” (Respondent 24) – (Partner’s need for a child; supportive relationship).

In only a few cases the sexual relationships of the HIV-positive men were not affected, while most others became scared and very tense, which inhibited their sexual life. The extents to which the sexual relationships of HIV-positive men are affected by their diagnosis are clear from the following quotes:

- “My sexual life is badly affected by my HIV-positive status. I feel exposed and scared, and I cannot be with her in a natural way” (Respondent 21) – (loss of spontaneity, strained).
- “My sexual relationship was very strained. With time, it became better” (Respondent 23) – (Strained; loss of trust).
- “My sexual relationship became very strained as it was very difficult to accept that I was HIV-positive and my wife was negative. I was weak at the time” (Respondent 22) – (loss of spontaneity, strained).

Most of the **HIV-positive pregnant women** reported they were not feeling strong and think that everybody knows about her status. They reported that they felt their lives were upset by their diagnosis because they fear rejection by their partners and the community as well as the burden of having a baby without the support of their partners. They described the effect of HIV on the quality of their lives as follows:

- “I am very scared of rejection because of my status. I do not want them to know, they will turn away from me” (Respondent 13) – (Negative effect).
- “I became scared and I do not feel strong like before” (Respondent 10) – (Negative effect).
- “I feel sad about my life, but I try to take good care of myself” (Respondent 16) – (Negative effect).

The majority of the **HIV-positive pregnant women** reported that their partners wanted a baby very much. Half of the women reported that they disclosed their status to their partners. The other women reported that they intended to disclose to their partners once the baby is born and tests negative. If the baby is healthy, they will be able to disclose, because they believe healthy babies will make their status more acceptable to the community. On the other hand the women perceive that everything will be fine for a mother if the baby is healthy, because, then they do not need to disclose her status to other parties. If the baby is unhealthy, people will ask questions, and then she will have to disclose and suffer the double rejection because of her own status and that of her baby. Only some women were in supportive relationships; while the rest of the women were either deserted or scared of being deserted by their partners once they disclose their status. The following quotes illustrate women’s unwillingness to disclose their status for fear of rejection by their communities and lack of supportive relationships with their significant other:

- “My partner was not keen on having another baby. We already had two other children. I do not know his status, and I did not disclose my status to him. I am very unsure of the relationship and for now, I am not going to tell him, the relationship is not so strong” (Respondent 10) – (Lack of disclosure in unsure relationship; fear rejection; unsupportive relationship).
- “My partner wanted another baby... I did not disclose my status... I am very scared to disclose, I fear rejection by my partner” (Respondent 16) – (Partner keen; HIV non-disclosure; fear rejection; unsupportive relationship).
- “My partner did not want another baby. He is also HIV-positive and knows my status. He left me and my children. I did not disclose to the family. I am very sad and depressed about my future” (Respondent 17) – (Partner not keen; HIV disclosure; unsupportive relationship; deserted by partner).

- “My partner wanted another baby. He does not know my status. I am not going to disclose” (Respondent 30) – (Partner keen; HIV non-disclosure).
- “My partner very much wanted the baby. He does not know my status. I am scared of rejection because I am living with his people. I will disclose when the baby tests negative, because it makes it better for me if there is a healthy baby” (Respondent 27) – (Partner keen; HIV non-disclosure; fear rejection; unsupportive relationship).

A few of the pregnant women said that they felt safe using condoms and that their sexual relationships were not affected, while all the others became scared of having intercourse. Half the women wanted to have the baby more, after knowing their status. They described the effect of HIV on their sexual lives as follows:

- “I continued the sexual relationship using condoms” (Respondent 13) – (Feeling safe using condoms).
- “I am scared of a sexual relationship because I am scared of rejection. My boyfriend does not know my status and we are not using condoms” (Respondent 10) – (strained).
- “I became very scared of a sexual relationship because my partner is not willing to use condoms” (Respondent 16) – (Loss of trust; strained).

The majority of **HIV-positive non-pregnant women** reported that they were taking better care of themselves in terms of diet, exercise and taking medicine. Some reported not to have any friends and that they have lost weight. Some of the women wanted a baby regardless of their status. They expressed themselves as follows about the effect of HIV on the quality of their lives:

- “I am taking better care of myself. I feel good and know what to do” (Respondent 39) – (Positive effect).
- “My life has changed and I am very lonely. My friends do not know about my status. I am very scared they might find out” (Respondent 42) – (Negative effect).

- “My lifestyle had to change from a carefree lifestyle to something I now consciously have to consider. I try to take better care of myself” (Respondent 43) – (Negative effect).

Some of the **HIV-positive non-pregnant women** reported that their partners wanted another baby. Most of their partners knew about her HIV-positive status. Some of the partners rejected the women because of her status; while other partners found it very difficult to accept her status. Some women, who did not disclose, would even lie to their partners about having to use condoms. Some of the women said:

- “My boyfriend has children from a previous relationship; he does not want another baby. He does not know my status. I am scared of being rejected by him. I told him to use condoms because I do not want another baby” (Respondent 9) – (Partner not keen; HIV non-disclosure; fear rejection; lying to partner about using condoms; unsupportive relationship).
- “My partner rejected me because of my HIV status. He is also HIV-positive and blames me. He was my first partner. He is older than me and had many previous relationships” (Respondent 42) – (HIV disclosure; rejection; unsupportive relationship).
- “My partner does not want another baby. He knows about my status. He is HIV negative. He finds it very difficult to accept my status” (Respondent 43) – (Partner not keen; HIV disclosure; supportive relationship).

In terms of the effect HIV had on the quality of their sexual lives, the non-pregnant women expressed themselves as follows:

- “My sexual relationship at first was very difficult; we are working very hard at our feelings towards each other” (Respondent 39) – (Strained; loss of spontaneity; loss of trust).
- “I am very scared they might find out. I do not want a sexual relationship and find it very difficult” (Respondent 42) – (loss of trust; strained).
- “My sexual relationship became very difficult as my partner experienced my suggestion to use condoms as rejection. I am very scared to be rejected by him” (Respondent 43) – (Strained; loss of trust; loss of spontaneity).

3.2.7 Emerging code: Awareness of risk reduction

The following themes emerged from the text obtained from the different study groups regarding the participants' reflection about their knowledge concerning HIV risk reducing interventions and future family planning:

- Lack of knowledge on RRI and FP
- Need for improved services
- Need for access to services

The majority of the **HIV-positive men and women** interviewed had no knowledge on becoming a parent in a safe way by employing HIV risk reducing interventions. The HIV-positive men were very surprised and excited to hear about the possibilities of being a parent in a safe way by means of risk reducing interventions. However, the HIV-positive women who were deserted by their partners because of their HIV status as well as those who felt unsure about their futures were not interested at all in the possibility to become a parent in a safe way. Most participants wanted counselling services to be expanded as the messages they got previously were to stop having children or occasionally to consult the doctor if they wanted more children. The following quotes illustrate both the lack of knowledge as well as their need to get more information and access to services:

- “I do not know about becoming a parent in a safe way. I will consult with the doctor in the clinic. I think HIV-positive people must be helped in becoming parents in a safe way. I do not know where to go for risk reducing intervention and family planning” (Respondent 21) – (lack knowledge on RRI; need for improved services; need for access to services).
- “Yes I know about RRI. I accidentally came across a research project on sperm washing on the Internet. I am very suspicious of the procedure. I definitely want more information and HIV-positive people to be helped in becoming parents in a safe way if possible” (Respondent 23) – (need for more information; need for improved services).
- “No honestly, I do not know about becoming a parent in a safe way. Lots of young people become infected. I know they still preach the message of prevention, but they do not tell you what happens afterwards... they do not tell

how to deal with it... all you see is ‘condomise!’” (Respondent 14) – (Lack of knowledge on RRI; need for improved services).

3.3 OPEN CODING: FOCUS GROUP DISCUSSIONS

The data obtained from the focus group discussions with HIV counsellors was carefully re-read by the researcher. Memos were written (e.g. Addendum: I) on the initial interpretation of this data. The researcher also went back to the original text in the transcriptions and applied the same questions as described during coding of the individual interviews (section 2.4.1) in coding the text. Two focus group discussions were held due to the limited availability of HIV counsellors at the time. The data between the discussions corresponded strongly and was therefore analysed together. However, in analysing the data a distinction was made between the responses of the HIV counsellors at the ANC and those counsellors at the VCT clinic, as the counsellors at the ANC were dealing only with pregnant women compared to the HIV counsellors at the VCT clinic who counselled men and non-pregnant women.

The following is an exposition of the emerging codes/concepts in breaking down text obtained from the HIV counsellors during the group discussions. Codes or concepts were substantiated by direct citations from the text where applicable. Table 3.2 is an overview of all codes organised according to themes and sub-themes obtained during the group discussions with the HIV counsellors:

Table 3.2: Codes and themes: Focus group discussions

<p>Code: (3.3.1) Perception of client's child desire</p> <p>Themes:</p> <ul style="list-style-type: none"> - Perceived reproductive needs - Different needs in age groups - Importance of biological offspring 	<p>Code: (3.3.2) Feelings about HIV and reproduction</p> <p>Themes:</p> <ul style="list-style-type: none"> - Attitudes positive negative - Personal beliefs - Orphan problem concerns 	<p>Code: (3.3.3) Reproduction counselling provided to clients</p> <p>Themes:</p> <ul style="list-style-type: none"> - Lack of knowledge on RRI/FP - Difference in counselling focus - Difference in acknowledging future reproductive needs 	<p>Code: (3.3.4) RRI/FP counselling training needs</p> <p>Themes:</p> <ul style="list-style-type: none"> - Lack of reproductive future awareness - Need for RRI/FP counselling training secondary transfer of knowledge concerns
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3.3.1 Emerging code: Counsellors' perception of clients' child desire

The following themes and sub-themes emerged from the text obtained during the group discussions where the counsellors reflected on whether they perceived their HIV-positive clients to have any reproductive needs:

- Perceived reproductive needs
- Different needs perceived in age groups
- Importance of biological offspring

HIV counsellors at both the **ANC** and the **VCT** clinics perceived their clients to have a definite need for more children regardless of their status. The typical response of counsellors was:

- "They do not give up because they are HIV-positive" – (Perceived reproductive need).
- "Some, they come there and they say they want to conceive the baby" – (Perceived reproductive need).

The value of having a healthy baby for women was observed by all counsellors. For most women, biological offspring is very important because through having a healthy

baby, she can prove her own health. That means she can live her life as usual and disguise her HIV status. The counsellors motivated their observations as follows:

- “They want another baby before they become sick. They believe they will have another healthy baby because the previous one was unaffected. Another baby will be proof of her own good health” – (Perceived reproductive need).
- “People try to get pregnant to proof that they are not HIV-positive. Because there are so many stigmas out there” – (Perceived reproductive need).
- “People say one plus one equals she is HIV-positive. And then they try to get pregnant to disproof that they are HIV-positive” – (Perceived reproductive need).

HIV counsellors at the **ANC** clinic reported older HIV-positive pregnant women who are already parents tend to accept the pregnancy better, compared to the younger HIV-positive women who want to abort their unborn babies when they receive their positive diagnosis. The HIV counsellors perceived the younger women are not yet ready to become parents compared to the older women who already had children. The counsellors expressed this as follows:

- “The older ones do not have a problem, but the younger ones do not want to be parents yet, but unfortunately, it is too late for them” – (Different reproductive needs in age groups among women).

HIV counsellors at the **VCT** clinic perceived a difference between younger and older HIV-positive men and women upon learning their HIV-positive status:

- “The younger persons that do not have children would ask:
 - ‘What am I going to do to be able to be a parent in the future?’”
- “The older persons were asking:
 - ‘For how long will I stay alive?’ – (Different reproductive needs in age groups among men and women).”

It was important to the older people not only to have a biological child, but also to ensure that the child’s future is secured, should the parent die. These perceived needs were expressed by the counsellors as:

“They will go so far as to inseminate the wife’s sister so that the husband can have his own biological offspring” – (Importance of biological off-spring).

- “They seek more information... they want to know “what are my options," uhm, they want to do the *in vitro*, or they want to do other forms of fertilisation. However, most people they do not have the information, and they live under the stigma” (Perceived reproductive needs: importance of biological off-spring).

Counsellors also perceived that men have different needs compared to women. The counsellors in general perceived that men did not often attend the clinics:

- “The men feel left out... as we are looking at the reproductive health of couples, this is also something that we should look at... men having their own specific needs. At the clinics, you see a lot of females; it has been packaged in that sense” – (Difference in reproductive needs among men and women).

This perception confirmed the responses of the HIV-positive men as reported in section 3.2.5.

3.3.2 Emerging code: Feelings about HIV and reproduction

The following themes and sub-themes emerged from the text obtained during the group discussions where the counsellors reflected on their personal feelings towards counselling their HIV-positive clients on reproductive needs:

- Attitudes:
 - positive
 - negative
- Personal beliefs:
 - orphan problem concern

HIV counsellors at the **ANC** clinic had negative attitudes towards HIV-positive people having babies. They did not believe that HIV treatment during pregnancy is effective enough to justify future pregnancies without the risk of transmission. They felt they are doing their best to help HIV-positive women who are already pregnant. They are convinced that life becomes very difficult for HIV-positive women during pregnancy. The HIV counsellors at the ANC advised their clients not to have any more babies and

to be sterilised because of the risk to the baby and the health implications of pregnancy for the woman. The counsellors voiced their concerns unanimously as:

- “I know the fact that there is a possibility that the mother who is pregnant while she is HIV-positive, that she might transmit the virus to her baby” – (Negative attitude).
- “After the delivery you become weak... when you are HIV-positive it is weak times two” – (Negative attitude).

HIV counsellors at the **VCT** clinic were mostly positive in their attitudes towards their clients’ reproductive needs. One of the HIV counsellors at the VCT clinic underwent risk reducing intervention with his wife and firmly believes in the possibility of HIV-positive people having babies in a safe way. Although the counsellor lacked training and information about the possibilities of risk reducing interventions, he motivated fellow counsellors and HIV-positive clients at the VCT clinic to consider HIV risk reducing interventions. HIV-positive clients were made aware of the cost of risk reducing interventions as a limiting factor. The HIV counsellors, therefore, informed their clients about the importance of a lower viral load and an increased CD4 count, should they want to conceive naturally. The majority of counsellors agreed in saying:

- “I think they have a right to that, I do support them and encourage them to go ahead and have more babies” – (Positive attitude).
- “They should have babies... as long as they go for the check-ups and do the right thing and not conceive on their own” – (Positive attitude).
- “No they must have babies... if you are HIV-positive it does not mean you must not have the family... you must have a family... they must know their status” – (Positive attitude).

However, some of the older counsellors were more conservative, and they were very cautious of enlarging the number of HIV orphans. They, therefore, did not encourage women to fall pregnant. Their concerns about contributing to the HIV orphan crisis were voiced as:

- “You just sit and think this grandparent is becoming a parent again... so on that grounds it is not easy for me to say they should, or they should not become parents” – (Orphan problem concern).
- “I think the HIV/AIDS program or the VCT clinic program is not encouraging... that is why you have the older nursing staff being more directive in discouraging people to conceive when they are HIV-positive... some of the nursing staff, they are very negative, and they express that” – (Negative attitude).

3.3.3 Emerging code: Reproductive counselling provided to clients

The following themes emerged from the text obtained during the group discussions where the HIV counsellors reflected on their knowledge levels regarding their reproductive HIV risk reducing counselling to their clients:

- Lack of knowledge on RRI
- Difference in counselling focus
- Difference in acknowledging future reproductive needs

HIV counsellors at the **ANC** clinic had no knowledge on risk reducing intervention. HIV-positive clients at the ANC are mainly counselled on viral transmission during pregnancy, birth and breastfeeding. The HIV counsellors’ response to questions about risk reducing intervention was that of surprise as they never considered the possibility before. They were of the opinion that they are doing their best to overcome a situation that has no end to it. They responded as follows:

- “I focus on the baby and the mother, to be honest I do not touch too much on the partner... usually the women do not want to talk about the partner” – (Difference in counselling focus; difference in acknowledging future reproductive needs).

At the VCT clinic, the HIV counsellors’ main focus is on HIV infection and prevention of transmission by advising clients to always use condoms to protect the partner from infection and re-infection. They also advised clients to watch the CD4 count when planning to conceive naturally. HIV counsellors at the VCT clinic had some knowledge in terms of *in vitro* and artificial insemination and knew about a program on risk

reducing intervention. At Kalafong hospital, clients are mostly referred to the doctor in the VCT clinic for more advice. The counsellors verbalised their strategies as follows:

- “I explain to them that there is a way that a doctor can assist them to have a baby in a safe way” – (Knowledge on RRI; acknowledging future reproductive needs).
- “I do not know if it is correct... but I think it is that they take a sperm from a man, and then they inject it into the womb... a female womb” (knowledge on RRI).
- “It is reducing the risk for the baby getting infected, so the safe way is to go for *in vitro*” – (Knowledge on RRI; difference in counselling focus).

3.3.4 Emerging code: RRI/FP counselling training needs

The following themes and sub-themes emerged from the text obtained during the group discussions as the HIV counsellors reflected on their need for training regarding family planning and HIV risk reducing interventions:

- Lack of reproductive future awareness
- Need for RRI/FP counselling training:
 - secondary transfer of knowledge concern

To the **HIV counsellors** at the **ANC** clinic it was a new perspective to consider their clients in terms of reproductive decision-making. They expressed themselves as:

- “We never thought about it, we never sat down and actually tell them about their future, especially these younger ones... 18 years, it is possible that she can have more children” – (Lack of reproductive future awareness).

They expressed their need for risk reducing interventions and family planning as:

- “No actually we do not know anything.”
- “I think we need lots of information... we are dealing with people who are already pregnant.”
- “If someone can come out and ask: ‘I want to have children in a safe way, how do I do it?’ I will not be able to counsel them.”

- “We do need training... we do not know about family planning, they must fit it in training for us, a ten-day course, to teach us how do you counsel, what are the various options and how does everything work at the laboratory.”

Although the main focus is on HIV infection and prevention at the VCT clinic, **HIV counsellors** at the **VCT** clinic also expressed a great need for more information and training regarding HIV risk reducing interventions and family planning. At the VCT clinic family planning counselling is only done when couples attend the clinic. The counsellors felt that with more knowledge and training they would be better equipped to advise their clients in coping with their HIV status. They expressed their training needs as:

- “We are given basic information” – (lack of knowledge).
- “Yes, there is a need because the HIV information changes every day... It is a very dynamic field, so we need training whenever there is a new thing, so we can give information... because if we are behind with information the people will not get the information” – (Lack of knowledge; need for training).
- “Uhm, especially the discordant couples... there is a big problem... cause we do not have the real information, how are we going to tell them how can one be positive and one be negative if we have been sleeping for over nine years?” – (Lack of knowledge; need for training).
- “They will just say this kid is playing with us... but if you have the information you just talk to them like this and to tell them where to go to people who can help them” – (Lack of knowledge; need for training).

All the HIV counsellors expressed a need for direct training and firsthand knowledge to be able to counsel the large number of HIV-positive clients they counsel daily. They did not approve of secondary transfer of knowledge through the nursing staff who attended the training courses and then give feedback to the counsellors. They experienced secondary training as severely limiting:

- “I think the training should be broader; I think that the training counsellors receive is very limited. Sometimes you find that the nursing staff would attend the sessions instead of the counsellors... and the nursing persons are

supposed to come back and give them feedback” – (Secondary transfer of knowledge concern).

- “So some of the information will be lost if they cannot ask their questions directly” – (Secondary transfer of knowledge concern).

“Angie blocks their way with the moon shade and delays them a bit until the others catch up...”

CHAPTER 4

RESULTS: AXIAL AND SELECTIVE CODING

“hard-shelled body old...”

4.1 INTRODUCTION

To summarise the foregoing: Individual interviews were held with participants from the three study groups and focus group discussions were held with HIV counsellors. Data obtained from the open coding of all these interviews and focus group discussions was subsequently subjected to axial and selective coding.

It will now be shown how new categories were established following a process of comparison of data between the various study groups. Through open coding these new categories, based on similarities, differences and variations in the data extend the first round of codes and concepts by revealing alternative properties and dimensions. All developments are visually represented in graphic displays as they are presented.

4.2 AXIAL CODING: INDIVIDUAL INTERVIEWS

During axial coding, data is put back together in new ways. All the comparisons of differences, similarities and subtle variations between and within the various study groups on the various aspects explored, are interpreted by the researcher asking questions based on:

- How do the people in this setting understand their reality?
- What are their reported perceptions and world views?
- What are the consequences of their understanding of reality for their behaviours and for those with whom they interact? (Patton, 2002).

In axial coding the focus is, therefore, on the conditions that gave rise to the various categories. The resulting comparisons and interpretations made by the researcher led to *writing the story* during the process of selective coding. The researcher ultimately needed to incorporate all main categories derived from axial coding in *writing the story* which explains the phenomena being studied. Axial coding can thus be described as

the process of “reconstructing” data that was fragmented during the open coding process. Emerging codes and concepts were compared between and within each group. The differences, similarities and subtle variations were interpreted by the researcher based upon the principles of the critical realist paradigm. This was done to be able to learn how reality was understood by the individual and how the individual is being influenced by the unobservable processes and structures of his or her community. However, throughout the study, the researcher was always cognizant that according to critical realism, interpretations can never be equated to be the ultimate reality. The process and results will be elucidated through the resultant categories.

4.2.1 Category: Knowledge on living with HIV

This category was abstracted from codes emerging from the HIV-positive participants’ knowledge of living with HIV and in the light of their emotions, wishes and expectations regarding their reproductive futures. All three HIV-positive groups were similar in that they had accurate knowledge on viral transmission. All groups were counselled to never have more babies and to always use condoms. There was a variation between the three groups in the way the participants talked during the interviews.

Figure 4.1 shows how the study groups compare regarding *knowledge of viral transmission*. Differences between the groups are shown in red, subtle variations in orange and similarities in green.

