THE IMPACT OF HIV AND AIDS ON PLANNED PARENTHOOD
IN THE AREA OF MTHATHA

BY
BULELWA PLAATJIE

Submitted in fulfilment of the requirements for the degree of

MASTER OF ARTS IN SOCIAL SCIENCE
in the subject

SOCIAL WORK
at the
UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: MRS A. PETTY

CO-SUPERVISOR: DR A. ALPASLAN

NOVEMBER 2009
SUMMARY

This was an ethnographic, exploratory, contextual and descriptive study on the impact of HIV & AIDS on planned parenthood in the area of Mthatha. This study explored the motivations behind the decision taken by HIV-positive women to procreate despite the risk of vertical transmission, infection or re-infection, and subsequent disease progression in themselves. Women who had taken this decision were observed and interviewed through participatory observation, focus group discussions, and semi-structured interviews. The decision to procreate in spite of the HIV-positive status was discovered to be influenced by Xhosa cultural prescripts, Christian beliefs and the non-inclusion and involvement of men in antenatal services. It emerged that men were viewed to be decision makers in sexual and reproductive matters. The findings of the study highlighted the need for counselling services to be offered by antenatal clinics to women and men so that more collective informative decisions around procreation will be made.

**Key words:** HIV, AIDS, planned parenthood, procreation, Xhosa culture, HIV-positive pregnant women, ethnographic field study, Mthatha region, post-test counselling, women and HIV, vertical transmission, ARVs, Christian belief, gender differences, orphans due to HIV & AIDS.
EXECUTIVE SUMMARY

This study was conducted in order to explore the reasons why HIV-positive women procreated despite the risks of vertical transmission, infection or re-infection of the partner, and subsequent disease progression within themselves. This study also aimed to assess the extent and the nature to which HIV-positive women are informed about such risks; and whether family planning antenatal clinics should offer specific counselling programmes to HIV-positive women and their families? To achieve this, the study observed HIV-positive pregnant women and those that had babies after being diagnosed with HIV using qualitative methods of enquiry. These were the explorative, descriptive, contextual and ethnographic strategies of enquiry. The study was guided by the culture life span approach of Trommsdorff (2002) based on the assumption that the life cycle development stages are influenced by culture. This approach helped the researcher to get a cultural perspective of the reasons why HIV-positive women procreated despite all the risks. This study also acted as a preliminary study that would generate hypotheses for more in-depth studies in order to help inform strategic planning aimed at mitigating HIV & AIDS.

The research process was conducted in four stages. The first stage was based on exploring the topic through overt and covert participatory observation and semi-structured interviews with the key informants for the study. These were two nurses, one social worker, an anthropologist, and a traditional chief. The second stage focused on developing the research methodology, where a total sample of forty eight HIV-positive women was selected from the People Living with HIV (PLWHIV) and the Prevention of Mother-to-Child Transmission of HIV (PMTCT) support groups conducted by four antenatal clinics in Mthatha. These were the Infectious Disease Centre (IDC), Ngangelizwe, City Centre, and Civic Centre clinics. To ensure a homogenous sample, the following variables were controlled: age (twenty to forty years), gender (women), ethnicity (Xhosa), and health condition (HIV-positive pregnant women, and women
who had given birth to babies after their HIV-status had been diagnosed). The selected sample was then divided into eight groups of six women according to age. These groups of women were interviewed using focus group discussions. Two of the eight groups were used for the pilot study, which served as the third stage of the research process. The pilot study gave direction to the number of focus group meetings that needed to be held for each group (three meetings), the length of each meeting (one and a half hours), the need to introduce ice-breakers in the form of songs and refreshments. The fourth and last stage of the research process was concerned with data collection from the participants of the study. Data was collected through focus group discussions and semi-structured interviews by the research team, which consisted of the researcher, two nurses and a social worker. Data was captured through process notes and a tape recorder, and later transcribed and coded by the research team.

The findings of the study yielded that the decision taken by HIV-positive women to procreate despite the associated risks was influenced by:

- The Xhosa cultural prescripts which exerted social pressure on those young adults who fail to procreate, particularly females. This social pressure is usually in the form of discrimination, condemnation and ostracism.
- The non-involvement and non-inclusion of men in antenatal services as they play a significant role in the decision to procreate. As Friedman, Bam, & Mthembu (2006) posited, men hold decision making power over sexual relation matters, such as when or whether to have a child and health seeking behaviour.

For those women who learned of their HIV-status when pregnant but opted to carry their babies to term instead of the alternative to terminate the pregnancies, their Christian beliefs together with the Xhosa cultural values were attributed as the main reasons for their decision to see their pregnancies to full-term. There was a strong anti-abortion view.
The findings of the study found the decision to procreate, to be a less informed one, because the post-test counselling offered as evaluated by the participants was considered to be ineffective, and the support groups lacking in professional facilitation.

The participants suggested follow-up post-test counselling sessions involving their partners and/or family members in order to help them cope with their HIV-status, and be in a better position to make a collective informed decision with partners about procreation.

The study therefore made the following recommendations:

- Counselling services should be regarded as a method of treatment in psychosocial care of HIV-positive pregnant women and should be rendered by professionally trained practitioners such as psychologists and social workers based in the health clinics.

- Practitioners in the Mthatha region should develop inter-sectoral debates with stake-holders involved in the fight against HIV & AIDS, such as Non Governmental Organizations (NGO’s), the church, community leaders, and Government Departments. These should attempt to empower and protect the rights of women in this region.

- The Department of Health’s policies should focus on strengthening psychosocial services offered within their health centres.

- Further research should investigate how the Xhosa culture can strengthen itself against the HIV pandemic, focus on prevention methods and develop culturally sensitive strategies to mitigate its impact.
ACKNOWLEDGEMENTS

My grateful thanks to:

- The National Research Foundation (NRF) for financial support.
- My supervisor, Mrs Ann Petty, who mentored, supported, and motivated me to complete this dissertation. Thank you for your patience. I have learned a lot from your mentorship.
- Prof. Van Delft and Dr Alpaslan, you have also played an important role in the completion of this dissertation. Thank you for your time, guidance, and kind words of encouragement.
- The two nurses, social worker, anthropologist, and traditional chief, for the part they played in providing information that helped to explore the topic.
- The research assistants who helped collect raw data for the study. This would have been an impossible exercise without your assistance.
- Spar, Spargx, and Kie Cash and Carry, who donated taxi fare and refreshments for the focus group discussions. Data collection would not have been possible without your donations.
- The research trainer, Siyabonga Mfuna, for training the research team.
- The participants who made this study possible. Thank you for welcoming me and my idea to explore such a sensitive topic. Thank you for sharing your experiences with the rest of South Africa.
- My family; my late mother, Zolelwa Plaatjie who aspired that her children excel academically. My father, Mlondolozi Plaatjie, brother Luthando Plaatjie, his wife, Khayakazi Plaatjie, and my two sisters, Bongiwe and Khanyisa Plaatjie thank you for your encouragement. “Dad I am one degree away to wearing the “red (PhD)” academic attire you so eagerly desire for your children to attain.”
• My friend, Yolanda Saunders, who although I have known her for a short while, her prayers and encouragement have helped me a lot. It is good to have a sister in Christ to fight the good fight of faith with. God bless you.

• My companion, Kabelo Cornelius Maduna, who edited this dissertation sacrificing his time which he could have invested on his own research study.

• To my children, Asavela and Mokhantso Plaatjie, who understood through the years that they had to share me with my studies. Thank you for understanding that mommy had to sacrifice some of our family time for studying. Thank you my children. My success is