Participants' knowledge on viral transmission

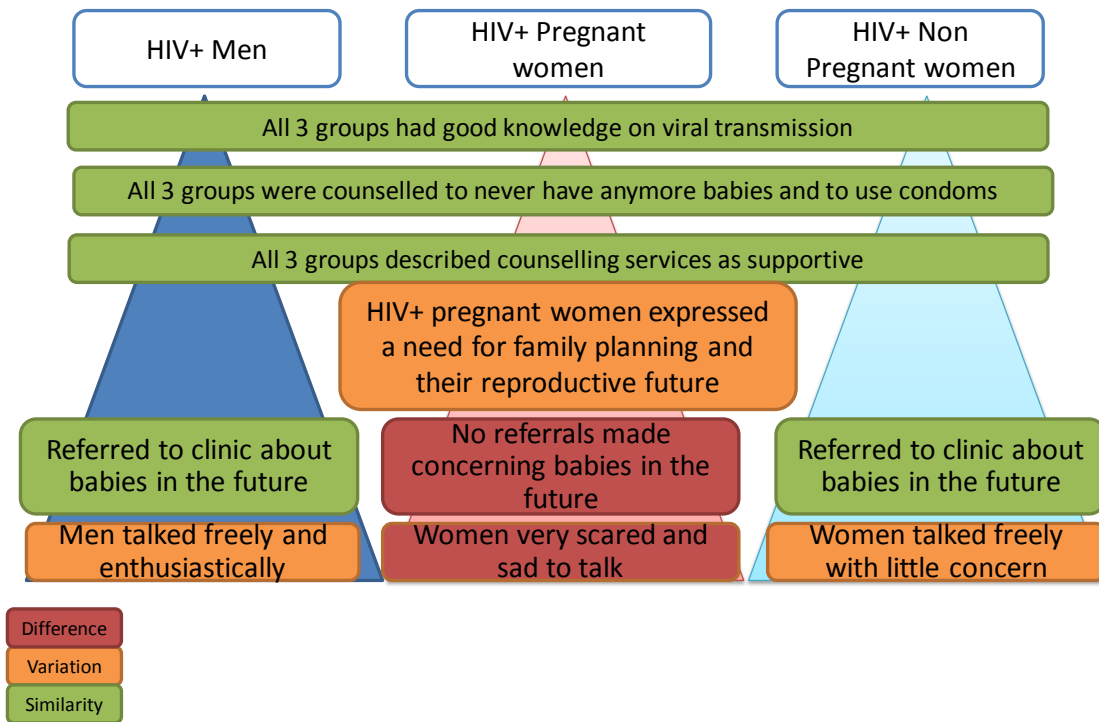


Figure 4.1: Participants' knowledge on viral transmission

Most participants in all three HIV-positive groups had no knowledge of risk reducing interventions (RRI) or family planning (FP) services.

Figure 4.2 shows how the study groups compare regarding *knowledge about risk reducing intervention and family planning*. Differences between the groups are shown in red, subtle variations in orange and similarities in green.

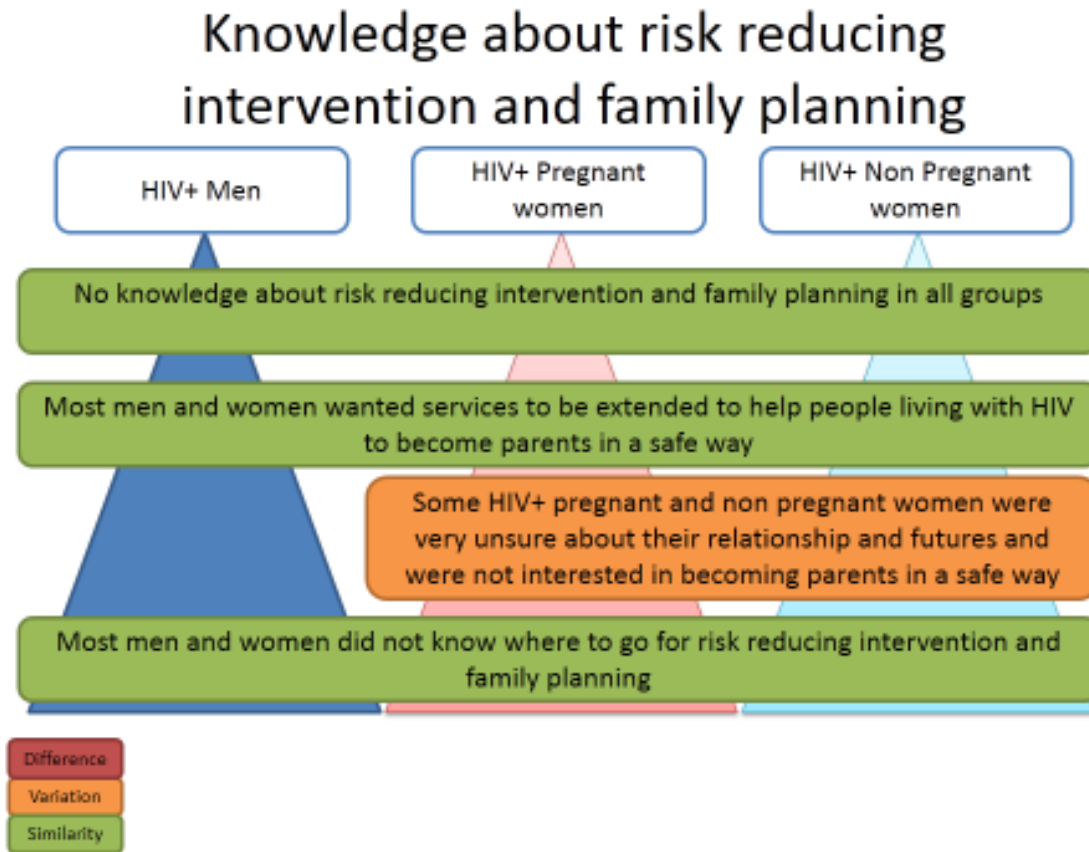


Figure 4.2: Knowledge about risk reducing intervention and family planning

Researcher's interpretation:

All HIV-positive men and women knew that their status places them in problematic situations (see section 3.2.6: effect of HIV on life and relationships), but most felt positive and supported by the counselling they have received. Most HIV-positive men and women were counselled not to have any babies in the future and to always use condoms. Some HIV-positive men and non-pregnant women were advised to contact the doctor in the clinic if they wanted more children, while having future babies was not an issue discussed with pregnant women. A pregnant woman was quoted as: "they did not tell me about another baby" (Respondent 16). The participants from the VCT clinic were counselled differently to pregnant participants from the ANC.

The researcher observed a difference in the way participants talked during the interviews. The HIV-positive men could talk reasonably freely and enthusiastically and wanted more information. The same was true for non-pregnant women, but the HIV-positive pregnant women seemed to be sad and scared and did not have a positive outlook on the future. The general message they received from the counsellors was

that they should stop having babies and must use condoms to protect themselves and their partners from re-infection. The counsellors probably blamed them for being pregnant and not complying with the counselling they received. Additionally, some of the babies were not planned, and most pregnant women did not disclose their status to their partners and consequently, continued to spread the virus. This could contribute to the counsellors' frustration that HIV-positive women continue to have babies and put their partners at risk of HIV. The HIV counsellors' negative attitudes towards women living with HIV having more babies resulted in some of the HIV-positive pregnant women feeling guilty and sad. This raised questions as to how they are treated in the clinics and by their families. It would appear; there is inconsistency between the attitudes of counsellors at the VCT clinic and the ANC, as participants attending the Ante-natal clinic felt negative about them for being HIV-positive and being pregnant.

With regards to knowledge on their reproductive futures, most HIV-positive men and women did not know anything about RRI and FP. Most HIV-positive men and non-pregnant women reacted with excitement and surprise to the possibility of RRI and FP as they were previously advised to not have any more children. In some cases, they were told to consult the doctor if they wanted more children. Only one man came across the concept of RRI and FP on the Internet and a few of the women had a vague idea of medical insemination procedures from watching soap operas on the TV.

Most of the HIV-positives participants wanted services to be extended to help people living with HIV to become parents in a safe way. They, however, did not know where to go for RRI and FP. There were some HIV-positive women who were very unsure about their relationships and futures and were not interested at all to even think about having more babies in the future.

4.2.2 Category: Meaning of parenthood

This category was abstracted from codes emerging from the meaning HIV-positive participants ascribed to being parents as well as the effect upon their lives of not having children. All three HIV-positive groups responded similar to the personal and cultural importance of parenthood. There was some variation with the pregnant women.

Figure 4.3 shows how the study groups compare regarding *the meaning they attach to parenthood*. Colours are applied as above.

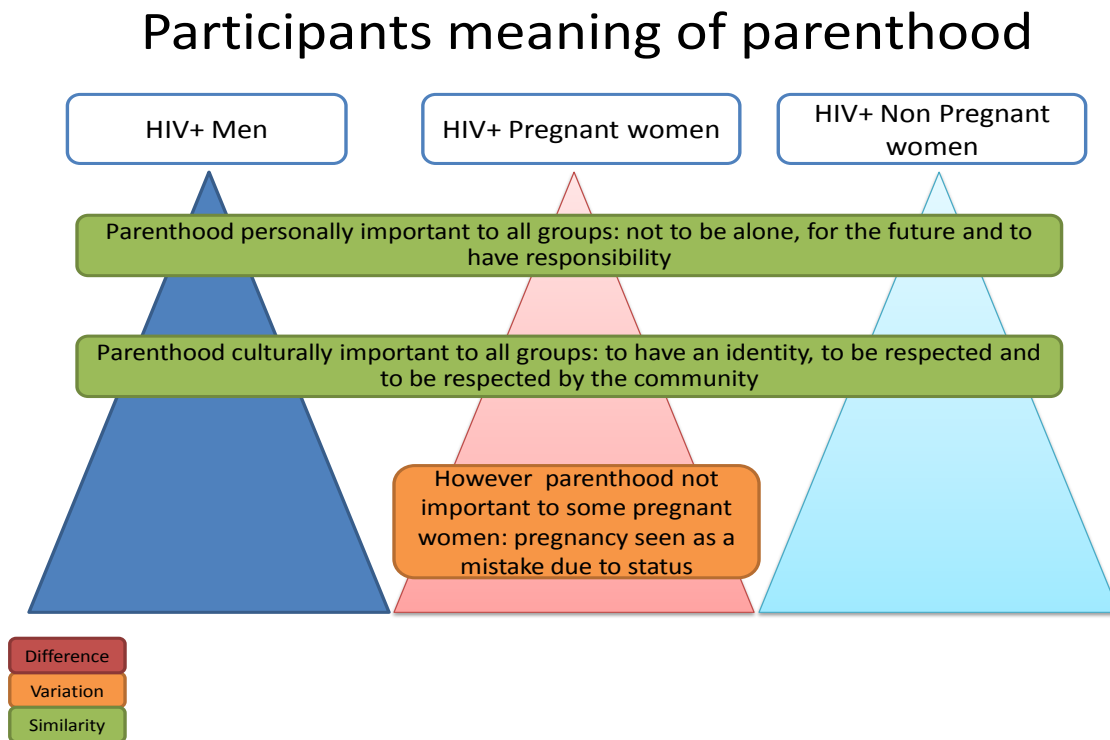


Figure 4.3: Participants' meaning of parenthood

The meaning of parenthood was further emphasised by the effect not having children had on their lives. All HIV-positive groups responded similarly in that they will be disrespected within their communities for not having children.

Figure 4.4 shows how the study groups compare regarding *the effect of not having children*. Colours are, of course, applied as above and will be applied accordingly in illustrations to follow.

The effect of not having children

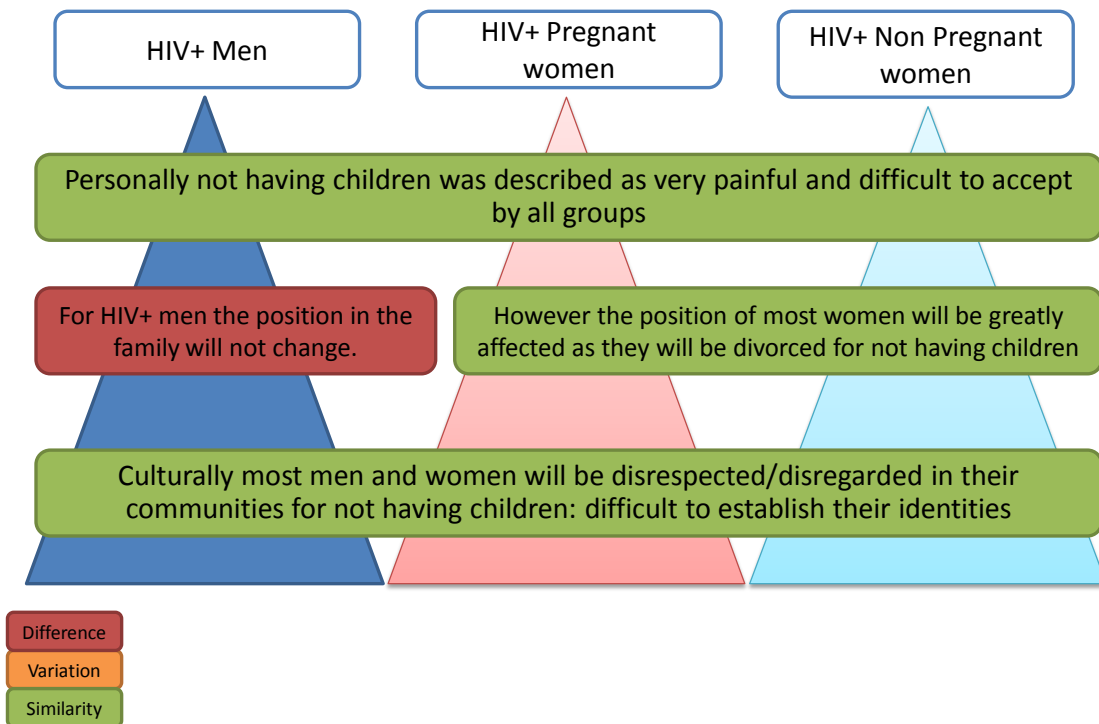


Figure 4.4: The effect of not having children

Researcher's interpretation:

Parenthood was personally important to most HIV-positive men and women in terms of having an identity as either a man or a woman within their respective cultures, as well as to have support in future and during old age. The following quotes are examples of their reported perceptions and world views with regards to the personal importance of parenthood:

- “The time will come for me to be old, and my children will buy me food” (Respondent 48).
- “If I die, my name must continue; it is important to me” (Respondent 50).
- “People will treat you like something is wrong with you, if you do not have a baby, so you must have a baby” (Respondent 43).

However, some HIV-positive pregnant women felt parenthood was not personally important as their pregnancy was seen as a mistake due to feeling guilty about their HIV status and being pregnant:

- “It is not very important; it was a mistake... my status” (Respondent 17).

Most men reported parenthood as very important to be respected as a man within the culture, to prove their masculinity, for their families to grow and their names to continue. The following quotes are examples of men’s reported perceptions and world views with regards to the cultural importance of parenthood:

- “If you do not have children you are not seen as a human being... you are respected if you have a child” (Respondent 48).
- “Especially a boy... he is the one who is going to carry your surname... your name must continue” (Respondent 45).

In comparison to HIV-positive men, most HIV-positive women agreed on the cultural importance of parenthood in terms of personal identity within their culture and care in the future. However, it was a very important means for women to keep their relationships, as men are allowed alternative strategies by the culture to get children if his wife or partner cannot have children. They may take a second wife or have a girlfriend or adopt a baby. Some pregnant women reported that a child could bring stability to a relationship. The following quotes are examples of the women’s reported perceptions and world views with regards to the cultural importance of parenthood:

- “It is how we measure your value and your being as a woman... it is a stamp of approval” (Respondent 14).
- “If you do not have a baby you are not women enough” (Respondent 16).
- “They will divorce you” (Respondent 28).
- “They say you have to have a husband and a big family” (Respondent 35).
- “Maybe when you fight with your husband the baby can destroy that fight” (Respondent 13).

Most HIV-positive men and women described the effect of not having children as painful and difficult to accept, and that they would feel alone and unhappy. The men

reported that, if they could not have children of their own, they would consider adopting children or using alternative strategies. The following quotes are examples of both men and women's reported perceptions and world views with regards to the effect of not having children:

- "It is so important that I will adopt a baby" (Respondent 47).
- "It actually kills the family" (Respondent 51).
- "If you do not have kids you do not survive in life" (Respondent 26).
- "You will not get married. Most men want babies... and if you do not have a child you will be lost" (Respondent 42).

Most HIV-positive men felt that their position within the family will not change if they did not have children as they are supported by their partners. However, some will be expected by the family to either divorce their wives, take a second wife or girlfriend or to adopt a child or care for the family's children. It is interesting that men have certain approved channels to satisfy their obligation of procreation. Cultural pressure is hereby demonstrated as there are accepted procedures to assist men having children. By implication, this put pressure on the women that they have to give them children. There were only a few women who reported not feeling this pressure. Interestingly only one woman said she would pursue a career if they could not have children (Respondent 14). The following quotes illustrated the family and community pressure on men to have children:

- "You have to get another woman who can make children" (Respondent 21).
- "I stay my mother's child, but if I have children, I become a man" (Respondent 20).

Conversely, it is the perception of most HIV-positive women that their position within the family will be negatively affected in terms of income and livelihood, if they do not have children. There will be pressure within the family for them to either have children or to be replaced by another wife or girlfriend who can produce offspring. The dilemma experienced by HIV-positive women is illustrated in the following statements:

- "If you are married, they give you one year, and if you do not have a baby you would have to divorce" (Respondent 27).

- “If you cannot have a baby, they take you back to your family, and they take another woman” (Respondent 39).
- “Mostly in my culture they divorce you and go for another wife” (Respondent 42).
- “Because of pressure by the in-laws it will ultimately cause your husband to turn against you” (Respondent 43).

For women, it is therefore, very important to have babies to be able to keep their partners and to be considered part of the family. However, one woman reported that she would be accepted in her family if her childlessness was considered as “God’s will.”

For HIV-positive men and women having children is a cultural obligation. They perceive the community will not accept them if they do not have children of their own. This community norm is causing problems for the HIV-positive individual who is counselled not to have children because of their HIV status. It was the perception of the HIV-positive men that they will be disrespected for not having children and consequently, that they will be excluded from decision-making within their communities. The men expressed themselves as follows:

- “You are not a father... you are not called BABA” (Respondent 20).
- “They will laugh at you... they will tease you” (Respondent 45).
- “The others they will not respect you because you are not a real man because you do not have children” (Respondent 50).

In much the same way as HIV-positive men, most HIV-positive women described the impact of being disregarded, disrespected and excluded from community life as follows:

- “If you do not have children, they do not understand” (Respondent 10).
- “If you do not have a baby you are nothing” (Respondent 25).
- “It is totally unacceptable if you cannot have a baby” (Respondent 14).
- “They call them names and it is very painful” (Respondent 34).
- “Your value as a woman is determined by your ability to have children” (Respondent 43).

4.2.3 Category: Cultural norms and personal fears

This category was abstracted from codes emerging from the cultural norms and personal fears of HIV-positive participants. All three HIV-positive groups perceived their communities to be unsupportive of people living with HIV having more babies. All participants similarly reported to be very scared of transmitting the virus to a child. A conflict between life and death was experienced by all participants as they were intensely aware of the consequence of their HIV status. Figure 4.5 shows how the study groups compare regarding *conflict between cultural norms and personal fear of HIV transmission*.

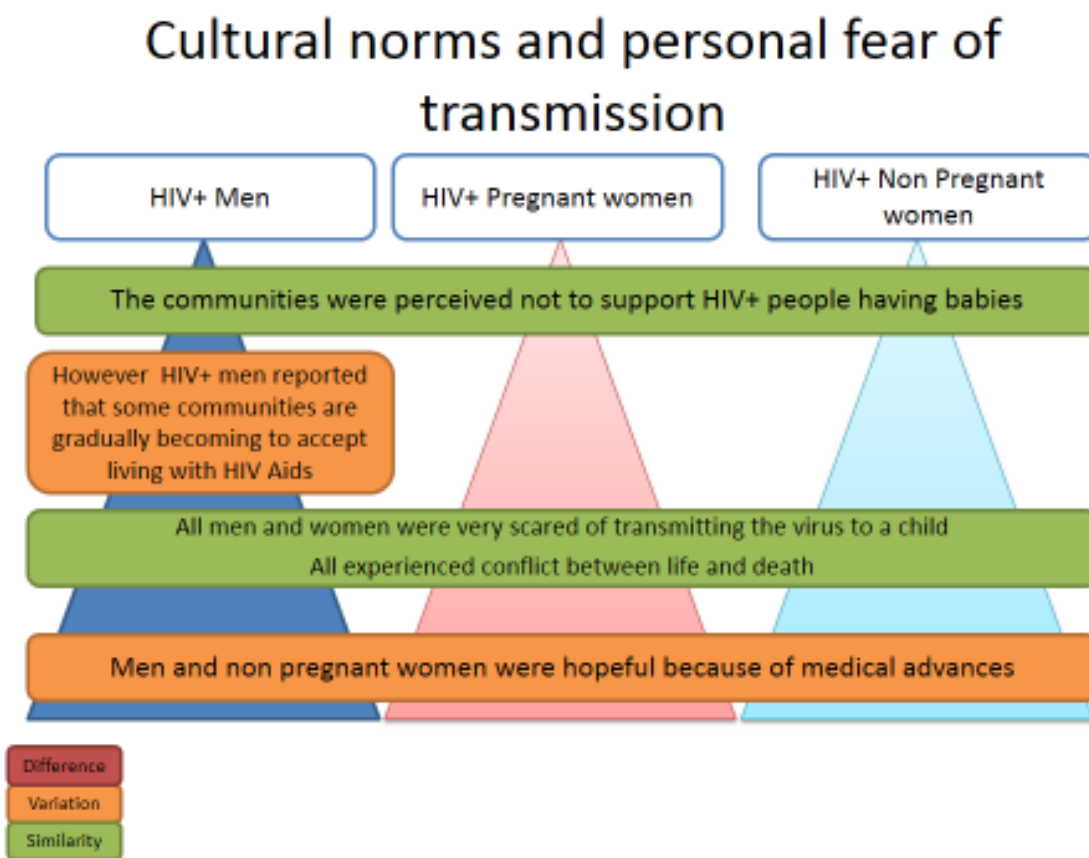


Figure 4.5: Cultural norms and personal fear of transmission

Researcher's interpretation:

HIV-positive men and non-pregnant women did not take part in prevention programs, while HIV-positive pregnant women all took part in PMTCT programs to protect their babies. The HIV-positive men and women perceived their communities not to support people living with HIV to have babies. The stigma is accentuated when a person has a child who is HIV-infected. This contributes to the conflict between life and death. If

the baby is healthy, they need not to disclose their status, but if the baby is HIV-infected, their status is automatically disclosed. They will suffer the double rejection of both their own HIV status and that of their babies.

Women expressed that they will much rather live as if not HIV-positive in order to be accepted. This perception of both HIV-positive men and women were aptly verbalised as:

- “They reject us; you are not the same as them... they think your baby is bad luck” (Respondent 21).
- “They do not like you because you are spreading the disease” (Respondent 50).
- “In my culture they will stay away from me... they think it is bad” (Respondent 11).
- “You are sick and you are dying, and you are better left alone” (Respondent 14).
- “They say it is bad, and once they know your status, they do not come into your house because they are scared that you might infect them” (Respondent 42).
- “If you want a child even if you know you are HIV-positive; you will not disclose it” (Respondent 43).

Interestingly some HIV-positive men reported that their communities were gradually becoming to accept living with HIV AIDS as illustrated from the following quote:

- “Before they thought it is bad people who have the disease, but now they do understand” (Respondent 22).

However, there were some HIV-positive men and women whom were hopeful because of medical advances and the chance that a baby might test HIV negative and have put their trust in medicine. Their hopes were expressed as:

- “If you got the condition... to get the child negative, I like that... it gives me hope” (Respondent 50).

- “I take my medicine, I told myself I was going to take my time, and I am going to live my life” (Respondent 35).

There were a few HIV-positive pregnant women who reported that the baby was planned and came at a good time. These women motivated their pregnancies because of the loss of a previous child or a marriage proposal that requires proof of fertility or a serious desire to have a baby. However, to some women, the baby was seen as a mistake because of her HIV status, the partner did not want to use condoms, or she was still at school. Many of the HIV-positive pregnant women did not disclose their HIV status to their partners and did not protect the partners from HIV, because they were scared of losing the relationship.

Conflicting messages are being sent to PLWHA. The community wants all men and women to have children to be accepted by the community. If, however, they are HIV-positive, they should not have children, because they will be rejected if the baby is not healthy. This conflicting message creates a double bind within PLWHA. It adds to the stigma that they are already experiencing. It is important that this double bind, which affects women most, should be taken into account in HIV family planning counselling. Currently, family planning for HIV-positive individuals consists of telling them not to have any more babies instead of counselling them on HIV risk reducing interventions that include safe future reproductive options.

4.2.4 Category: Influence of the significant other

This category was abstracted from codes pertaining to the influence of the significant other in terms of reproductive decision-making as well as the effect of HIV/AIDS on the sexual relationship with the significant other. Most HIV-positive participants in the groups agreed that their partners (their significant other) would want another baby. All HIV-positive men reported that they disclosed their HIV status to their partners and that their partners pressured them to have another baby. All men had supportive relationships compared to very few of the HIV-positive women. Many of the HIV-positive women did not disclose their status. Figure 4.6 shows how the study groups compare regarding *the influence of the significant other*.

Influence of the significant other

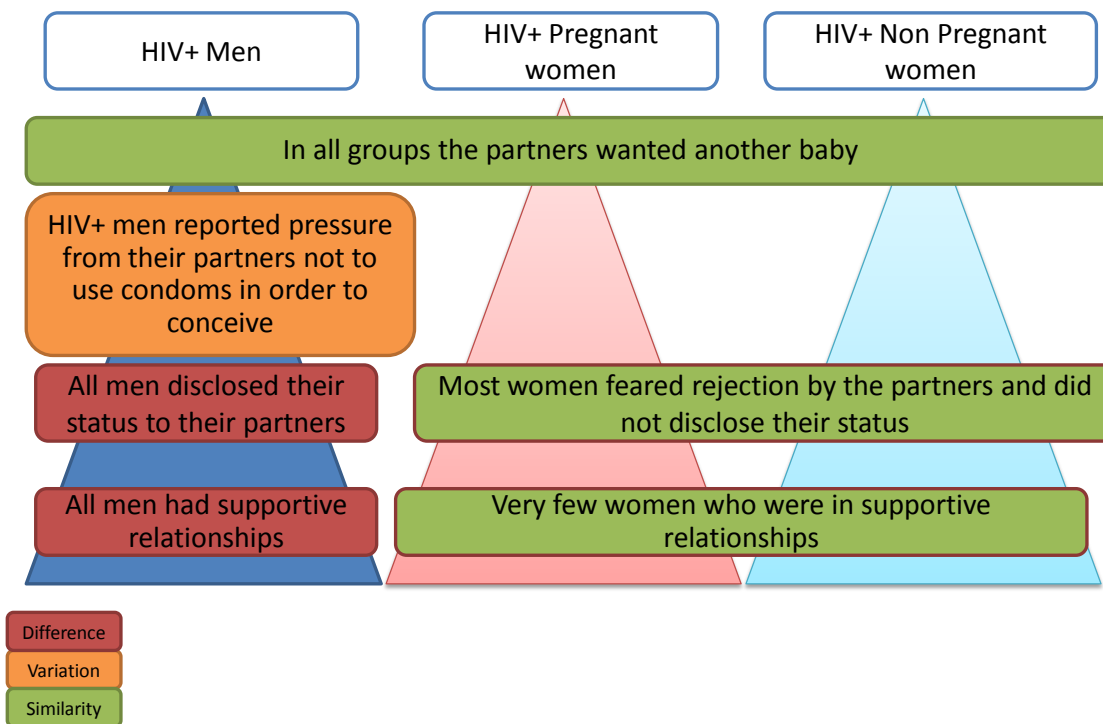


Figure 4.6: Influence of the significant other

In terms of the effect of HIV/AIDS on their sexual relationships with the significant other, most HIV-positive men and women had a similar response. They all became scared of having sexual relationships. Figure 4.7 shows how the study groups compare regarding *influences of HIV diagnoses on sexual relationships with their significant other*.

Influences of HIV diagnosis on sexual life

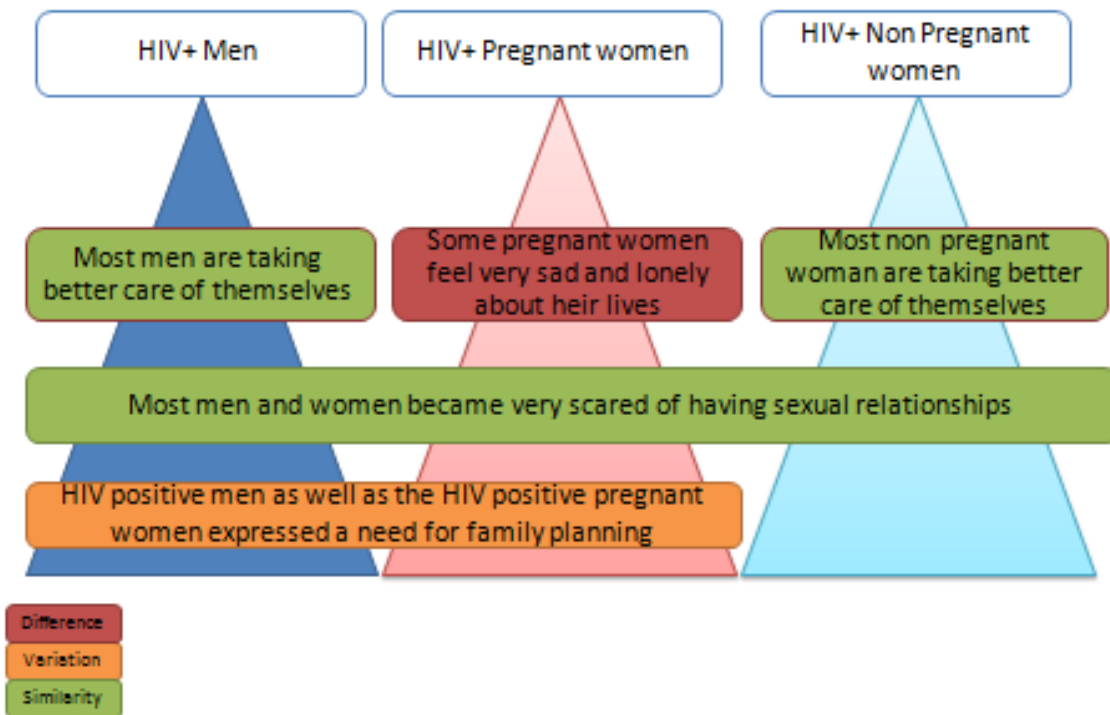


Figure 4.7: The influences of HIV diagnosis on sexual life

Researcher's interpretation:

Most of the HIV-positive men and pregnant women reported that their partners still very much wanted to have another baby, while only some of the non-pregnant women's partners wanted more babies. Some HIV-positive men are even pressured by their partners not to use condoms in order for them to conceive, despite the risk of HIV transmission. All HIV-positive men reported that they had disclosed their status to their partners, while only a few HIV-positive pregnant women disclosed their HIV status to their partners, for fear of rejection. In contrast to the HIV-positive men, most HIV-positive women feared rejection by their partners because of their HIV-positive status and have not disclosed their status.

This is illustrated in the following quotes of both men and women:

- "My wife was very helpful she knew of these things before I did" (Male respondent; no 22).

- “For now I am not going to tell him... the relationship is not so strong” (Female respondent; no 10).
- “It makes it better for me if there is a healthy baby” (Female respondent; no 27).

Only some HIV-positive women have supportive relationships, while most of the others are very sad and unsure about their futures. Most HIV-positive men had supportive relationships despite their HIV status. Gender issues caused women to be in an unsure position as they feared rejection if their status became known. They, therefore, had to follow the rules of the culture in order to gain acceptance in the community. Consequently, some women live as if not HIV-positive in order to avoid the HIV stigma contributing to the conflict mentioned earlier in section 4.2.3.

Most of the HIV-positive men and non-pregnant women reported to take better care of themselves in terms of diet, exercise and taking medication as they valued life more after the HIV diagnosis. However, they were worried about dying and the men were especially worried about another man “taking his family”. In contrast, most HIV-positive pregnant women reported they felt very sad and lonely about their lives as most of them were rejected by their partners. They were sad about their futures as they were without support and felt the additional burden of having to raise the baby by themselves. Only some women who were in supportive relationships had a positive outlook on life.

Although HIV-positive men are supported by their partners, most men reported that their sexual relationship became very strained and difficult since their HIV diagnosis. Life had become difficult as they felt the disease was holding them back, and they were scared to engage in sexual activities with a woman in a spontaneous way. Similarly most HIV-positive women became very scared about having sexual relationships. Some women were even lying to their partners about having to use condoms as their partners were not willing to use condoms. A few women who were in supportive relationships and who had disclosed their status to their partners felt safe using condoms.

4.3 AXIAL CODING: FOCUS GROUP DISCUSSIONS

Emerging codes obtained from coding both the ANC and the VCT clinic counsellors’ focus group discussion data, were compared between and within each group in terms

of differences, subtle variations and similarities on each of the aspects explored. This was done to be able to learn how reality was understood by the HIV counsellors as well as how they as individuals are collectively influenced by the unobservable structures and processes of their communities. As in the case of the individual interviews, the differences, similarities and subtle variations that were found during the focus group discussions were interpreted by the researcher based upon the principles of the critical realist paradigm. The effects of the abovementioned comparisons within the HIV counsellor group are described as categories and visually portrayed in the same way as for the HIV-positive men and women:

4.3.1 Category: Counsellors' perception

This category was abstracted from codes pertaining to the perceptions of the HIV counsellors regarding the reproductive needs of the clients. All HIV counsellors at both the ANC and the VCT clinic similarly agreed that they perceived reproductive needs in their HIV-positive clients. Figure 4.8 shows how the counsellor groups compare regarding *their perception of their HIV client's reproductive needs*.

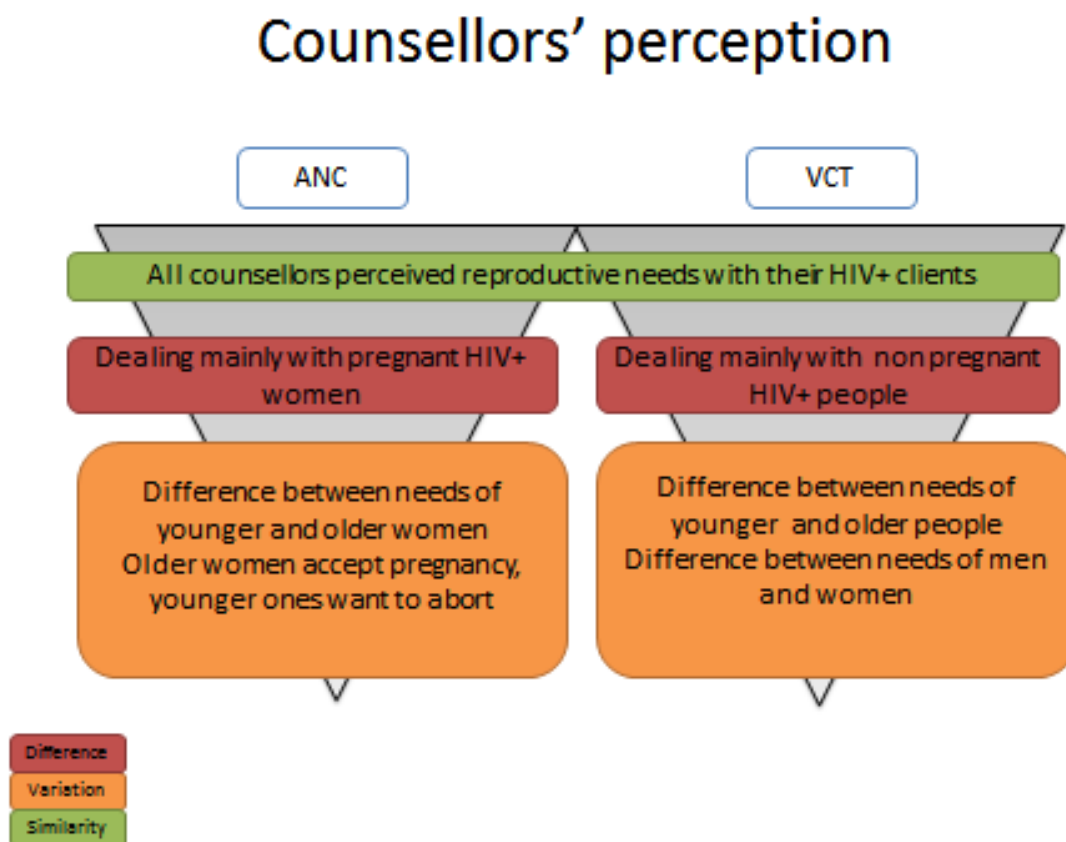


Figure 4.8: HIV Counsellors' perception

Researcher's interpretation:

The counsellors observed that most of the HIV-positive clients expressed their reproductive needs in terms of having another baby. They wanted to have a baby for various reasons: before they become sick, or having a healthy baby who will be proof of their own good health. Some women believed they can have a healthy baby because they previously had a healthy baby. Many HIV-positive people asked about surrogacy, and the counsellors reported on the urgency of their perceived reproductive needs as:

- “They will go so far as to inseminate the wife’s sister so that the husband can have his own biological offspring” (the VCT clinic counsellor).

The ANC counsellors observed that older HIV-positive pregnant women accepted the pregnancy while the younger pregnant women did not want to be parents and wanted to abort the baby. In contrast, counsellors at the VCT clinic reported young people and people without children wanted to know what they can do to be able to have children in the future. Parenthood is still very important to them in terms of their culture, their inheritance and for their relationship regardless of their HIV status. Older people are more concerned about how long they are going to live and about the upbringing of their children. This indicates that young people (men and women) and people without children might be more at risk of transmission of the HI virus to their partners and their future children in an attempt to realise their parenting needs. Counsellors at the VCT clinic also experienced HIV-positive men to have different needs compared to the women who regularly attended the clinics.

4.3.2 Category: Counsellors' knowledge regarding RRI and FP

This category was abstracted from codes pertaining to the attitudes, the knowledge and the training needs of the HIV counsellors regarding risk reducing interventions and future family planning. The HIV counsellors at the ANC had negative attitudes towards their client's reproductive needs compared to HIV counsellors at the VCT clinic. Figure 4.9 shows how the counsellor groups compare regarding *their attitudes towards their HIV-positive client's reproductive needs*.

Counsellor's attitudes

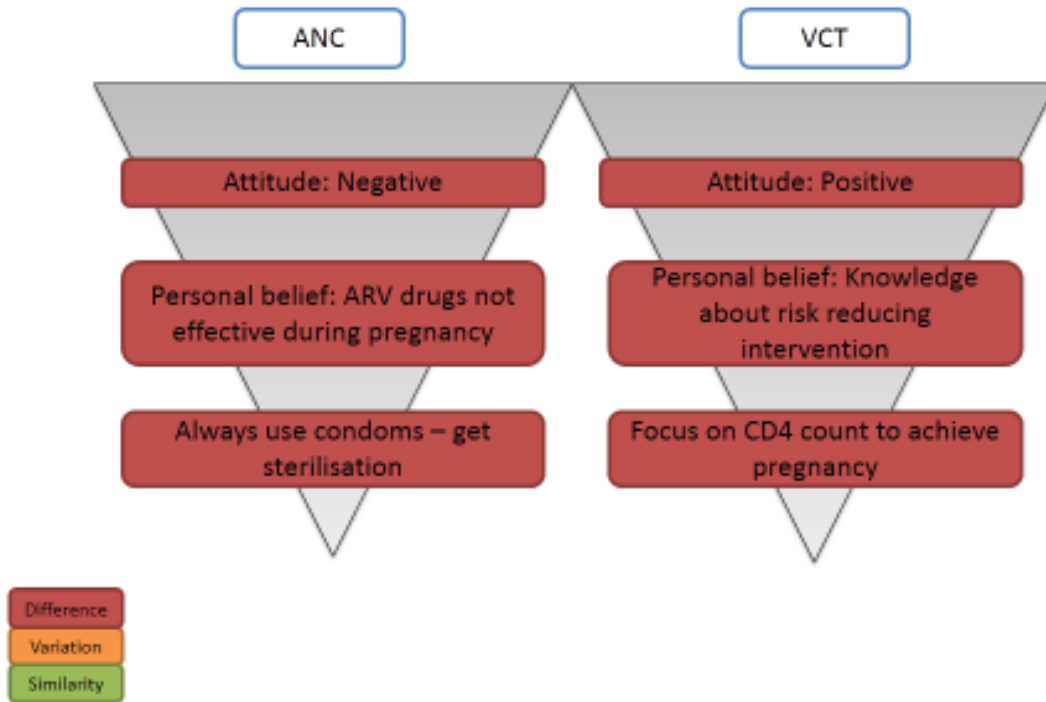


Figure 4.9: HIV Counsellors' attitudes

None of the HIV counsellors at the ANC had any knowledge about risk reducing intervention compared to some HIV counsellors at the VCT clinic. Figure 4.10 shows how the counsellor groups compare regarding *knowledge about risk reducing intervention*.

Counsellor's knowledge

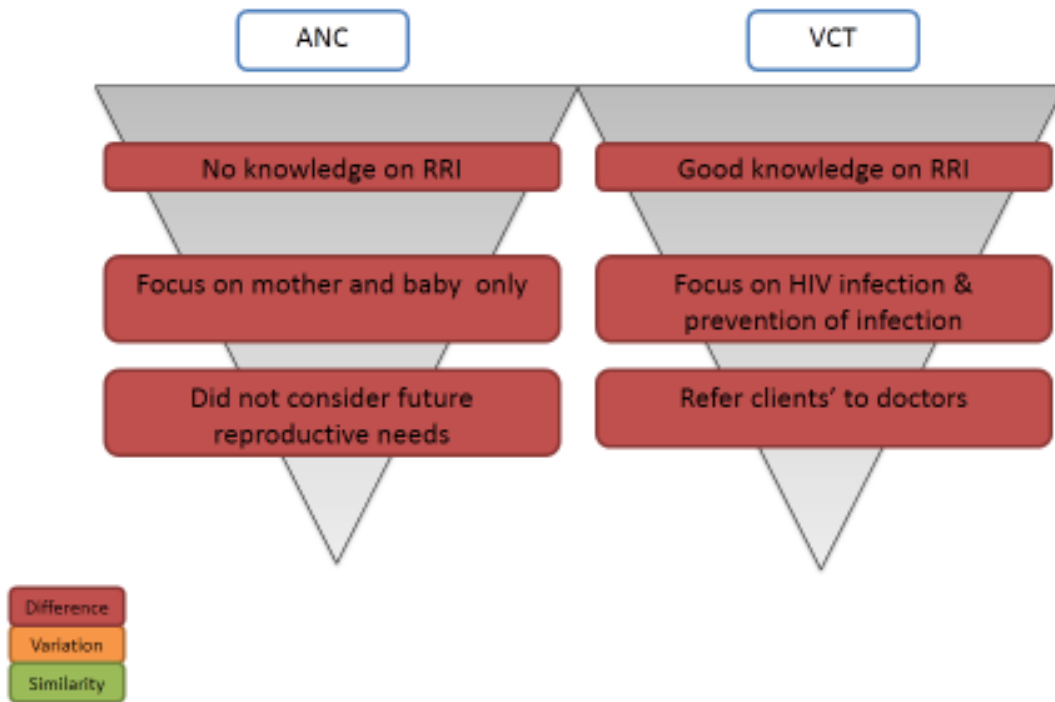


Figure 4.10: HIV Counsellors' knowledge

Researcher's interpretation:

The HIV counsellors at the ANC reported that they were dealing with already pregnant women and felt that they were doing their best in helping them. The researcher got the impression that they felt inundated by the numbers of HIV-positive pregnant women who continuously present at the clinic. The HIV counsellors might feel that the women are not paying attention to the importance of what is conveyed to them during the counselling sessions. They became cross at HIV-positive clients who act irresponsibly and continue to expose their partners and children to the HI virus. Consequently, they strictly advised their clients always to use condoms and to get a sterilisation to avoid getting pregnant again.

Contrastingly, the HIV counsellors at the VCT clinic mostly had positive attitudes towards their HIV-positive client's reproductive needs because one counsellor had first-hand knowledge and experience of HIV risk reducing interventions. He and his wife took part in sperm washing procedures in trying to achieve a pregnancy in a safe way. Some counsellors were conscious of the rise in HIV orphan numbers; however,

they still advised their clients to focus on their CD4 count in an attempt to conceive naturally due to the high cost of treatment procedures.

Having no knowledge on risk reducing interventions to have a baby in a safe way the HIV counsellors at the ANC primarily focused on the health of the baby and the mother. They did not realise that their client’s future reproductive needs are not considered at the time, as they deal with already pregnant women. In sharp contrast to the above, the HIV counsellors at the VCT clinic had some knowledge on HIV risk reducing interventions. The counsellors at the VCT clinic focused on HIV infection and prevention of infection and therefore, referred their clients to either Steve Biko hospital or the doctors at the VCT clinic if the clients were planning to have a baby. A counsellor at the VCT clinic is quoted as follows:

- “I explain to them that there is a way that a doctor can assist them to have a baby” (the VCT clinic counsellor).

All HIV counsellors expressed a great need for more training. Figure 4.11 shows how the counsellor groups compare regarding *their training needs*.

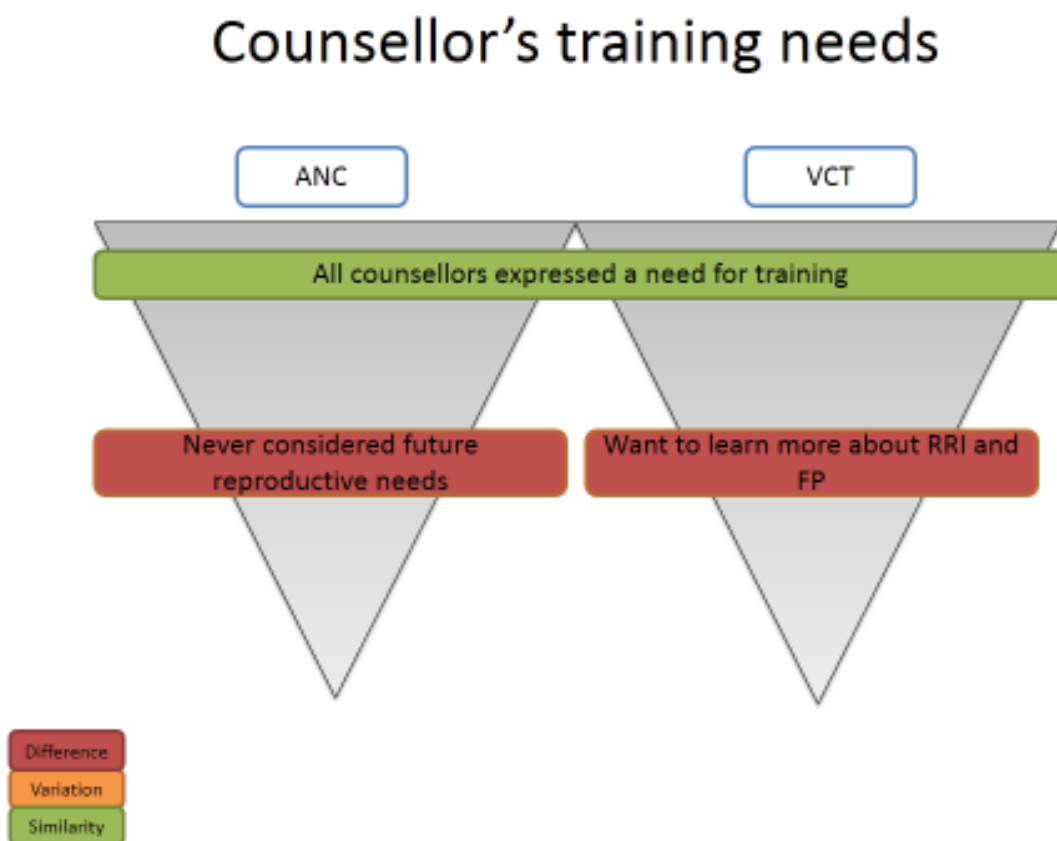


Figure 4.11: HIV Counsellors’ training needs

A great need for training and more information regarding HIV risk reducing interventions and family planning were expressed by all HIV counsellors. The researcher found a marked difference between counsellors at the respective clinics in that the HIV-positive client's future reproductive needs were not recognised at the ANC, while some counsellors at the VCT clinic acknowledged the need for safe future reproduction. This can be demonstrated by the following quotes:

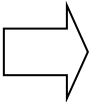
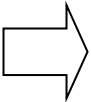
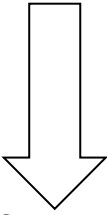
- “I think we need lots of information... we are dealing with people who are already pregnant” (counsellor at the ANC).
- “We never thought about it, we never sat down and actually tell them about their future, especially these younger ones...18 years, it is possible that she can have more children” (counsellor at the ANC).

However, some counsellors were very concerned about the quality of training and complained about nursing staff having the opportunity to attend training sessions with possible loss of information during consequent feedback sessions by the nursing staff to the counsellors.

4.4 SELECTIVE CODING

Interpreting the categories and themes that were created through comparison of the various similarities, differences and variations between and within the study groups, lead to *writing the story* concerning the reproductive needs of men and women who are living with HIV/AIDS and the implication it has for family planning counselling. The researcher, therefore, interpreted and organised the data obtained from open and axial coding around one or more integrated themes. These themes ultimately lead to new insights into the data. Strauss and Corbin (1990) explained the conceptualisation of a descriptive story about the central phenomenon under study as the commitment to *write a story* integrating all the emerging themes. In *writing the story* the researcher conceptually interacted with the data and integrated the various categories and themes into a core category. Table 4.1 depicts the abstraction of the core category from the initial categories.

Table 4.1: Initial codes, main categories and main themes

Open Coding Chapter 3 Codes	Axial coding Chapter 4 Main categories	Selective Coding Chapter 4 Main themes
Background information Value of having children Effect of not having children Cultural acceptance/rejection Involvement in prevention programmes Effect of HIV on life and relationships Awareness of risk reduction Counsellor's perception of child desire Counsellor's feelings about reproduction Reproductive counselling provided Counsellor's training needs	 Knowledge on living with HIV Meaning of parenthood Cultural norms and personal fears/desires Influence of the significant other Counsellor's perceptions Counsellor's knowledge on RRI/FP	 Gender identity issues within the family and community Gender inequality in procreation Community stigmatisation of HIV resulting in different procreation rules for HIV-positive individuals Lack of information, training and counselling regarding safe future family planning  Core category Section 4.5

The following will be an attempt by the researcher to *tell the story* based on insights gained by conducting research into the reproductive needs of men and women living with HIV/AIDS and the implications of such needs to HIV family planning counselling:

Spurred on by statistics, the risk of HIV transmission to partners and infants as well as stigmatisation, people in the South African population do not hesitate to ask “Why is

the pregnancy rate so high among HIV-positive people despite the risk of HIV transmission?” As a result the focus of the research was on PLWHA within their reproductive years at two critical junctures: firstly, when patients are diagnosed as HIV-positive and secondly when HIV-positive women are pregnant or having just delivered a baby.

Although fully aware of the dire consequences of their HIV-positive status on the quality of their lives, the meaning of parenthood remained both personally and culturally very important to most participants. Parenthood was important to them in terms of their future support as well as to establish their gender identities within their families and communities. Regardless of the fact that some HIV-positive women described their pregnancies as a mistake due to their HIV status, all participants viewed parenthood as giving them an identity either as a man or a woman to be respected within their cultures. In general, women without children were disrespected in the community and could be abandoned by their partners. They were referred to as “the prostitutes living by themselves” – (Gender identity).

The effect of not having children was described by all participants as painful, because of the loss of support within their communities and with regards to their future support. On a cultural level, both HIV-positive men and women can be disregarded for not having any children, and consequently, they can be excluded from family or community life. However, comparing the influence of not having children on their position in the family, women suffer most. The family often put pressure on the man to either divorce her or to take a second wife to be able to have children. Childless women thus lose their families and their financial support while the culture provides alternatives for men to realise their parenting needs. Women thus experience an urgency to have children in order to maintain their relationships and their status within the community – (Gender inequality; community stigmatization of HIV resulting in different procreation rules for HIV-positive individuals).

Most of the participants experienced their communities to be stigmatising towards people living with HIV. This complicates disclosure of HIV status. Women would not disclose their status in fear of being rejected by their partners or families. Communities are generally not supportive of HIV-positive people having babies. This is a cause of internal conflict of especially women as they have to have children to be accepted, but they may not have children if they are HIV-positive. Women thus have

to choose which of the norms to obey, to be accepted. Ultimately, a double bind is created for people with HIV, which strengthens the effect of the stigma already in the community.

The effect is that women do not disclose their status and have babies to be accepted. The problem is that they place their partners at risk of HIV-infection. The fear of transmitting the virus to their children is very real to all participants. A healthy baby would implicate that a woman does not have to disclose her status. If the baby is HIV-infected, it means that she will have to disclose her status and carry the blame for both infections. A healthy baby is thus crucial for an HIV-positive mother. Men reported fear about some other men who will take over their families once they themselves have died and worried about the well-being of their children. Some participants were putting their trust and hope in medicine and medical interventions – (Community stigmatisation resulting from conflicting rules).

The partners of most participants wanted another baby. However, compared to all the male participants who reported being in supportive relationships, only some of the female participants disclosed their HIV status to their partners for fear of rejection. A few women reported that they were in supportive relationships, while others were rejected by their partners for being HIV-positive, whether she was the one bringing HIV into the relationship or not – (Gender inequality).

Although most participants reported that they were taking better care of themselves in terms of their diet and exercise, some of the HIV-positive pregnant women were very sad and did not have a positive outlook on life. These women did not welcome their pregnancies because of their HIV status and felt the burden of being deserted by their partners. The counsellors at the ANC strongly advise HIV-positive pregnant women not to have any more babies in the future. The negative attitudes of counsellors towards pregnant HIV-positive women could also have contributed towards the negative feelings expressed by these women. All participants reported that they became hesitant to be sexually active after the diagnosis, because they understood the risk and consequences of HIV transmission. Some women were lying to their partners about having to use condoms as the partners were not willing to co-operate. Most women feared rejection by their partners upon disclosure of their positive HIV status – (Gender inequality).

Counselling services was reported by all HIV-positive participants as very supportive and helpful in becoming strong; however, a definite need was expressed in terms of information regarding safe future pregnancies and family planning. Very few participants had any knowledge of risk reducing interventions, apart from one man who had read about it on the Internet and some women who had heard about it on television soap operas. Most participants wanted services to be improved to help PLWHA to become parents in a safe way; however some of the female participants who were unhappy and unsure about their futures were not interested at all. Except for one male participant who took part in a sperm wash research study, most participants did not know where to apply for help regarding RRI and FP. Only some participants would contact the doctor in the clinic for help – (Information/education needs).

The HIV counsellors spontaneously took part in the discussions and freely gave their opinions within the group. As only pregnant women attended the ANC clinic and both male and female clients presented at the VCT clinic, the responses of the HIV counsellors were analysed and reported separately. Counsellors are doing their best to help their HIV-positive clients to adopt a positive lifestyle with strong emphasis on the use of condoms and not having any more babies. However, due to a lack in knowledge about risk- reducing therapy and family planning (RRI and FP), there is a difference in attitudes among the counsellors towards their HIV-positive clients' reproductive needs.

Counsellors at the VCT clinic refer their clients to the doctor in the clinic, should they have a need for future babies, whereas counsellors at the ANC strongly advise their HIV-positive clients, who are only pregnant women, not to have any more babies in future or to abort. Counsellors at the VCT clinic confirmed the fact that men have different counselling needs compared to women and that these needs should be addressed in a proper way. All counsellors expressed a need for more information on HIV risk reducing interventions and family planning as their focus does not necessarily include the reproductive futures of their clients – (Difference in attitudes; need for information; gender issues).

It came to the researcher's attention that the HIV counsellors did not all get the same training. This could account for the difference in their attitudes towards the reproductive needs of people living with HIV. The HIV counsellors were of the opinion

that some of them, for example, were considered part of the mainstream at the departments where they served and thus got invited to staff meetings and training opportunities, whereas counsellors based at remote clinics were rarely invited to these meetings. Consequently, they perceived the training they got as second or third hand. In some instances nurses who attended the training sessions, came back and showed the counsellors “how it is supposed to happen” – (Training needs).

By *writing the story* the researcher used description to put her thoughts on paper (Strauss & Corbin, 1990). The story provided the researcher with a glimpse of how people living with HIV and the HIV counsellors interpreted their realities, what their reported perceptions and world views are as well as what the consequences are for their behaviours and for those with whom they interact. However, moving beyond description to conceptualisation, *the story* now has to be told analytically. A possible answer to “why the pregnancy rate is high among HIV-positive people despite the risk of HIV transmission” becomes clear in the next section describing the core category.

4.5 THE CORE CATEGORY

The core category is defined by Strauss and Corbin (1990) as being that one category from your list of categories that is abstract enough to encompass all that has been described in the above story. The main categories resulting from the axial and selective coding processes were therefore conceptually integrated during writing the storyline which in turn led to the emergence of the core category. The core category for this study is as follows:

In order to establish their gender identities, HIV-positive men and women, within their reproductive years, choose to obey the rules of the societies in which they live by actively trying to negate the rules and stigma surrounding HIV.

4.6 CONCLUSION

The processes of axial and selective coding helped the researcher to *write the story* describing the reproductive needs of men and women living with HIV/AIDS, including the implications to family planning counselling. In moving from concrete description to conceptualisation of the story that was told, the recurring themes that emerged were:

- Gender identity issues within the family and community;

- gender inequality in procreation;
- community stigmatisation of HIV resulting in different procreation rules for HIV-positive individuals and
- a lack of information, training and counselling regarding safe future family planning.

These themes will be further explicated in Chapter 5 based on current literature in an attempt to formulate a substantive theory (Chapter 6) describing the implications of the phenomenon studied.

CHAPTER 5

INTEGRATING THE LITERATURE AND RESULTS

“still sure and sound...”

5.1 INTRODUCTION

Integrating the literature and results of the study pertaining to the reproductive needs of PLWHA will be an attempt to compare and validate the main themes obtained from the final phase of grounded theory analysis. This is necessary to facilitate the conceptualisation of the phenomenon under study culminating into the substantive theory. The following main themes emerging from the study contributed to a better understanding of the reproductive needs of people living with HIV:

- Gender identity within the family and community;
- Gender inequality in procreation;
- Community stigmatisation of HIV resulting in different procreation rules for HIV-positive individuals and
- Lack of information, training and counselling regarding safe family planning.

5.2 UNDERSTANDING THE REPRODUCTIVE NEEDS OF PLWHA

The researcher carefully explored the reproductive needs of PLWHA in an effort to understand the high incidence of pregnancy regardless of their HIV positive status. Individual interviews were conducted to explore details of individual experiences, choices and issues of particular sensitivity. Sensitive individual interviews were less likely to induce anxiety. In this way the researcher attempted to discover the following underlying unobserved motivating factors that could be involved during the reproductive-decision making processes of PLWHA:

5.2.1 Gender identity within the family and community

The need for men and women of reproductive age, living with HIV/AIDS, to establish their gender identities within their communities was both confirmed and emphasised by the findings of this study as well as by literature. The literature study revealed identity crises issues concerning:

- the identity of the person living with HIV;

- the masculine identity as well as
- the often yearned for identity of motherhood.

Long (2009) recounted that HIV-infected individuals were previously given the identity of the dying person, being diagnosed with a terminal illness. Many of their activities were associated with HIV/AIDS and dying. This changed the past few years when HAART contributed to HIV becoming a chronic disease. PLWHA now had to adapt their identities to that of people living with a chronic illness. In the process of change, PLWHA expressed a desire to move away from the central identity of being HIV-positive and to focus more on living and the future. That contributed to a renewed interest in procreation, which is a natural desire for individuals in the reproductive age group. Both the masculine and feminine identities became important for different reasons (Long, 2009).

According to the literature, the normative masculine identity can generally be described as the socialisation of men to be self-reliant, sexually dominant, to have multiple sex partners and to be omniscient about sex. Men and boys who do not fit these norms in maintaining a masculine identity may be stigmatised in some societies (Long, 2009). Paiva et al. (2003) stated that the desire to have children is central to the construction of a masculine identity. According to Bell, Mthembu, O'Sullivan and Moody (2007), men are generally expected to be self-reliant and invincible. It is the perception in communities that men do not feel vulnerable to HIV infection or see any value in finding out more about HIV and sexuality. Due to cultural or community pressures to express masculinity, it is expected of men in general to adhere to a sexual behaviour code that may include multiple sex partners, sexual prowess and sometimes even some form of violence.

However, the above construction of normative masculine identity is severely affected by HIV in positioning HIV-positive men as “helpless and dependent on others” (Lynch, Brouard & Visser, 2010, p.22). The HIV-positive men taking part in the current study were all eager to learn about having a baby in a safe way, managing the disease, informing their children, nurturing a healthy relationship after knowing their partner's status and planning their reproductive futures. The HIV-positive men taking part in this study therefore demonstrated a need for more information and were motivated to make an effort to minimize the transmission risk of HIV/AIDS. These men were also examples of a transformed masculinity where they reflected on the harmful

consequences of their risk-taking behaviour in attaining normative masculinity (Lynch et al., 2010). As further proof of a transformed masculinity, the HIV-positive men in this study declared that they wanted to warn other men about the dangers of jeopardising their health in contracting HIV through risky behaviour in attaining a masculine identity. The transformed masculinity makes it possible for men to protect their partners and children from infection (Lynch et al., 2010).

The term fatherhood means more than contributing half the child's genetic material. Datta (2007) describes fatherhood as being a more complex term embracing a broad range of parenting functions. Men are often seen as providers and disciplinarians or as absent fathers without responsibility. In explaining that fatherhood in South Africa is a social role and not simply a matter of biology, Richter and Morrell (2006) use the term "baba" to demonstrate a certain relationship between an older man fulfilling a role of care, protection and/or provision in relation to children. Fatherhood is seen by young middle-class black men as the key to being a man and thus critical for the construction of masculinity (Datta, 2007). In the current study, the importance of fatherhood was emphasised by most of the HIV-positive male participants when reflecting on life without children in saying, "*There is no one to call you Baba.*"

Biological fathering is a vital marker to male virility and masculinity. This fact was emphasized by Taylor, Mantell, Nywagi, Cishe and Cooper (2013) reporting that a biological connection with their children was important to a group of HIV-positive Xhosa-speaking men who rejected non-biological approaches to safer-conception such as donor insemination and adoption. The importance of biological fathering was further emphasised by the results of the current research study, where the HIV counsellors reported the accepted cultural or community norm that a man was offered his infertile wife's younger sister in order to test his fertility. HIV counsellors should therefore take note of the various different social and cultural beliefs related to certain risk reducing interventions, like donor insemination, that might negatively impact on the need PLWHA have regarding a biological connection to their children.

Fatherhood presupposes an ability to provide financially for the needs of children and families. Inability to do so may cause men to retreat from responsibilities. Datta (2007) contended that having children contributes to the important patrilineal process whereby men move through the series of developmental statuses from son, father to grandfather as well as from child to adult to old man. Fatherhood is also socially

constructed by women and children and in relation to what fathers and mothers do. Being a parent means different things to men and women. The social reconstruction of fatherhood holds the potential to foster and bolster gender equality in family matters.

HIV/AIDS demand the redefining of fatherhood. In some cases, fathers have to take responsibility for caring for the sick and dying. They thus have to become the caretakers in the family. Failure to do so has serious repercussions, in that children who have lost their mothers to HIV/AIDS often lose their fathers as well. They are then sent to live with other relatives (Datta, 2007). The importance of the social reconstruction of fatherhood is accentuated by the work of Buseh et al. (2010). They stated that traditionally women are seen as “caretakers of the whole family and if a woman dies, it means that the family is already destroyed” (p. 177). The HIV-positive men in the current study were worried that their children will be raised by other people when they themselves die. The researcher interpreted this alternative view on fatherhood as a community expectation that could be the underlying pressure necessary for social reconstruction of the fatherhood concept.

Conversely, motherhood is described by Long (2009) as one of the many childhood fantasies that actually come true. The identity of motherhood is seen as the ultimate act of creativity in which life is given from the association of chastity rather than sexuality. The idealised identity of motherhood is therefore associated with goodness and purity and is expressed when a good mother breastfeeds. There is, however, a problem with the idealisation of motherhood in that it sets an impossible standard against which women are expected to measure themselves (Long, 2009). Mothers are often not able to live up to this ideal, as motherhood is constructed as universally valued but only as long as the mother fits the normative stereotypes.

Motherhood is important for black women in terms of the value placed on fertility, and the relative power that motherhood offers these women (Long, 2009). African motherhood is therefore idealised and holds consequences for women who do not have children. These women are seen as deviating from what is considered by the community as normal behaviour for women. “Defiant mothers” are those who are too young, too old, in unstable relationships, have chosen an inappropriate partner or being HIV infected (Long, 2009). The word mother is therefore, both a compliment as well as a description in the dominant cultural construction; mothers are “real” women.

Childless women may be described as bad women, whether their childlessness is voluntary or caused by infertility. The HIV-positive women taking part in this study stated that women without children are marginalised in their communities and seen as “*prostitutes living by themselves*”.

However, many of the pregnant HIV-positive women from this study expressed sadness about having new life growing inside them whilst being HIV positive. They feel sad about being confronted with both life and death. Most of them were not in supportive relationships, and they did not have positive future expectations. In studying the experiences of being given both death and life sentences at once; being pregnant and being HIV positive at the very same moment, Long (2009) contends that the emotions associated with hearing one is pregnant now varies from being excited to being scared and devastated.

Motherhood and HIV are both created in a moment of intimate sexual contact; however, motherhood is associated with chastity rather than sexuality where HIV is a metaphor for aberrant sexuality. However, having children was important to most HIV-positive women from this study in order to secure future support in terms of their relationships with partners; from their children during old age as well as acceptance into the community. The participants in this study were scared to be alone and without the support of their children during old-age and feared that they will not survive in life without offspring.

The emphasises on the need for women to retain their relationships at all costs was further evident in this study from the fact that all the HIV-positive men were in supportive relationships and reported pressure from their female partners to continue to have babies. In the current study, the researcher inferred the importance of the HIV-positive women’s need to be regarded as “real” women. This need was confirmed by the fact that, although the men disclosed their HIV-positive status to their female partners, it did not deter these women from wanting to have more babies, even though some of them were indeed HIV-negative.

5.2.2 Gender inequality in procreation

Unequal gender power relations are often ignored by the community in social and cultural aspects of reproductive behaviour. The man has much power and support from the wives’ family, and this leaves the women with little power. Buseh et al. (2010)

stated that gender-related issues that are entrenched into cultural traditions form a major factor in advancing the spread of HIV/AIDS in Africa. Having multiple partners is interpreted by men as being rich and having an elevated status in the community. This practice may not have positive consequences for women. If a man pays “*lobola*” (brides’ price) for a woman, it is the perception of women that they do not have negotiating power within their relationships with men. A male-dominant-decision-making society where women have no or little power in sexual relationships is described in the research of Gogna, Pecheny, Ibarlucia, Manzelli and Lopez (2009).

Buseh et al. (2010) stated that this traditional cultural norm was weakening as more women move into the city and become educated and self-supporting. However, aspects of this traditional culture are still found in the behaviour of men and women in terms of culturally defined gender roles determining what men and women are expected to know about sexual matters and how they should behave (Buseh et al., 2010). In this study gender inequality was reported by some of the HIV-positive women who experienced that they did not have a “voice” to speak about reproductive issues to the researcher without consent from their husbands.

The perception is that women are less informed about reproductive health and sex, while men are often expected to know much more. However, this assumption does not hold true as a WHO/UNAIDS (1999) investigation found men not to be prepared for the knowledge and skills required for leadership roles in discussing HIV/AIDS-related matters with partners. This corresponded with the results of the current study where some of the HIV-positive men reported their female partners supported them because the women had more knowledge about HIV than the men. Helzner and Roitstein (1995) indicated similar sexual behaviour in Western cultures. Consequently, to make matters worse “condom use cannot be suggested by a woman, because of the stereotype that she will appear loose and dirty if she does” (Helzner & Roitstein, 1995, p. 84). Most HIV-positive women taking part in this study reported not to have negotiating power in using condoms. Some women gave this as the reason for them being pregnant despite their HIV status.

In order for men and women to engage in satisfying sexual relationships, it is necessary to transform how men and women approach sex by giving women more power to take decisions about practices, partners, pleasure and procreation while at the same time engaging men in the process and not disempowering them (Bell et al.,

2007). Gogna et al. (2009) contends that uneven power relationships in sexual encounters keep affecting the ability of individuals and couples to protect themselves from sexual transmitted infections and unwanted pregnancies. Calls are made for radical shifts in attitudes towards HIV/AIDS in terms of normative definitions of gender relations between sexes and what constitutes a family. Most of the HIV-positive men in the current study requested more information on having a relationship after knowing their partners' status.

5.2.3 Community stigmatisation of HIV

Stigmatisation and discrimination are social responses to HIV/AIDS that can only be understood in terms of broader relations of power and dominance in society (Link & Phelan, 2001; Parker & Aggleton, 2003). According to Paiva et al. (2003) perceptions of those with HIV infection continue to be confined to the stereotypes of promiscuity constructed from the outset of the epidemic. The results from the current research study indicated that most communities do not support HIV-positive individuals having babies as they fear the spread of the HI virus. PLWHA taking part in this study reported that they experienced rules and stigma regarding HIV/AIDS because their communities may still think of them in terms of a dying identity (Long, 2009). They are seen as people who according to culture and tradition should not have children as the stigma attached to HIV infection does not fit the meaning wife-mother or husband-father cultural contexts. Because of stigmatisation of HIV, many PLWHA do not disclose their status (Visser, Neufeld, de Villiers, Makin & Forsyth, 2008). This enables them to live as if they were not HIV-positive. This contributes to spreading the virus.

The attitudes of health-care workers and the prescribed norms of HIV/AIDS care models can result in stigmatisation of patients and consequently, violation of their rights (Paiva et al. (2003). This was confirmed by the work of Kawale, Mindry, Stramotas, Chilikh, Phoya, Henry, Elashoff, Jansen and Hoffman (2013) in Malawi, reporting 87% of HIV-positive women in their study who either had no discussion or a discouraging discussion with a health care provider about having a baby. As reproduction was always considered a woman's affair, doctors are stunned when HIV-positive men say they want to start a family, as they are rarely seen as future fathers (Paiva et al., 2003). This was evident from the HIV-positive men taking part in this study as most of them were interested in having more children in the future. Long (2009) stated that some messages on posters used during campaigns in the

prevention of HIV/AIDS, for example “be wise condomise” focus the attention to further stigmatization by implying that being pregnant is proof of being foolish and irresponsible about sex. Slogans like this might also contribute to the HIV-positive women in this study reporting to feel disempowered and negative about their lives.

Because of the possibility of being rejected in families and communities, HIV-positive individuals often decide not to disclose their status or to disclose selectively (Visser et al., 2008). In this way, they avoid the experience of stigma. Stigmatising attitudes also result in a negative attitude towards PLWHA who want more children. This attitude might be because of the perception that people are considered irresponsible having more children, because they can infect their children or they may be sick themselves so that they cannot take care of their children (Ingram & Hutchinson, 2000). Visser et al. (2008) define disclosure of HIV status as a “process of decision-making, based on numerous factors, including psychological state, communication skills, motivation and anticipated reactions” (p.1). Non-disclosure due to fear of stigmatisation and abandonment was evident among the HIV-positive women taking part in this study. The women’s evaluation of the quality of their relationships played a role in their decision to disclose their status or not.

Community stigmatisation of HIV results in different procreation rules for HIV-positive individuals. The researcher interpreted the reproductive needs and choices of PLWHA that became clear as a result of this study as confirmation that, according to the principles of critical realism, the individual is not at the mercy of the community’s underlying rules and expectation as the individual can actively transform his or her social world and is in turn transformed by it (Houston, 2001). By implication, people have agency or the ability to decide for themselves how they want to handle or react to these unobserved underlying motivational forces. The researcher consequently concluded that although people are exposed to various underlying cultural forces or demands, only they will ultimately decide which forces they will either accept or negate in an effort to live their lives accordingly. In addition to cultural demands, HIV places its own demands on the individual. Therefore, individuals make their own decisions regarding adherence to any societal rules. Although they bear the risk and stress of double rejection should their secrets be revealed when the baby tested HIV positive, they choose to negate the rules of HIV by not disclosing their status, which enables them to live as if they are not HIV positive.

5.3 THE LACK OF RRI INFORMATION, TRAINING AND COUNSELLING

The above explanation regarding the reproductive needs of PLWHA was further holistically echoed by the responses of the HIV counsellors taking part in the study. The lack of knowledge on RRI, training and counselling demonstrated by HIV counsellors will be discussed during the following section in terms of HIV counsellor training as well as having access to services.

5.3.1 HIV counsellor training

The emerging theme of the HIV counsellor's need for training in this study confirmed the statement of Helzner and Roitstein (1995) that the training of counselling staff is seen as a strategy for change. The need for continued counsellor training is further emphasised by Nulty and Edwards (2005). Although the Lay Counsellor Project was set up to train counsellors according to common national standards, only a small number of certified trainers have access to the manual for training HIV/AIDS counsellors. The authors described the nature of HIV counselling training in South Africa as a once off service of factual education lacking a client-centred focus (Nulty & Edwards, 2005). Counsellors are mainly females who find it very difficult to counsel men regarding sexual matters.

It was subsequently suggested to use the opportunity of World AIDS Day on the 1st of December each year as a specific time to offer refresher training courses to HIV counsellors. As HIV counsellors are mostly lay people with short periods of training, the training agendas of these refresher courses are tailored according to a needs-assessment obtained from the counsellors. This notion was further promulgated by Bell et al. (2007) who stated that an investment in the training of existing health-care providers and an increase in their numbers in order to provide quality care for PLWHA, would help to improve services to everyone needing health-care. There are a couple of "low-technology" risk reducing conception options available to resource-limited PLWHA who want to conceive, e.g. manual insemination and timed unprotected intercourse (Mantell et al., 2009). Unfortunately, these safer-conception techniques (section 1.4.5.1) are not optimally used due to the limited clinical knowledge of health-care providers (Taylor et al., 2013).

African research showed the adverse effects associated with disclosure to be much less severe than anticipated (Visser et al., 2008). In addition, the voluntary disclosure of HIV status resulted in many participants (74%) reporting supportive responses of others, even after an initial upset of partners. Realistic outcome expectations should therefore be incorporated into post-test counselling by all HIV counsellors to promote an increase in HIV disclosure and thereby decrease the potential transmission risk of HIV (Visser et al., 2008).

For counsellors to become agents of change empowering their clients, they need to see sex and sexuality as positive and full of enjoyment rather than to only focus on the negative risk consequences (Helzner & Roitstein, 1995). Bell et al. (2007) emphasised that although PLWHA continue to be sexual beings even after a diagnosis, their feelings and needs related to sexual relationships can change over time. Sexual dysfunction in PLWHA due to anti-retroviral treatment and depression needs to be highlighted more in reproductive health and treatment services. Bekker et al. (2011) stated that a 25-year old person living with HIV can enjoy a median survival of 35 years when appropriately treated with HAART and therefore emphasised the importance of normalising the lives of PLWHA. HIV-positive men and women taking part in the current study reported feelings of strain and loss regarding the influence of HIV on their sexual relationships.

“Governments, policymakers and health systems need to acknowledge that health-care workers are humans too and need support in facing these issues in their own lives as well” (Bell et al., 2007, p.114).

5.3.2 Access to HIV services

Once people have the information they need, they still need access to services (whether for contraception or assisted conception) both to attain sexual health as well as to realise their reproductive decisions. Most of the participants taking part in this study had no knowledge as to where to apply for RRI, other than to consult the doctor at the VCT clinic. Bagratee (2007) stated that sexual and reproductive health services do not only mean providing access to family planning clinics. According to the author, the core components of sexual and reproductive health-care are:

- improvement of pregnancy and new-born care;
- provision of family planning, including infertility services;

- elimination of unsafe abortions as well as
- prevention and treatment of sexually transmitted infections; including HIV, reproductive infections, cervical cancer and the promotion of healthy sexuality.

According to Yallop, Lowth, Fitzgerald, Reid and Morelli (2002), many HIV services are struggling to adjust their attitude to changing from treating sick patients to caring for PLWHA. In their study on barriers to sexual and reproductive health-care, Lindberg, Lewis-Spruill and Crownover (2006) reported that there is little research available to guide health-care providers in making existing services more attractive to young males and in developing effective sexual health, including reproductive health, services to the HIV population. According to Lindberg et al. (2006) adolescents taking part in the study reported that obtaining sexual health-care was a stressful experience and specified a fear of stigma, a loss of status, shame and embarrassment as personal barriers. External barriers to accessing sexual health-care were specified as disrespectful service providers and a lack of confidentiality in accessing the health-care system. A welcoming, informal, respectful clinic environment was idealized by these young people.

In moving the focus from HIV prevention to reproductive health choices, Stevens (2008) stated that, while access to HIV treatment has been rolled out in South Africa, women's sexual and reproductive health has been neglected. Mantell et al. (2009) in their study regarding the right to choose parenthood among HIV-infected individuals, reported on the lack of access to complete information and counselling about reproductive options that would help PLWHA make fully informed decisions about whether or not to have children. Health-care providers were found to rarely give their HIV positive clients the opportunity to discuss their fertility intentions. Additionally, clients themselves may not raise the issue of parenting with health-care providers because of the negative counsellor attitudes experienced. Mantell et al. (2009) contend that in the absence of appropriate counselling on how best to avoid transmission of infection when trying to conceive, PLWHA are likely to follow their own reproductive desires without guidance.

Therefore, based on the findings of this study it can be concluded that both counsellor training and access to services are important aspects of HIV family planning counselling contributing to HIV prevention.

5.4 CONCLUSION

The above literature review both established and confirmed the unobserved personal, interpersonal and cultural influences underlying the reproductive needs of a group of South African men and women living with HIV/AIDS attending public health services. The implications of these reproductive needs as well as the lack of knowledge and access to services to the future counselling of PLWHA will be explicated in Chapter 6.

CHAPTER 6

CONCLUSION: THE SUBSTANTIVE THEORY AND ITS IMPLICATIONS

“she swims home alone...”

6.1 INTRODUCTION

In this chapter, the researcher aims to develop a substantive theory founded on the reproductive needs of men and women, within their reproductive years, living with HIV/AIDS in South Africa. Strauss and Corbin (1990) stated, “the development of theoretical informed interpretations is the most powerful way to bring reality to light... a reality that cannot actually be known, but is always interpreted” (p.22). The resulting theoretical formulation can therefore be used to explain the reality that was studied as well as provide an answer to the research questions (section 1.5), namely:

- Why is the pregnancy rate high among HIV-positive people despite the risk of HIV transmission?
- What are the reproductive needs of a group of South African men and women living with HIV/AIDS attending public health services?
- What are the implications of such needs for family planning counselling contributing to HIV prevention?

It also provides a framework, according to the principles of critical realism (section 2.2.1) and grounded theory (section 2.2.2), for future action, where facilitating programs can lead to the emancipatory transformation of the current HIV counselling services. The substantive theory is therefore formulated as an attempt to ultimately understand and explain why the pregnancy rate is high among HIV-positive people despite the risk of HIV transmission.

6.2 THE SUBSTANTIVE THEORY

Based on the wealth of data gathered, the core category resulting from the research states that “in order to establish their gender identities, HIV-positive men and women, within their reproductive years, choose to obey some of the rules of the societies in which they live by actively trying to negate the rules and stigma surrounding HIV” (see

section 4.5). This can be further conceptualised to formulate the substantive theory as follows:

In a poor and male-dominated society with different cultural norms dictating male and female procreation, it is important for people of reproductive age, living with HIV/AIDS, to establish their identities as being men and women through realising their reproductive needs. This contributes to their acceptance in their communities. However, gender inequalities in terms of realising parenthood and community HIV-related stigma create a double bind, especially for HIV-positive women. They cannot abide to both at the same time. This result in the choices they make not to disclose their status and further reproductive risk-taking in communities.

The conceptualisation of theory from this research gives a representation of the reality of a group of reproductive-aged people living with HIV. Gender identity, gender inequality, and different procreation rules for these individuals living with HIV were identified as the dominant unobserved underlying mechanisms, powers and structures that possibly influenced the high pregnancy rate among men and women within their reproductive years. The pregnancy rate is probably not higher than in other groups, but higher than expected given the stigma and community attitude creating the expectation that they should not become pregnant.

Confronted with these unobserved underlying mechanisms, powers and structures the research shows that men and women tend to make different decisions related to their reproductive needs. The HIV-positive men who participated in the research have a number of options because their partners supported them, and their cultures provide them with alternative options to realise their reproductive needs. However, the HIV-positive women have fewer options. A substantial number of women who participated in the research have chosen not to disclose their status and live as if they are not HIV positive. In this way, they could gain acceptance in the community by being free to have a baby and to avoid being stigmatised because of their HIV status. However, they still carry the burden of keeping secrets regarding their HIV status as well as the fear that their babies might be HIV positive. Some HIV-positive women who were pregnant were confronted with the double stigma of having HIV and becoming pregnant. The ANC counsellors' attitudes may be a representation of the stigmatising attitudes present in the community.

What is clear from this research is that reproductive-aged men and women living with HIV want to have children for various personal and cultural reasons, to prove their own health, to have future support and to be accepted in their communities. Having children is so important to them that they will risk their own health, the health of their partners and their babies. Because of the reproductive needs of men and women with HIV, the prevention of transmission of the virus is ultimately jeopardised. This could possibly motivate PLWHA to continue having babies as if they are not HIV positive.

Facilitating programs, such as the introduction of risk reducing strategies during HIV counselling sessions focusing on future reproduction and having access to accredited centres specialising in HIV risk reducing interventions can contribute to the emancipatory transformation of HIV counselling services to assist PLWHA in becoming parents in a healthy way. The transmission risk of HIV to partners and unborn children during unprotected sex can be minimised by having access to knowledge and HIV risk reducing services such as sperm wash and artificial insemination. In general, the improved access to information, treatment facilities and training regarding HIV risk reducing interventions to both the HIV counsellors and the PLWHA will enhance HIV counselling and family planning to fulfil the reproductive needs of PLWHA in a safe way. This can reduce the stigma attached to HIV; promote less HIV transmission, more disclosure of HIV status and healthy living. In the process, many partners and babies may be protected from becoming HIV infected

6.3 THE IMPLICATIONS OF REPRODUCTIVE NEEDS TO FUTURE HIV COUNSELLING

Concerning family planning counselling, the results of this research indicated that counsellors (especially at ante-natal clinics) should be made aware of the fact that a judgmental and directive approach by health-care providers can constrain care-seeking behaviour. Negative HIV counsellor attitudes can therefore have a negative impact on individual and public health (Cooper, Harries, Myer, Orner & Bracken, 2007). The difference in HIV counsellor attitudes, due to a lack of knowledge regarding the reproductive needs of their HIV-positive clients that became evident in this study, emphasised the need for continued training of these counsellors. The idea of HIV-positive women and men having children needs to be normalised. This can be achieved during renewed counsellor training sessions by focussing on guidelines on safer conception in fertile HIV-infected individuals and couples as proposed by Bekker and colleagues (2011). It is also important for HIV counsellors to help PLWHA to

realise that the adverse consequences which they fear will follow disclosure of HIV status may never realise (Visser et al., 2008). The HIV counsellors taking part in this study felt frustrated with the fact that scheduling of staff training often takes an elitist stance allowing nursing staff the opportunities to attend such training ahead of counsellors who need it more. The HIV counsellors in this study experienced the passing on of information to them as secondary and insufficient.

Most of the HIV positive participants taking part in the current study did not know where to go for risk reducing interventions should they want to have a baby in a safe way. Some of them reported that they would ask the doctor in the Immunology clinic. However, most of them would not dare to ask because of the attitudes of the counsellors (at ANC) which were extremely negative towards HIV-positive women who were pregnant. As the results from the current study were obtained from areas within the Kalafong Hospital, these areas could in the future serve as possible intervention areas to improve service delivery concerning both HIV-positive men and women.

Overall, the results of this research indicated that current efforts by medical workers and counsellors are not successful in preventing PLWHA from having more babies. The researcher interpreted the ineffectiveness of these efforts as probably due to motivations or powers beyond the messages of HIV/AIDS prevention programs influencing the behaviour of PLWHA. It is therefore crucial that HIV/AIDS prevention campaigns are adjusted according to community cultures in order to be successful. The acknowledgement and consideration of the reproductive needs of PLWHA are imperative to the development of successful HIV prevention strategies. RRI should thus be integrated with family planning counselling according to the recommendations made by the researcher as discussed in section 6.6.

6.4 CONTRIBUTION OF THE STUDY

This study demonstrated that qualitative research based on critical realism using grounded theory is well suited for studying the reproductive needs of men and women living with HIV/AIDS. "Understanding what people value and the meanings they attach to experiences, from their own personal and cultural perspectives, are major inquiry arenas for qualitative inquiry" (Patton, 2002, p. 147). As a result sensitive unobservable structures, powers and mechanisms, operative in the real dimension of reality (Bhaskar, 1978; Maree, 1990), could be extracted from a population that easily suffers stigmatisation due to the issue of being HIV positive. In order to identify

patterns of unmet need in the society or in a person, the researcher needed to adopt a critical and systematic approach. This enabled the researcher to expose any oppressive mechanism that was identified (Houston, 2001). Consequently, the researcher attempted to reclaim reality “through eliminating prejudice, errors, unsupported claims and philosophical false trails which have covered or disguised reality” (Corson, 1991, p.232). By making recommendations based on the results of this study, emancipation and transformation occurred “when we made the move from unwanted to wanted sources of determination” (Corson, 1991, p. 232). HIV-positive people living disempowered lives were, therefore, given a “voice” without exposing any individual by disclosing his or her status. That would not have been possible using methods relating to quantitative research approaches.

One of the most interesting study findings relates to the cultural tension of community stigmatisation and rejection of HIV-positive people that have children, fear of HIV transmission to an HIV-negative partner or baby, against cultural norms to have children because of community pressure, the importance of parenthood to women and men’s gender identity, as well as preservation of one’s name by leaving a legacy (a child) in the advent of death. The effect of these conflicting community norms and messages on HIV-positive women’s and men’s decisions to have or not to have children is an area that warrants more in-depth probing, especially how they deal with this double bind.

6.5 LIMITATIONS IN THE STUDY

Qualitative research results from this study cannot be generalised to all people living with HIV. Within the paradigm of critical realism, the researcher is cognizant of the fact that all findings can only refer to the specific population studied and stand to be rectified by any forthcoming research in the future. Even so, it is of note that the application of qualitative research results need not be restricted only to the specific context where data was generated. Qualitative research results may be applicable in other similar contexts. The transferability of results can be enhanced by the production of detailed and rich descriptions of the contexts where data was generated and by giving the readers detailed accounts of the structures of meaning which developed within a specific context. For example, such understanding of the accounts pertaining to the pregnancies among PLWHA in their reproductive years despite the risk of HIV/AIDS transmission can possibly be transferred to other PLWHA from similar cultural groups using public health services. The researcher’s resultant own

perceptions and passions will not be completely absent from the qualitative data interpretation (Denzin & Lincoln, 2005).

The substantive theory which has been developed regarding the reproductive needs of PLWHA was in terms of the researcher's conceptual interpretations. The relationship of the researcher with the research area can be described as moving backwards and forwards along a continuum of outsider/insider. Initially, the researcher started off by "looking" in from the outside and not being personally involved in the research. As the researcher got to know the participants better during the interviews, the "outsider position" shifted towards that of the "insider position" (Reed & Procter, 1995). Being involved with the research process the researcher was touched by the emotions of the participants and thus developed a better understanding for their way of life as well as their reproductive needs and choices. The researcher was aware that the compassion she had developed for the participants as well as the needs they expressed could have influenced her interpretation of the data. In writing memos the researcher consciously attempted to use this awareness, as well as the knowledge gained from the early literature review, to sensitise her towards the development of increased theoretical sampling. In handling the data the researcher adhered to the principles of theoretical sensitivity in order to be able "to develop a theory that is grounded, conceptually dense and well integrated" (Strauss & Corbin, 1990, p.41). The researcher elaborated on the core category in order to show how the resulting substantive theory had originated from it.

The research was done in a limited context involving a small number of people living with HIV. The research sample was further limited in that it included only black South African men and women living with HIV. Although a counsellor known to the participants was involved in the interviews to put them at ease and to assist in language interpretation, where it was necessary, the researcher had the challenge to gain acceptance from a group of people quite unlike her. This could have influenced the validity of the data. However, the qualitative research paradigm allowed the researcher to do in-depth personal interviews in order to understand more of the reality the participants are faced with.

6.6 RECOMMENDATIONS

Although cognizant of the fact that the research results cannot be generalised to all people living with HIV in their reproductive years, the researcher would like to make the following recommendations:

- As a global consideration it can be stated that, with its high prevalence of HIV/AIDS, South Africa as a country may consider itself morally obligated to contribute valid data to universal databases, e.g. The Centres for Reproductive Assistance Techniques in hiv in Europe (CREAThE). While this study did not aim to catalogue all the reproductive needs of men and women living with HIV/AIDS, it may suggest some themes that should be taken into account in dealing with reproductive health issues. Such information obtained from accredited HIV RRI centres in South Africa can make a global contribution to the prevention of the transmission of HIV.
- Regarding men and women living with HIV/AIDS within their reproductive years:
 - Because the desire to have children does not disappear due to one's HIV status, it is of great importance that reproductive aged men and women be counselled on their reproductive futures. Their reproductive needs should be acknowledged by educating them about HIV risk reducing interventions. They should have access to information and accredited HIV services to be able to attain their reproductive decision making in having a baby in a safe way. People should also have access to accredited government HIV risk reducing treatment centres. It is therefore suggested by the researcher that, in accordance with basic human rights enshrined within the South African Constitution (section 1.1), the reproductive needs of PLWHA should be acknowledged and people should have access to accredited RRI service centres.
- Regarding the HIV counsellors:
 - The reproductive futures of PLWHA must be brought into focus with all HIV counsellors. Sensitivity must be created with HIV counsellors about the effect of their own negative attitudes towards their clients living with

HIV/AIDS, especially towards pregnant women. They must be aware of the influence of cultural beliefs regarding the effectiveness of non-biological safer conception. They must also consider the fact that adverse effects following the HIV disclosure of status are seldom as severe as was feared beforehand by the disclosing person. It is also recommended by the researcher that value clarification should be included in the counsellor training suggested, as didactic information most likely will be insufficient to change counsellors' attitudes about HIV-positive people having children. In this way the HIV counsellors will be better equipped to influence existing dominant social and cultural perceptions and attitudes towards parenthood and HIV that significantly impact on the dilemmas experienced by PLWHA.

- Regarding the Government as HIV medical service provider:
 - The reproductive needs of PLWHA need to be recognised by the Health Department in providing accredited centres where people can go to receive basic HIV risk reducing interventions, e.g. sperm-wash and artificial insemination. Using advertisements on television and in written media, Government services could impact society at large by creating more public awareness challenging existing dominant social and cultural perceptions and attitudes towards parenthood and HIV in publishing the contact details and localities of such accredited HIV risk-reducing intervention services throughout South Africa. The department should also recognize and optimise the HIV counsellors' considerable sphere of influence. In so-doing the Government should provide ongoing training to HIV counsellors regarding the latest developments in HIV risk reducing interventions. It should revise and update current protocols for HIV counselling and family planning. This will equip HIV counsellors better to counsel people within their reproductive years living with HIV/AIDS regarding their future reproductive choices.

6.7 PROPOSED FUTURE RESEARCH

The researcher would like to propose the following research as a follow-up of this study:

- A comparative study into the reproductive needs of white, coloured and Indian men and women living with HIV/AIDS within their reproductive years. Such a study could highlight similarities and differences between groups to holistically enhance the quality of future HIV family planning and counselling services.
- A study of the influence and effect of HIV-positive men's suggestions to enhance male attendance at the clinics.
- Intervention-based research regarding the long-term effect of enhanced access to knowledge, training, HIV counselling and future family planning as well as HIV risk reducing services with regards to the incidence of HIV pregnancy rates and PMTCT programs in South Africa.
- Other potential research areas are: in-depth exploration of the gender differences in the importance of having children; how the age of HIV-positive women and men affects their perspectives on having children; how HIV-positive women and men deal with the conflicting community norms about HIV-positive people having children; the impact of HIV counsellors' counselling on their HIV-positive clients' fertility intentions.

6.8 CONCLUSION

During this research I was often asked: "Why are you doing this?" I heard: "*Silly girl.....Don't you know anything at all?*" I truly hope and trust that, in attaining the goals of this study,

"it helped many babies to safety."

long long way back

deep water cold black

mind shut muddy down

hard-shelled body old

still sure and sound

she swims home alone...

(LOGGERHEAD TURTLE: MICHAEL FIREWALKER)

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Addendum A: Research Institution Informed Consent

Official document signed by the Kalafong Hospital Chief Executive Officer

(CEO):

Permission to access Records / Files / Data base at
KALAFONG HOSPITAL
[Type in name of hospital / government department / hospital / school / company / NGO / etc]¹

TO: DR L PHALATSI [Name]¹ FROM: MRS C VAN ZYL [Name]¹
 Chief Executive Officer/Information Officer Investigator

KALAFONG HOSPITAL
[Name of hospital / government dept. / hospital / school / company / NGO / etc]¹

DEPT OF PSYCHOLOGY
UNIVERSITY OF PRETORIA
[Name of hospital / government dept. / hospital / school / company / NGO / etc OR investigator's home address]¹

Re: Permission to do research at KALAFONG HOSPITAL
[Name of hospital / government department / hospital / school / company / NGO / etc]¹
REPRODUCTIVE NEEDS OF MEN AND WOMEN LIVING WITH HIV: IMPLICATIONS TO FAMILY PLANNING COUNSELLING
 TITLE OF STUDY: HIV: IMPLICATIONS TO FAMILY PLANNING COUNSELLING

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a ~~researcher~~ / student² at the Department of PSYCHOLOGY at the University of Pretoria STUDENT NO 28683260
~~Hospital~~. I am working with PROF MJ VISSER [Title(s) and surname(s) of co-investigator(s) / supervisor(s)]¹. I herewith request permission on behalf of all of us to conduct a study on the above topic on the hospital grounds / at your facility / IMMUNOLOGY² This study involves access to patient / client / ~~teacher / student~~ / ANTE NATAL CLINICS records.
TO CONDUCT INTERVIEWS WITH PATIENTS / COUNSELLORS

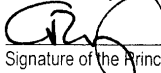
The researchers request access to the following information: patient / client / ~~teacher / student~~ / ANTE NATAL CLINICS records, record books and data bases.

We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients / clients / ~~teachers / students~~ / ANTE NATAL CLINICS by assigning each individual a random code number.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

 9.01.09
 Signature of the Principal Investigator

Permission to do the research study at this institution / facility and to access the information as requested, is hereby approved.

Title and name of Chief Executive Officer: L.M. PHALATSI

Name of institution: KALAFONG HOSPITAL

Signature: 

Date: 9/1/09



¹ Delete all highlighted instructions before submitting the form for a signature. Also delete this footnote.
² Delete which is not applicable and/or add a more appropriate description.

Official document signed by the Head of the Ante-Natal Clinic, Kalafong Hospital:

Reproductive needs of men and women living with HIV: Implications for family planning counselling.

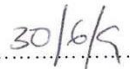
This research aims to investigate the reproductive needs of men and women living with HIV/Aids using a qualitative research approach to ultimately contribute to more comprehensive HIV/Aids counselling and family planning services in the public health system in South Africa.

As part of the research the researcher will conduct interviews with participants of about 90 – 120 minutes at a time convenient to them. The researcher will make use of a tape recorder to record the discussions during the interviews to be able to transcribe information at a later stage. All tape recordings will be handled confidentially and will be stored at the university for a period of 15 years. There is no risk to the safety of participants and their names will never be made public. The information obtained in this study will be used to prepare a research report. Any information obtained from participants in connection with this study will be kept confidential. There is no immediate direct benefit to participation, but hopefully it will lead to improved counselling conditions at family planning clinics and in the end benefit family planning and counselling to people living with HIV/Aids in South Africa in general. Participation to the study is voluntary. Any participant is free to withdraw at any time. The investigator will answer any additional questions regarding this study. The information obtained in this study will be used to prepare a research report. Any information obtained from this study will be kept confidential. If the research report is published, no names will be disclosed apart from acknowledgements to the departments of the Kalafong Hospital. Any complaints regarding the conduct of the study can be directed to:

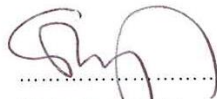
Prof Maretha Visser
MA (Counselling Psychology) (RAU), PhD (UP)
Telephone 012 420 2549



Head of the Ante Natal Clinic
Kalafong Hospital



Date



Cornelia van Zyl
Principle Investigator



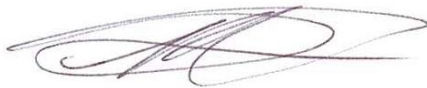
Official document signed by the Head of Immunology Clinic, Kalafong Hospital

Reproductive needs of men and women living with HIV: Implications for family planning counselling.

This research aims to investigate the reproductive needs of men and women living with HIV/Aids using a qualitative research approach to ultimately contribute to more comprehensive HIV/Aids counselling and family planning services in the public health system in South Africa.

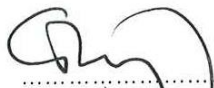
As part of the research the researcher will conduct interviews with participants of about 90 – 120 minutes at a time convenient to them. The researcher will make use of a tape recorder to record the discussions during the interviews to be able to transcribe information at a later stage. All tape recordings will be handled confidentially and will be stored at the university for a period of 15 years. There is no risk to the safety of participants and their names will never be made public. The information obtained in this study will be used to prepare a research report. Any information obtained from participants in connection with this study will be kept confidential. There is no immediate direct benefit to participation, but hopefully it will lead to improved counselling conditions at family planning clinics and in the end benefit family planning and counselling to people living with HIV/Aids in South Africa in general. Participation to the study is voluntary. Any participant is free to withdraw at any time. The investigator will answer any additional questions regarding this study. The information obtained in this study will be used to prepare a research report. Any information obtained from this study will be kept confidential. If the research report is published, no names will be disclosed apart from acknowledgements to the departments of the Kalafong Hospital. Any complaints regarding the conduct of the study can be directed to:

Prof Maretha Visser
MA (Counselling Psychology) (RAU), PhD (UP)
Telephone 012 420 2549



Head of the Department of Immunology
Kalafong Hospital *DR. M. SWANEPOEL*
MBCURB DA(SA)

07/07/09
Date



Cornelia van Zyl
Principle Investigator



Addendum B: Participant Information

Date of the interview.....
Place of the interview.....
Duration of the interview.....
Interviewer.....
Indicator for identifying the interviewee.....
The interviewee's gender.....
Age of the interviewee.....
The interviewee's profession.....
Working in this profession since.....
Professional field.....
Raised (countryside/city).....
Number of children.....
Age of the children.....
Gender of the children.....

Peculiarities of the interview

.....
.....
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Addendum C: Participant Informed Consent



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Department of Psychology

Principal investigator: Mrs C. van Zyl, MSc (Psychology)

Study Leader: Prof M. Visser, Department of Psychology, University of Pretoria

Study title: Reproductive needs of men and women living with HIV: implications for family planning counselling.

Purpose of the study: This research aims to investigate the reproductive needs of men and women living with HIV/AIDS using a qualitative research approach to ultimately contribute to more comprehensive HIV/AIDS counselling and family planning services in the public health system in South Africa.

Procedures: As part of the research I would like to conduct an interview with you of about 90 – 120 minutes at a time convenient to you. We will explore the impact of your HIV/AIDS status on your reproductive needs and family planning decision-making. I would also like to include your husband/male partner into our discussions, if at all possible, but will only do so with your consent. I will make use of a tape recorder to record the discussions during the interview to be able to follow everything you have said. This will be used only for the research and will be wiped out afterwards.

Confidentiality: All information will be handled confidentially and will be stored in locked cabinets at the university for a period of 5 years. Any information obtained from you will be kept confidential and your name will never be made public. Should you decide to withdraw from the study at any stage; all your recorded contributions will be destroyed.

Risks: There is no risk to your safety. Should you have the need to further explore risk reducing interventions and your reproductive needs, you will be referred to a specialized unit providing such services.

Benefits: There is no immediate direct benefit to your participation, but hopefully your contribution to the study will lead to improved counselling conditions at family planning clinics and in the end benefit family planning and counselling to PLWHA in South Africa in general.

Participant's rights: Your participation to the study is voluntary. You may wish not to be interviewed. If you do decide to participate, you are free to withdraw your consent at any time without any negative consequences for you. The investigator will answer any additional questions that you may have regarding this study.

Any complaints regarding the conduct of the study can be directed to:

Prof Maretha Visser

Telephone 012 420 2549

Participant consent:

I agree to participate in the study. I am willing to be interviewed. I have been informed about the purpose of the study. I understand that my participation is voluntary and that I can withdraw at any time without negative consequences.

.....
Signature Participant.

.....
Date

.....
Cornelia van Zyl
Principle Investigator

.....
Date

Addendum D: Discussion Guide: HIV-positive men

HIV-positive men attending the Immunology Clinic at Kalafong Hospital: explored what they think; how they feel and what their responses were to each question.

When did you first discover your HIV-status?

Do you know how HIV is transmitted from one person to another?

Can your partner get it?

Can your baby get it?

What have you been told about having babies in future?

What does it personally mean to you to be a parent?

What does it mean to be a parent in your culture?

If you could not have a child, how would it change your life?

How will it change your position in the family?

How will it change your position as a man in your community/culture?

What are the attitudes of people from your culture towards HIV-positive people having babies? What are your feelings on the risk of having a HIV-positive baby?

How eager is your partner to have a baby?

Does your partner know about your HIV status? If not, why not?

Do you think your partner will be willing to take part in this study?

Have you lost any children due to HIV/AIDS?

Did you take part in prevention of transmission from mother to child programmes (PMTCT)? What services can be improved for men at the HIV clinic?

Do you have a need for more information?

How motivated are you to take steps in actively combating the risk of transmission of HIV/AIDS?

Do you make use of condoms?

How is your life different now that you know you are HIV-positive?

How was your need to have a baby influenced by the HIV diagnoses?

How was your sexual relationship influenced by the HIV diagnoses?

What family planning counselling did you receive?

Was your life influenced by the counselling you have received?

Where did you go for counselling?

Do you know about safe ways to become a parent when you are HIV-positive?

Do you think something should be done to help make it safer for HIV-positive people to become parents?

Do you know where to get information about risk reducing intervention?

These questions might create the impression of being based implicitly on the theory of reasoned action; however it was only intended to know how HIV-positive men are thinking in terms of their reproductive needs. The theoretical framework of the study will be based on critical realist grounded theory.

Addendum E: Discussion Guide: HIV-positive pregnant women

HIV-positive pregnant women attending the Ante Natal Clinic at Kalafong Hospital: explored what they think; how they feel and what their responses were to each question.

When did you first discover your HIV-status?

Do you know how HIV is transmitted from one person to another?

Can your partner get it?

Can your baby get it?

What have you been told about having babies in future?

What does it personally mean to you to be a parent?

What does it mean to be a parent in your culture?

If you could not have a child, how would it change your life?

How will it change your position in the family?

How will it change your position as a woman in your community/culture?

What helped you to decide to have this child?

Did this baby come at a good time?

What are the attitudes of people from your culture towards HIV-positive people having babies? What are your feelings on the risk of having a HIV-positive baby?

How eager is your partner to have a baby?

Does your partner know about your HIV status? If not, why not?

Do you think your partner will be willing to take part in this study?

Have you lost any children due to HIV/AIDS?

Did you take part in prevention of transmission from mother to child programmes (PMTCT)?

How is your life different now that you know you are HIV-positive?

How was your need to have a baby influenced by the HIV diagnoses?

How was your sexual relationship influenced by the HIV diagnoses?

What family planning counselling did you receive?

Was your life influenced by the counselling you have received?

Where did you go for counselling?

Do you know about safe ways to become a parent when you are HIV-positive?

Do you think something should be done to help make it safer for HIV-positive people to become parents?

Do you know where to get information about risk reducing intervention?

These questions might create the impression of being based implicitly on the theory of reasoned action; however it was only intended to know how HIV-positive men are thinking in terms of their reproductive needs. The theoretical framework of the study will be based on critical realist grounded theory.

Addendum F: Discussion Guide: HIV-positive non-pregnant women

HIV-positive non-pregnant women attending the Immunology Clinic at Kalafong Hospital: explored what they think; how they feel and what their responses were to each question.

When did you first discover your HIV-status?

Do you know how HIV is transmitted from one person to another?

Can your partner get it?

Can your baby get it?

What have you been told about having babies in future?

What does it personally mean to you to be a parent?

What does it mean to be a parent in your culture?

If you could not have a child, how would it change your life?

How will it change your position in the family?

How will it change your position as a woman in your community/culture?

What are the attitudes of people from your culture towards HIV-positive people having babies? What are your feelings on the risk of having a HIV-positive baby?

How eager is your partner to have a baby?

Does your partner know about your HIV status? If not, why not?

Do you think your partner will be willing to take part in this study?

Have you lost any children due to HIV/AIDS?

Did you take part in prevention of transmission from mother to child programmes (PMTCT)?

How is your life different now that you know you are HIV-positive?

How was your need to have a baby influenced by the HIV diagnoses?

How was your sexual relationship influenced by the HIV diagnoses?

What family planning counselling did you receive?

Was your life influenced by the counselling you have received?

Where did you go for counselling?

Do you know about safe ways to become a parent when you are HIV-positive?

Do you think something should be done to help make it safer for HIV-positive people to become parents?

Do you know where to get information about risk reducing intervention?

These questions might create the impression of being based implicitly on the theory of reasoned action; however it was only intended to know how HIV-positive men are thinking in terms of their reproductive needs. The theoretical framework of the study will be based on critical realist grounded theory.

Addendum G: Discussion Guide: HIV Counsellors

Counsellors giving HIV/AIDS counselling at the Immunology and the Ante Natal Clinics at Kalafong Hospital: explored what they think; how they feel and what their responses were to each question.

How do you perceive their reproductive needs?

Do they want more information?

What advice do you give them with regards to having future children?

How do they react to your advice?

Do you think it would help to make it safer for HIV-positive people to become parents in a safe way?

How often do you give family planning counselling to HIV-positive men and women?

What do you think can be done?

Do you know where to refer your clients regarding risk reducing interventions and family planning?

Do you feel there is a need for better training of the counsellors with regards to risk reducing interventions and family planning?

These questions might create the impression of being based implicitly on the theory of reasoned action; however it was only intended to know how counsellors are thinking about the reproductive needs of their HIV-positive clients. The theoretical framework of the study will be based on critical realist grounded theory.

Addendum H: Participants' responses

(a) Code/concept: HIV background information

The following codes/concepts emerged from the text: time of HIV test; knowledge; counselling on future babies; referral to clinic; condoms.

(a)HIV-positive men

(21) Good knowledge on transmission of HIV. Counselling not to have any more babies. To always use condoms

(20) Good knowledge about viral transmission. Counselling not to have any more babies. To always use medicine. Always use condoms. "You must stop having children, you must use condoms, you must drink tablets in time"

(22) Good knowledge on viral transmission. Counselling not to have any more babies. To always use condoms."They said we must rather not have children otherwise it is going to cost us a lot of money"

(50, 52) Good knowledge on viral transmission. Counselling to consult with the doctor at the clinic if they wanted another baby. To always use condoms.

(23, 24) Good knowledge about viral transmission. Counselling not to have any more children. Always use condoms.

(45) Good knowledge on viral transmission. Counselling to never have more babies unless speak to doctor at clinic. To always use condoms.

(47) Fairly good knowledge on viral transmission. Counselling to always use condoms.

(48) Good knowledge on viral transmission. Nothing said about children in the future. To always use condoms.

(50) Good knowledge on viral transmission. Counselling to consult doctor at clinic if they want babies. To always use condoms.

(51) Good knowledge on viral transmission. Nothing said about having children in the future. To always use condoms.

(a)HIV-positive pregnant women

(13) Good knowledge on viral transmission. Counselling not to have any more babies. Belief that taking ARV's will protect unborn baby.

(10) Good knowledge on viral transmission. Very sad because she was rejected by previous partner. Only counselling to look after baby. No family planning received.

(11,12) Good knowledge about viral transmission. Very scared to talk. Counselling to always use condoms.

(14) Good knowledge on viral transmission. Counselling not to have any more babies.

(16) Good knowledge on viral transmission. Counselling to always use condoms “they told me about the disease, they said I must use condoms...they did not tell me about another baby”

(17) Some knowledge on viral transmission. |counselled not to have babies in the future. Always use condoms “you must use condoms...you must not have another baby”

(25,26) She had some knowledge on viral transmission. Counselling to take medicine if she wants another baby. “they tell me if I make another children I have to take the medicine strictly”

(27) She had some knowledge on viral transmission. Nothing was said about babies in the future.

(28, 29) she had some knowledge on viral transmission. Very unsure previous husband died. Nothing was said about babies in the future.

(30, 31) She had some knowledge on viral transmission. Nothing was said about babies in the future. Told to always use condoms.

(a)HIV-positive non pregnant women

(8) She had fairly good knowledge on viral transmission. She was told to consult the doctor at the clinic should she want another baby. She must always use condoms.

(9) She had some knowledge on viral transmission. She knew it was important to always use condoms.

(32, 33) She had good knowledge on viral transmission. She was told not to have any more babies. She must always use condoms.

(34) She had good knowledge on viral transmission. She must speak to the doctor at the clinic if she wants another baby. She must always use condoms.

(35) She had good knowledge on viral transmission. She was counselled to never have any more babies. She must always use condoms.

(36) She had good knowledge on viral transmission. She was counselled to come to the clinic if planned another baby. She must always use condoms.

(39) She had fairly good knowledge on viral transmission. She was counselled to consult the doctor at the clinic if she wanted another baby. She must always use condoms.

(42) She had good knowledge on viral transmission. Nothing was said during counselling about having children in the future.

(43) She had good knowledge on viral transmission. She was counselled strictly not to have any babies in the future. She must always use condoms.

(46) She had good knowledge on viral transmission. Nothing was said about babies in the future. She was counselled to always use condoms.

(b) Code/concept: Value of having children

The following codes emerged from the text obtained from the different study groups:
Personal importance: responsibility and not to be alone; cultural importance: identity and acceptance.

(b) HIV-positive men

(21) Personally parenthood very important. "I want to take care of them, they are my future". Culturally parenthood very important." They want us to have children...the male child is very important, the surname must grow...with a girl child our surname dies"

(20) Personally parenthood very important."I work for them". Culturally parenthood important for his future." You live with them it is my future"

(22) Personally parenthood important, gives him responsibility. Culturally parenthood very important, seen as a blessing. "In our culture, having children...is a blessing and the family grows.

(51, 52) Personally parenthood very important. Culturally parenthood very important it gives him responsibility.

(23, 24) Personally parenthood very important. "For me parenting is all about caring and guidance to the young ones". Culturally parenthood not very important. "whether you have children or not, you are regarded as important to society...a child for one family is a child for the whole society"

(45) Parenthood personally very important, he was an only child. "I was always alone with my mother". Culturally parenthood was very important. "Especially a boy...he is the one who is going to carry your surname...the name must continue"

(47) Personally parenthood very important for his future. "so that when I grow old they will be there for me". Culturally parenthood also very important. "Your name must go on"

(48) Parenthood personally very important for his future. "the time will come for me to be old, and my children will buy me food". Culturally parenthood very important "if you have no children, you are not seen as a human being...you are respected if you have a child.

(50) Parenthood very important. "if I die my name must continue, it is very important to me" Culturally parenthood is very important. "my family continue to grow"

(51) Personally parenthood very important to his future. Culturally parenthood is very important to have a family.

(b)HIV-positive pregnant women

(13) Parenthood personally very important. Baby can bring peace in marriage "maybe you fight with your husband; the baby can destroy that fight" Culturally parenthood very important before marriage.

(10) Considers her pregnancy a mistake due to her status. Culturally it is very important being a parent "for them having babies is a big thing"

(17) "...the baby was not planned...was a mistake... because I am HIV-positive"

(25,26) "...this one was a mistake...eish, I was using condoms with my partner, and then one day he was drunk and said he wanted to sleep with me without using condoms and I said no...then we started fighting...and then it was... (*participant started to cry*)

(11,12) Parenthood personally very important. "It gives you reason to live." Culturally parenthood very important "it shows how much women you are"

(14) Parenthood personally very important. "i have always loved the role of nurturing" Culturally parenthood very important "it is how we measure your value and your being as a women...it is a stamp of approval"

(16) Parenthood personally very important "I do not want to be alone" Culturally parenthood very important "if you do not have a baby you are not women enough"

(17) Parenthood personally not important because of status. Her baby was a mistake. Culturally parenthood very important.

(25, 26) Personally parenthood very important “because I am a mum... I love to be a family” Parenthood culturally very important.

(27) Parenthood personally and culturally very important.

(28, 29) Parenthood personally very important to establish identity as a woman. Culturally parenthood very important “they will divorce you”

(30, 31) Parenthood personally very important. Parenthood culturally also very important.

(b) HIV-positive non pregnant women

(8) She already had a child and personally parenthood was not important. Parenthood not important in her culture.

(9) Personally parenthood very important “I need one”. Culturally parenthood not important.

(32, 33) Personally parenthood very important, it gives her responsibility and she does not want to be alone. Culturally parenthood very important to have more than one child.

(34) Parenthood personally very important she wants her mother to be a grandmother. Culturally parenthood very important but only to married women.

(35) Parenthood personally very important “I want to be a mother, I do not want to die, I want a baby first”. Culturally parenthood very important “They say you have to have a husband and a big family”.

(36) Personally parenthood very important, for her future and not to be alone. Culturally parenthood very important must be married first.

(39) Personally parenthood very important, gives responsibility, for her future, does not want to be alone. Culturally parenthood very important, “Once lebola was paid”.

(42) Personally parenthood very important “To proof that I am a mother” Culturally parenthood very important.

(43) Personally parenthood very important “People will treat you like something is wrong with you if you don’t have a baby, so you MUST have a baby”. Culturally parenthood very important she will be disrespected.

(46) Parenthood personally very important not to be alone. Culturally parenthood important to please the in-laws.

(c) Code/concept: Life without children

The following codes/concepts emerged from the text obtained from the different study groups: personal effect; position in the family; cultural isolation.

(c) HIV-positive men

(21) Personally he will be unhappy and alone without children. His position in the family will not change because of belief in the ancestors. “you have to get another women who can make children...this is very much important you must have children...we believe that everything you get is them giving you, you must go and thank them and you must please them and keep the ancestors happy”. Culturally you will still be respected.” In the culture they do... because they believe it was the ancestor’s choice that you should not have children”.

(20) Personally not having children will be painful.” Something that makes me different”. In the family he will not be seen as a man.” I stay my mother’s child but if I have children I become a man”. Culturally he will be disrespected.” You are not a farther...you are not called baba”.

(22) Personally not having children will be difficult because he will be alone. In his family he will be disregarded. “you are not seen as a man if you do not have children...they do not regard you.” In the community he will not be able to speak about children because he does not have any himself.” You do not know what you are talking about.”

(51, 52) Personally not having children will be very difficult because he does not want to be alone. His position in the family will not change because they will pursue medical options. Culturally he will be accepted as being born that way.

(23, 24) Personally not having children is going to be difficult. His position in the family will not change; his focus will shift towards the children in the community. He will maintain his role as a man in the community but the elders in his culture will put pressure on him and will arrange for his youngest sister in law to test his fertility.

(45) Personally not having children will be stressful to him. His position in the family will not change because he does not have to divorce his wife but he can take another

girlfriend to have a baby. Culturally he will be disregarded as a man “they will laugh at you...they will tease you...they will tell you must make a baby”

(47) Personally not having children is so important that he will adopt “it is so important that i will adopt a baby” His position in the family will not change “ I will stay with my wife and I will adopt a child”. Culturally he will be disrespected “ they do not respect you...if you adopt then they look at you differently, you are responsible then”

(48) Personally he will accept not having children as given by GOD. His position in the family will not change, he will stay with his wife and he will adopt. Culturally he will be disregarded as a man and will be expected to take care of his brother’s children.

(50) Personally not having children will be very difficult. His position in the family will change if the problem is with his wife. He will have to divorce her. Culturally he will be disrespected “the other ones will not respect you, because you are not a real man, because you do not have children”.

(51) Personally not having children is seen as “actually it kills the family”. His position in the family will not change but he will be supplied by a second wife, he will not divorce. Culturally he will be disrespected “the men always disrespect each other...you are on the outside”

(c)HIV-positive pregnant women

(13) Personally she feels very bad not to have any children. Her position in the family will not change as her family will support her “because it is not you... it is GOD” Her culture will accept adoption.

(10) Personally she will be very sad and lonely not to have children. The family will put pressure on her to have a baby “especially my granny will put pressure on me to have a baby” Culturally she will be excluded and disregarded if she did not have a baby “if you do not have a child they do not understand”

(11, 12) Personally not having a baby will be very painful “my life will be empty...and no one can feel that pain” Her position in the family will not change as her family will support her. Culturally she will be excluded “to be a women is by children”

(14) Personally not having children will not be a problem, she will pursue her career. Within the family there would be great pressure on her to have a baby “even my grandma will tell me” She will be excluded from cultural affairs “ it is totally unacceptable if you cannot have a baby...they will laugh at you”

(16) Personally very difficult not to have children. Her parents will support her but the rest of the family will stigmatise her “they are going to call you names...the names that hurt” Culturally she will be disregarded for not having children.

(17) Personally it will be very difficult not having children. The family will support her and love her. Culturally she will be disregarded and disrespected for not having children.

(25, 26) Personally very important to have children for the future. “if you do not have kids you do not survive in life” Her position in the family will be greatly affected” If you do not have a baby you are nothing. Culturally she will be disrespected.

(27) Personally very painful not to have children. Her position in the family will be greatly affected “the behaviour of black people...if you are married they give one year and if you do not have babies you have to divorce.” Culturally she will be disrespected.

(28, 29) Personally she will be very sad not to have any children. Her position in the family will be greatly affected. Her husband will divorce her and she will lose everything, income and housing. Culturally she will be disregarded.

(29) “there are the others who become divorced because they cannot have babies,...they become the prostitutes... they work for themselves... they stay alone... it is not good.

(30, 31) Personally not having children will be difficult. She sees it as her right to have children. Her position in the family will be affected as the husband will divorce her.

(c)HIV-positive non pregnant women

(8) Personally very painful not to have any children “I am going to feel a pain”. Her family will put pressure on her to have children. As a women her culture expects her to have babies, but “They must be healthy”

(9) Personally not having children was not a problem as her sister did not have children either. Her position in the family will not change “The other people they do not care”. Her position as a woman in her culture will not be affected.

(32, 33) Not having children is seen as very bad and painful. Her position in the family will be affected because her husband will divorce her and get a new wife. Culturally she will be exclude and deserted.

(34) Not having children will be heartbreaking for her. Her position in the family will be affected because her husband will cheat on her and take a second wife. Culturally she will be disrespected “They call them names and it is very painful”

(35) Not having children is very stressful as everybody will ask why? The position in the family will not change but they will put pressure on her. Culturally she will be embarrassed as people keep on asking why?

(36) Personally not having children is very stressful because she is alone. Her position in the family will be affected, the family in law will not support her and the husband will divorce her. Culturally childless women are disrespected and excluded from family life.

(39) Personally not having children very difficult, called names by people and being alone. Position in the family will be severely affected “If you cannot have a baby, they take you back to your family and they take another woman “Culturally childless women may help raise other children but later they have to go back to their own families.

(42) Not having children will be very painful “You will not get married, most men they want babies and if you do not have a child you will be lost”. Position in the family will be affected “Mostly in my culture they divorce you and go for another wife” Culturally she will be disrespected “They will call you rubbish, it is not nice”.

(43) Personally not having children is very important “People look down on you and it changes everything”. Position in the family will be affected “Because of pressure by the in laws will ultimately cause your husband to turn against you”. Culturally she will be outside the community and very lonely “Your value as woman is determined by your ability to have children”

(46) Personally not having children is very lonely. Her position in the family will be affected as he will take a second wife and she will have to stay in the same house with wife number two. Culturally she will be disregarded “They have no respect for you... no children, they do not love you... we do not adopt, you stay alone”

(d) Code/concept: Cultural acceptance/rejection

The following codes/concepts emerged from the text obtained from the different study groups: community support/rejection; fear of transmission and conflict between life and death.

(d)HIV-positive men

(21) His culture is not supportive towards HIV-positive people having babies “they are rejecting us, you are not the same as them...they look at it like it is bad”. He has a great concern about the health of the baby because of his own experience of having to live with HIV.

(20) His culture is not supportive of HIV-positive people having babies “ it is bad...because if you are sick that baby is going to be sick” He is very concerned about the health of the child “i am scared...i want the baby to be healthy”

(22) His community is gradually becoming to accept living with HIV.” Before they would think it is bad people who have the disease, but now they do understand” He is very scared about transmitting the virus to his child.

(51, 52) His community accepts HIV and will not discriminate against HIV-positive people having babies. He is very scared about transmitting the virus to his child.

(23, 24) His community is not supportive of HIV-positive people having babies. ”if you are HIV-positive it is like you have done something wrong...they condemn it completely”

(45) His community is not supportive of HIV-positive people having babies. “They will make sure that they keep their distance, they think your baby is bad luck” He is very concerned about transmitting the virus to his baby.

(47) His community does not support HIV-positive people having babies. “they think it is bad because they are going to die soon” He is very concerned about transmitting the virus “ I do not want to be responsible if the baby is sick”

(48) His community is very enlightened and supportive towards HIV-positive people having babies. ”they are feeling pity... they pray to GOD to give people more knowledge and drugs to fight this disease” He is very concerned about transmitting the virus to the baby.

(50) His culture is not supportive of HIV-positive people having babies. ”they do not like you, because you spread disease” He is very scared of transmitting the virus to his children “if you got the condition to get the child negative, i like that...it gives me hope”

(51) His culture is not supportive of HIV-positive people having children. “they do not support...it is shift under the carpet” He is very scared of transmitting the virus to his child.

(d) HIV-positive pregnant women

(13) She felt she was ready to have a baby. The baby came at a good time. Her community does not support HIV-positive people having babies. She is very concerned about the baby's health.

(10) She had a great need to have a baby "I want my children to be family". She is unsure about her community's feeling towards HIV-positive babies. She is very concerned about her baby's health.

(11, 12) This baby is very important to her "This is the one I want". She always wanted a family. She knows this one will be her last baby because of her status. Her community does not support HIV-positive people having babies. "In my culture they will stay away from me, they think it is bad". She is very concerned about the baby's health.

(14) The baby is very important to her because of her boyfriend's marriage proposal. She had some pressure from her boyfriend to get pregnant. The baby came at a good time. Her community does not support HIV-positive people having babies. "You are sick and you are dying and you are better left alone" She is very concerned about the health of her baby.

(16) She very much wants this baby. She lost her previous baby. She does not think it is a good time for her baby because of her positive status. Her community does not support HIV-positive people having babies. She is very sad and concerned about the health of her baby. "Eish it worries me very much"

(17) She did not plan the baby. The baby was a mistake. Her community does not support HIV-positive people having babies. She is very concerned about the health of her baby.

(25, 26) The baby was not planned and is seen as a mistake. The partner did not want to use condoms, they had a violent relationship. Her community understands HIV as a common affliction and support HIV positive people having babies. She is very concerned about her baby's health.

(27) The baby was unplanned and called a mistake, because of her status and she was at school. Her community is not supportive of HIV-positive people having babies. She is very concerned about the health of her baby.

(28, 29) She very much wanted this baby regardless of her status. This is her last baby. Her community does not support HIV-positive people having babies. She is not too concerned about the baby's health because the father is – .??

(30, 31) She planned the baby. The baby came at a good time regardless of her status. She is unsure about her community's support of HIV-positive people having babies. She is very concerned about the health of her baby.

(d) HIV-positive non pregnant women

(8) Her community does not support HIV-positive people having babies. "They think it is bad...they say it is bad people" She is very scared of having an affected baby.

(9) Her community does not support HIV-positive people having babies. "They do not want baby, they think it is bad" She is very scared of having an affected baby.

(32,33) Her community does not support HIV-positive people having babies. "They say it is a risk...they say you must stay without a child". She badly wants another child but is very scared of transmitting the virus to her baby.

(34) Her community does not support HIV-positive people having babies. She is very scared of transmitting the virus to her baby.

(35) Her community is getting more informed and is therefore tolerant of HIV-positive people having babies. She is not scared of transmission as she believes ARV's are effective "I take my medicine, I told myself I am going to take my time and I am going to live my life"

(36) Her community does not support HIV-positive people having babies. She is very scared of transmitting the virus to her baby.

(39) Her community does not support HIV-positive people having babies. She is scared of transmitting the virus but beliefs in the strength of medication.

(42) Her community does not support HIV-positive people having babies."They say it is bad and once they know you status they do not come to your house, because they are scared you might infect them". She is very scared of transmitting the virus. She feels very helpless.

(43) Her community does not support HIV-positive people having babies. "They still have that stigma...you are sick and you are going to die...if you want a child even if you know you are HIV-positive, you will not disclose it" She is concerned about transmitting the virus but takes courage from medical advances.

(46) Her community does not support HIV-positive people having babies.

(e) Code/concept: Relationships and decisions

The following codes/concepts emerged from the text obtained from the different study groups: partner's parenthood need; disclosure of HIV status; relationship: support, protection, pressure to be pregnant.

(e)HIV-positive men

(21) His girlfriend very much wants another baby having just lost their baby due to liver failure. She puts lots of pressure on him not to use condoms. They are both HIV-positive, they have a supportive relationship.

(20) His wife very much wants another baby, she puts pressure on him they are both HIV-positive. They have a supportive relationship.

(22) His wife very much wants another baby but they have mutually agreed not to have anymore. She is HIV- but is very supportive of him. They have a good relationship "my wife was very helpful because she knew about these things before I did"

(51, 52) His girlfriend is very keen to have another baby. She is HIV- and knows about his status. They have a very supportive relationship.

(23,24) His wife very much wants another baby. They planned for a long time. They are both HIV-positive. They are very supportive of each other in their relationship. "she is always on my side"

(45) He is unsure how much the girlfriend wants a baby however he very much wants another baby. His girlfriend is HIV- . They have a supportive relationship.

(47) His girlfriend is not eager to have another baby, already has two children of which one is sick. Both partners are HIV-positive. They have a supportive relationship.\

(48) He is very adamant to never have any babies; partner has no say in the matter. She is HIV- and knows about his status. They have a supportive relationship. "i want to protect my wife, she supports me too much"

(50) His partner very much wants another baby "that is why I am going to talk to the doctor" She is also HIV-positive. They have a supportive relationship.

(51) His partner very much wants another baby. They are both HIV-positive. They have a supportive relationship.

(e)HIV-positive pregnant women

(13) Her partner very much wanted the baby before they had tested. He is HIV- and knows her status. He works far away and does not stay with her. She is very unsure about her relationship.

(10) Her partner was not keen having another baby, already had two other children. She does not know his status; she did not disclose her status to him. She is very unsure about the relationship “for now I am not going to tell him, the relationship is not so strong”

(11, 12) Her partner also wanted a baby. He is HIV-positive, they know each other’s status, they have a supportive relationship. She encourages him when he is afraid of being HIV-positive.

(14) Her partner very much wanted the baby. He is HIV- and accepts her positive status. They have a supportive relationship.

(16) Her partner did not want a baby it was her decision. She did not disclose her status and does not know his status. She is very scared to disclose, fear of rejection.

(17) Her partner did not want another baby. He is also HIV-positive and knows her status. He left her and her children. She did not disclose to the family. She is very sad and depressed about her future.

(25, 26) Her partner wanted a baby for a long time. He does not know her status and he did not want to test himself. She is scared he will reject her if she discloses. She is very sad and cries a lot.

(27) Her partner very much wanted the baby. He does not know her status. She is scared of rejecting because she is living with his people. She will disclose when the baby test negative “It makes it better for me if there is a healthy baby”

(28, 29) Her partner wanted the baby very much. He is HIV- and knows her status. They have a supportive relationship.

(30, 31) Her partner wanted another baby. He does not know her status. She is not going to disclose.

(e)HIV-positive non pregnant women

(8) She is unsure whether her partner wants another baby. Her partner knows her status. He did not go for the test, said he will but stay far away.

(9) Her boyfriend has children from a previous relationship does not want another baby. He does not know her status. She is scared of being rejected by him. She told him to use condoms because she does not want another baby.

(32, 33) Partner does not want children. He deserted her because of her status. He did not believe in HIV.

(34) Her boyfriend promised to marry her but first he wants a baby. He knows about her status and they have a supportive relationship. He is HIV negative.

(35) Her partner supports her and very much wanted another baby. He knows about her status. He is HIV-.

(36) Her partner has died of HIV without disclosing his status to her. Currently she is not in a relationship. She will disclose her status to her next partner to protect him.

(39) Her partner very much wants a baby. He knows about her status. He is also HIV-positive. They are supporting each other and always use condoms.

(42) Her partner rejected her because of her status. He is also HIV-positive and blames her. He was her first partner. He is older than her and had many previous relationships.

(43) Her partner does not want another baby. He knows about her status. He is HIV-. He finds it very difficult to accept her status.

(46) Her partner does not want another baby. He does not know about her status. He does not want to know about his status. They do not have a supportive relationship.

(f) Code/concept: Prevention programs

The following codes/concepts emerged from the text obtained from the different study groups: participation; men's suggestions to enhance attendance.

(f)HIV-positive men

(21) They did not take part in PMTCT programmes "we did not know our status at the time so we did not take part in prevention of transmission programs". Basically happy with the services as they are at the clinic "they must give us letters of appointment so you come at a certain time and you do not have to stay the whole day...it will make it easier for men to attend"

(20) They did take part in PMTCT programmes. He is happy with service at the VCT clinic. He wants more info on "how to get a long life"

(22) They did not take part in PMTCT programmes. He wants more male staff at the clinic “someone when you are talking about your problem they know what you are speaking about...not so much from what they have learnt but from own experience”

(51, 52) They did not take part in PMTCT programmes. He wants men to be taught about the disease “a group of people that go out there and teach like most of the men that they can have knowledge of this disease...so they can start their treatment” He want more information on managing the disease.

(23, 24) They did take part in PMTCT programmes. He felt that men needed to be treated at the same level as the ladies, need to be given more information. Wants to enhance communication amongst partners. Wanted more information on reproductive cycles, disclosure to their children and having a healthy relationship after knowing partner status.

(45) Did not take part in PMTCT. Wanted services to be speeded up at the clinics. He wanted mobile clinics to the people. Wanted to attend anonymously because of fear for stigmatisation. Being recognised at the clinics keep men away from attending the clinics.

(47) Did not take part in PMTCT programmes. Wanted services to be speeded up at the clinics “They must get more staff and they must give you an appointment.” Wanted more information on staying healthy.

(48) Did not take part in PMTCT. Wanted to attend the clinic anonymously, not in the same area where he lives. Wanted more information on managing the disease.

(50) Did not take part in PMTCT programmes. Suggested programmes to convince men to know their status. Want to attend clinic anonymously, scared of people recognising him. Wants more information on the disease and the future.

(51) Wanted more counsellors at the clinic. He wanted appointments at the clinic because they lose their jobs if they stay away to long. Wanted more information on living with HIV.

(f)HIV-positive pregnant women

(13) She did not lose any babies due to HIV. She took part in prevention programmes.

(10) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(11, 12) She did not lose any babies due to HIV. She took part in prevention programmes.

(14) She did not lose any babies due to HIV. She took part in prevention programmes. She has seen the effect of HIV deaths on the family and child headed households in her community.

(16) She lost a baby, unsure about the baby's HIV status. She is taking part in prevention programmes.

(17) She did not lose any babies due to HIV. She took part in prevention programmes.

(25, 26) She did not lose any babies due to HIV. She took part in prevention programmes.

(27) She did not lose any babies due to HIV. She took part in prevention programmes.

(28, 29) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(30, 31) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(f) HIV-positive non pregnant women

(8) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(9) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(32, 33) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(34) She had lost a baby. Unsure if it was due to HIV. She did not take part in prevention programmes.

(35) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(36) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(39) She did not lose any babies due to HIV. She did not take part in prevention programmes. She consulted a sangoma.

(42) She did not lose any babies due to HIV. She took part in prevention programmes.

(43) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(46) She did not lose any babies due to HIV. She did not take part in prevention programmes.

(g) Code/concept: HIV status and quality of life

The following codes/concepts emerged from the text obtained from the different study groups: quality of life; sexual relationship.

(g)HIV-positive men

(21) His life became more difficult because of his HIV status. He had skin lesions and lost an eye. He is lying to people about his status. His sexual life was badly affected by his positive status. He feels exposed and scared “i cannot be with her in a natural way” He felt good about the counselling services as they were very supportive “they treated me in a nice way...I am doing what they say”

(20) He is taking better care of himself. Only his immediate family knows about his positive status. His sexual life was not affected as he feels safe using condoms. He felt good about counselling services. “they supported us when my wife got pregnant, they showed us how to stay healthy”

(22) He is taking better care of himself in terms of his diet. His sexual relationship became very strained “it was very difficult to accept that I was positive and my wife was negative. I was weak at the time” The counselling services was experiences as mostly sympathetic “the counselling helped me a lot because I know I am not alone...I can still have some more years to live.”

(51, 52) He is taking better care of himself. His sexual life was not affected too much. He experienced counselling services as supportive.

(23, 24) He values life more and he is taking good care of himself. His sexual relationship was very strained. With time it became better. He is very motivated about risk reducing intervention and planned the pregnancy accordingly. He accidentally became across a research project on the internet and decided to partake.

(45) He is taking better care of himself. However he is very concerned about dying and another man taking his family. His sexual life became very strained “at some

stage I got scared...it has become better” He did not receive any family planning counselling.

(47) He has become used to his status but feel that is holding him back on enjoying life as he has no long lifespan. I think in 5 years I will be dead...I am not enjoying life so much anymore” His sexual relationship became very strained because of the lost of trust. They are trying to support each other. He did not get any family planning counselling.

(48) He feels his life was not changed by his status and he is taking better care of himself in terms of diet and using condoms. His sexual relationship did not suffer as he was honest with his wife. He wants to protect her and always use condoms. He is positive about the counselling he received “they helped me to stay healthy”

(50) He became used to his status and has a very positive outlook on life. He takes better care of himself and sees himself as encouragement to others. His sexual relationship did not suffer as his partner is also HIV-positive and they support each other. They did not receive any family planning counselling. He is however very positive about the counselling he did receive. They encourage me and keep me focussed.

(51) He takes better care of himself. His sexual relationship was very strained but they both helped and support each other. He feels very positive about the counselling received “they were good to me”. They did not receive any family planning counselling.

(g)HIV-positive pregnant women

(13) She is very scared of rejection because of her status. “I do not want them to know, they will turn away from me.” She continued the sexual relationship using condoms. She did not receive any family planning counselling. She felt good about the counselling she received.

(10) She became scared and does not feel strong like before. She is scared of a sexual relationship because she is scared of rejection. Her boyfriend does not know her status and they are not using condoms. She did not receive any family planning counselling, only to protect her against re-infection.

(11, 12) Her life is very different now. She has a positive outlook on life and takes better care of herself. She became very scared of a sexual relationship. She

experienced the counselling as very supportive “It was good , they supported me” No family planning counselling.

(14) Her life is very different now but she feels positive because of her supportive relationship “He is so strong for me... we planned for the future”. Her sex life was influenced negatively, “to use condoms was like starting to be strangers again” She received no future family planning counselling. She experienced the counselling services as very supportive. “My life was really touched by what I have learnt”

(16) She feels sad about her life but tries to take good care of herself. She became very scared of a sexual relationship. Her partner is not willing to use condoms. She expressed the need for family planning counselling as she wants more babies in the future.

(17) She feels very bad about her life and about being deserted by her partner. She tries taking better care of herself. She did not become scared of a sexual relationship. She feels safe using condoms.

(25, 26) She feels her life is still the same. She become very scared having sexual relationship. She felt positive about the counselling she received.

(27) She is very concerned about her life and her future. She becomes very scared of having a sexual relationship. She lied to her partner about having to use condoms during the pregnancy. She received no family planning counselling and was very positive about the counselling she receive “ I have got hope”

(28, 29) She feels her life is much the same. She did not become scared of sex they are using condoms. She did not have any family planning counselling. She experienced the counselling services as very supportive but she wants to know about her reproductive future.

(30, 31) She has not disclosed her status to her friends. She became very scared of sexual relationship. She was counselled to have a sterilisation.

(g)HIV-positive non pregnant women

(8) She is scared to disclose and she does not have any friends, only her family knows. Her need to have another baby was negatively influenced by her status. Her sexual relationship was not influenced as she felt safe using condoms. Her partner is willing to use condoms. She feels positive about the counselling she received. “They were good to me...very good to me”

(9) She lost a lot of weight. Her need to have a baby was negatively influenced by her status. She became scared to have a sexual relationship. She was told to abort the baby should she become pregnant by mistake. She experience the counselling as supportive “I feel better I do not have the stress”

(32, 33) She is taking better care of herself. Both her parents died of HIV. She fears that she is also going to die very soon. She became scared of a sexual relationship “I am afraid now, because the warts...they do not disappear”. Her current boyfriend is very supportive and knows her status. He does not want to get tested. She experienced the counselling as positive and supportive.

(34) She is taking better care of herself. She is very scared of the future. She badly wants another child so that her other child is not alone when she dies. Her sexual relationship did not suffer, they are using condoms.

(35) She is taking better care of herself. She is very worried about her future. She wants a baby very much regardless of her status. She became very scared of a sexual relationship. Her partner is very supportive and accepts her status. They are always using condoms. She did not receive any FPC. She experienced the counselling as supportive.

(36) She takes better care of herself, in terms of diet medicine and exercise. She does not want another baby now, depends on her next partner. She will continue having a sexual relationship in the future. She feels confident using condoms.

(39) She is taking better care of herself. She feels good and knows what to do. Her sexual relationship at first was very difficult; they are working very hard at their feelings towards each other. She experienced counselling services as very supportive.

(42) Her life has changed and she is very lonely. Her friends do not know about her status. She is very scared they might find out. She does not want a sexual relationship and finds it very difficult. She did not get any FPC.

(43) Her lifestyle had to change. She tries to take better care of herself “From a carefree lifestyle to something you now consciously have to consider”. Her sexual relationship became very difficult. Her partner experienced the use of condoms as rejecting from herself. She is very scared. She did not experience the counselling as very supportive.

(46) She does not feel good about life anymore. She tries to take better care of herself. She does not want another baby. She became scared to have a sexual relationship. She feels positive about counselling “It helped me to become strong”.

(h) Code/concept: Future family planning

The following codes emerged from the text obtained from the different study groups: knowledge on risk reducing intervention (RRI) and family planning (FP); need for improved services; access to RRI and FP.

(h) HIV-positive men

(21) He did not know about risk reducing intervention in becoming a parent in a safe way. Will consult with doctor at the clinic. He very much wanted services to be extended to help HIV-positive people becoming parents. He did not know about any specific place to go for risk reducing intervention and family planning.

(20) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(22) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(51, 52) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(23, 24) Knew about RRI. Accidently became across research project on the internet. Was very suspicious of the procedure. Wants more information and services to be extended to other HIV positive people. Knew where to go for RRI and FP.

(45) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(47) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(48) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(50) Had some idea about RRI but not sure. Wanted services to be extended to other HIV-positive people. Did not know where to go for RRI and FP will speak to doctor at the VCT clinic.

(51) No knowledge on RRI. Very much wanted services to be extended to other HIV-positive people. Had no idea where to go for RRI and FP.

(h)HIV-positive pregnant women

(13) She had some idea of AI procedures from watching TV. She does not want to explore RRI and FP because she is very unsure about her future.

(10) She had no knowledge on RRI and FP. She was not interested in RRI and FP as she has no support from her partner.

(11, 12) She had some knowledge about having a baby in a safe way by watching TV programmes. She wanted services to be expanded to help HIV-positive people. She knew about a hospital offering IVF treatment.

(14) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(16) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(17) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(25, 26) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She will contact the doctor at the clinic.

(27) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(28, 29) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(30, 31) She had no knowledge on RRI and FP. She wanted services to be expanded to help HIV-positive people. She did not know where to go to get RRI and FP.

(h)HIV-positive non pregnant women

(8) She did not know about safe ways of becoming a parent. She wished for the virus to be taken away. She did not know where to go for RRI but will consult the doctor at the VCT clinic.

(9) She did not know about safe ways of becoming a parent. She was not interested in any way to have another baby. She did not know where to go for RRI> she wanted a husband.

(32, 33) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI but will consult the doctor at the VCT clinic.

(34) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(35) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(36) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(39) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(42) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(43) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(46) She did not know about safe ways of becoming a parent. She wanted services to be expanded. She did not know where to go for RRI

(i) Code/concept: Counsellors' perception of HIV clients' child desire

The following codes/concepts emerged from the text obtained from the group discussions at both clinics: perceived need; age related difference in need; biological offspring

(i) ANC

Counsellors perceived a need with HIV-positive women to be parents.

“They do not give up because they are HIV positive”

However older HIV-positive women who are already parents tend to accept the pregnancy compared to younger HIV-positive women who would want to abort.

“The older ones do not have a problem, but the younger ones do not want to be parents, but unfortunately it is too late for them”

They want another baby before they become sick. They will have another baby because previous baby was unaffected. Another baby will be proof of her own good health.

(i) VCT clinic

Counsellors perceived some need with their clients to have more children. However there is a difference between younger and older people. The younger persons will ask “what am I going to do?” Compared to older persons asking “how long will I stay alive?” It is of great importance to have biological child.

“Especially people who do not have children”

“Even if they die they have left something of their own”

“The seek more information...they want to know what are my options, uhm, they want to do the *in vitro* or they want to do other forms of fertilisation. But most people they do not have the information and they live in the stigma...”

“The young people still want to know how they can become parents in a safe way”

” Some they come there and they say they want to conceive the baby...”

“... people say one plus one equals she is HIV-positive. And then they try and get pregnant to disproof that they are HIV-positive.”

“and now what you find is that people try to get pregnant to proof that they are not HIV-positive. Because there are so many stigmas out there...”

“They will go so far as to inseminate the wife’s sister so that the husband can have his own biological offspring”

(j) Code/concepts: Counsellors’ feelings about HIV and reproduction

The following codes/concepts emerged from the text obtained from the group discussions at both clinics: positive/negative attitudes; personal belief; advice on future babies.

(j) ANC

Regardless of adhering to effective treatment regime all counsellors at the ANC were negative in their attitudes towards their clients’ reproductive needs.

“I know the fact that there is a possibility that the mother who is pregnant while she is HIV-positive there is a possibility that she might transmit the virus to her baby”

“The fact that I am HIV-positive change nothing”

“After the deliver you become weak...when you are HIV-positive it is weak times 2”

Counsellors do not believe that treatment during pregnancy is effective. They are convinced that life become very difficult for HIV-positive women during pregnancy. The counsellors advised their clients not to have any more babies and to be sterilised.

(j) VCT clinic

Counsellors were positive in their attitudes towards their clients' reproductive needs.

“I think they have a right to that, I do support them and encourage them to go ahead”

“I think the HIV/AIDS program or the VCT clinic program is not encouraging ...that is why you have the older nursing staff being more directive in discouraging people to conceive when they are HIV-positive...some of the nursing staff they are very negative and they express that..”

” They should have babies...as long as they go for the check-ups and do the right thing and not conceive on their own.

“no they must have babies... if you are HIV-positive it does not mean you must not have the family...you must have a family... they must know their status...”

.” it is difficult... you just sit and think this grandparent is becoming a parent again...so on that grounds it is not easy for me to say they should or they should not become parents, it is just.”

(k) Code/concept: Counsellors' HIV knowledge/information needs

The following codes/concepts emerged from the text obtained from the group discussions at both clinics: knowledge on RRI; counselling focus.

(k) ANC

Counsellors had no knowledge on risk reducing intervention. Clients are mainly counselled on viral transmission during pregnancy, birth and breastfeeding. The counsellor's response to questions about risk reducing intervention was the following.

“I focus on the baby and the mother, to be honest I do not touch too much on the partner...usually the women do not want to talk about the partner.”

“I can say 80% of the women are faithful women...their husbands bring HIV into their relationships”

(k) VCT clinic

Counsellors had some knowledge on risk reducing intervention and knew about the program on risk reducing intervention at the Steve Biko Hospital. At Kalafong hospital clients are mostly referred to counsel the doctor at the VCT clinic. The Counsellor's main focus is on HIV infection and prevention of transmission by advising clients to always use condoms to protect the partner and the baby from infection. They also advised clients to watch the CD4 count when planning to conceive naturally.

"It is reducing the risk of the baby getting infected..."

"So the safe way is to go for *in vitro*..."

"From partner to partner there is a high risk because most men do not allow their partners to use condoms"

"I do not know if it is correct...but I think it is that they take a sperm from a man and then they inject it into the womb...a female womb.."

"I explain to them that there is a way that a doctor can assist them to have a baby"

(l) Code/concept: Counsellors' HIV training needs

The following codes/concepts emerged from the text obtained from the group discussions at both clinics: reproductive future awareness; RRI and FP knowledge level; need for training.

(l) ANC

Counsellors had no knowledge on risk reducing intervention. To them it was a new perspective to consider their clients in terms of their reproductive future.

"No actually we do not know anything"

A great training need was expressed with regards to risk reducing intervention and family planning.

"I think we need lots of information... we are dealing with people who are already pregnant".

"If someone can come out and ask I want to have children in a safe way, how do I do it? I will not be able to counsel them"

"We never thought about it, we never sat down and actually tell them about their future, especially these younger ones...18 years, it is possible that she can have more children"

“No we do not talk about the future”

“We do need training...we do not know about family planning, they must fit it in training for us, a ten day course, to teach us how do you counsel, what are the various options and how does everything work in the laboratory”

(I) VCT clinic

Although the main focus is on HIV infection and prevention counsellors expressed a great need for more information and training regarding risk reducing intervention and family planning. Family planning counselling is only done when couples attend the clinic.

“We are given basic information”

“We are doing our best to give family planning and to prevent the transmission of the virus”

“For family planning I send them to the clinic. I do not know about a specific place where they can get risk reducing intervention.”

” yes, there is a need because the HIV information changes everyday..it is a very dynamic field so we need training whenever there is a new thing so we can give information...because if we are behind with information the people will not get the information..”

“..it starts with 15 up to 20 clients per day, so they see a lot...and unfortunately with the training that they had its...I think the training should be broader, I think that the training counsellors receive is very limited..and one of the discussions that I had with them is that sometimes you find that the nursing staff would attend the sessions instead of the counsellors...and the nursing persons is supposed to come back and give them feedback...”

“... so some of the information will be lost if they cannot ask their questions directly...”

” uhm, especially the discordant couples...there is a big big problem...cause we do not have the real information, how are we going to tell them how can one be positive and one be negative if we have been sleeping for over 9 years...?”

“they just say this kid is playing with us...but if you have the information you just talk to them like this and to tell them where to go to people who can help them...”

Addendum I: Memo of Initial Interpretation

To all **HIV-positive men** parenthood was personally important. Reasons given: “to be a family, to care for my future, to have responsibility and not to be alone.” Culturally parenthood is important mainly because: **of having an identity**: e.g. as a Zulu “you are not a man”; as a Ndebele “you are not seen as a human being” and as a Tswana “a child for one family is a child for the whole society”.

Most of the **HIV-positive pregnant women** reported parenthood as being important. They said: “give you reason to live, child is ally in marital dispute, to nurture and love the family, not to be alone, future security, **to establish my value as a woman.**”

Parenthood was culturally important to most women: “it shows how much woman you are, it is a stamp of approval”.

Most of the **HIV-positive non pregnant women** reported parenthood personally important, as saying: “I need a baby, gives me responsibility, I will not be alone, my mother wants a grandchild, I want a baby before I dies, for my future. To prove that I am a mother. People will treat you that there is something wrong with you.” Culturally the majority reported that parenthood was important to married couples: “his **family would want you to have a baby, you must have a husband and a big family, they will disrespect you for not having a baby.**”

The **HIV-positive men** expressed not having children as: “personally very painful, unhappy, alone, difficult, stressful, forced to adopt and **actually kills the family**”. With regards to their position in the family, they said: “ I stay my mother’s child, I must get another women, I must marry another wife, I stay with my wife and adopt or divorce and remarry”. Culturally “ there is nobody to call you Baba, you are not man enough, disregarded as a man, being pressured once you are 21 to have children, they look at you differently, he will be expected to take care of his brothers children.” Most of the **HIV-positive pregnant women** described not having children as: “sad, painful, difficult, alone, without support in old age, devastating, **having a baby was seen as her right.**” Her position in the family was described as: “there will be pressure from the family in-law and she will be divorced by the husband.” Most women reported not having children will seriously impact on their role as women within their cultures:

“They are disregarded as women, childless women who have been divorced become the prostitutes and live by themselves.”

Most **HIV-positive non pregnant women also** reported not having children as “painful, very bad, heartbreaking, stressful as everybody ask why, you will be alone, difficult because people calling names.” “You will not get married because most men want babies. If you don't have a child you will be lost. People look down at you and that changes everything.” Most women reported that her position in the family will change because " family will put pressure on her to have a baby, ultimately that will turn her husband against her, her husband will divorce her and re marry, husband will cheat on her and take a second wife, the man will not marry her.” Most women reported that not having children is culturally important because : “she is expected to have many children but they must be healthy, she will not be respected and called names **"they will call you rubbish", your value as a women is determined by your ability to have children.**”

The respective communities of both men and women living with HIV/AIDS were not supportive of HIV-positive people having babies. I quote some of the participants: “We are seen as sick people, going to die. Once they know your status they do not come to your house because you might infect them”.

All **HIV-positive men** were very scared of transmitting the virus but some wanted another baby regardless of status.

Most **HIV-positive pregnant women were** very concerned about the health of their babies. One woman was not concerned about transmission of the virus to her baby as the father tested HIV-. Most women reported that the baby came at a good time in their lives, while others reported the baby was a mistake, because their partners did not want to use condoms

The HIV-positive non pregnant women were very scared of transmitting the virus to their babies. One woman trusted the effectiveness of ARV medication and was not scared of transmitting the virus.

Most of the **HIV-positive men's** partners wanted to have another baby regardless of their status. All of the men were in supportive relationships. In most couples both parties were HIV-positive.

Most of the **HIV-positive pregnant women's** partners very much wanted a baby. Half of partners knew about her HIV-positive status: the rest will disclose once the baby test negative, and I quote: "It makes it better for me if there is a healthy baby." Only some women were in supportive relationships; while the other women were deserted or were scared of being deserted by the partners once they disclose.

Some of the **HIV-positive non pregnant women's** partners wanted another baby. Most of their partners knew about her HIV-positive status. Some of the partners rejected the women because of her status; while other partners find it very difficult to accept her status.

Most **HIV-positive men** did not take part in prevention programmes, however they were happy to always use condoms and they were motivated to combat viral transmission. They made valuable suggestions to improve men's attendance at the clinics: "men want appointments, more male staff, men's focus groups to enhance communication, mobile clinics to the people, to be able to attend clinic anonymously, programs to convince men to test and clinics to be open over weekends." Men wanted information on: "how to get a long life, to have a baby in a safe way, managing the disease, how parents should disclose to children, to have a healthy relationship after knowing partners status and about their future."

In contrast to **HIV-positive pregnant women**, most **HIV-positive non pregnant women** did not take part in prevention programmes. 1 woman reported to have consulted a sangoma.

Most **HIV-positive men** were taking better care of themselves. In some cases the sexual relationships did not suffer while others became scared and very strained. Counselling was experienced as very positive and supportive by most, but only half received family planning counselling.

Only some of the **HIV-positive pregnant women** reported life is better and they are taking better care of themselves. Most reported she is not feeling strong, thinks everybody knows about her status. Her life is upset by her diagnosis. She feels sad about her future. She is very lonely. Some felt safe using condoms and the sexual relationship did not suffer, while all the others became scared of having intercourse. Half the women wanted to have the baby more after knowing their status. Counselling

services was reported as supportive and good by half the women, but only some reported to have received family planning counselling.

The majority of **HIV-positive non pregnant women were** taking better care of themselves in terms of diet, exercise and taking medicine. Others reported not to have any friends, to have lost weight, to be very lonely, her life has changed from a carefree lifestyle to something she now had to consciously consider. Some women wanted a baby regardless of her status. Although half the number of women was in supportive relationships, most women became scared of a sexual relationship and did not get family planning counselling. Counselling services were described as supportive, I quote: "it helped me to become strong".

Both HIV-positive men and women had no knowledge on becoming a parent in a safe way. They all wanted services to be expanded, but nobody knew where to go for risk reducing intervention.

I quote the HIV-positive pregnant women as saying: "They still preach the message of prevention but they do not tell you what happens afterwards".

To get a holistic view on studying the reproductive needs of men and women living with HIV/AIDS and the implication to family planning, it was necessary to include the HIV counsellors as well.

Counsellors at the ANC and the VCT clinic had both positive and negative attitudes towards HIV-positive people having babies (refer to slide). Older counsellors were more cautious with regards to contributing towards HIV orphan numbers.

Counsellors at both the ANC and the VCT clinic perceived their clients to have a need for more children regardless of their status. There was a difference in needs among men and women as well as a difference in needs among older and younger people.

Counsellors at the ANC did not have knowledge on RRI. The focus is on the baby and the mother. Patients are counselled not to have any more babies. They are advised to have a sterilisation.

Counsellors at the VCT clinic had a fairly good knowledge about RRI. Their main focus is on family planning and prevention of infection. Clients are referred to the doctor, the clinic and Steve Biko hospital. When their attention was directed towards their clients' reproductive future **counsellors at the ANC also** wanted to learn more about RRI. However, counsellors concerned about quality of training and effect of secondary knowledge transfer by nursing staff.

To Summarise: Most of the participants were unemployed, poor and very scared to talk about something they might have to endure further stigmatisation.

The **HIV-positive men** taking part in the study were experienced as very motivated to combat viral transmission. They contributed practical suggestions to enhance men's attendance at the clinics by focussing on the different needs that men have. They were very interested to learn more about safe ways of becoming parents.

The **HIV-positive pregnant women** were experienced as very sad and scared to talk about their future. Most of them were not in supportive relationships while others feared they will be deserted by their partners upon disclosure of their status. Some of them said **they do not have a voice** to speak of such matters and described their babies as a mistake because their partners would not use condoms.

The **HIV-positive non pregnant women** were experienced as having a middle of the road attitude towards having more children in the future. Only some of them wanted to have more babies. Most of them have disclosed their status to their partners.

The **HIV counsellors** at both clinics are doing the best they can to support men and women living with HIV/AIDS; however their focus does not necessarily include the reproductive futures of their clients. All counsellors expressed a need for more information on risk reducing intervention as they have a considerable span of influence in terms of the numbers of HIV-positive clients that they serve.

On a personal note, the research project was experienced as challenging but very enriching. It was very difficult to setup a research project in an environment where people are too scared to talk about such a sensitive issue as HIV/AIDS. It felt good to reach out to them and to hold their babies; it gave a "face" to the disease. I was often asked the question **WHY...**, am I doing this?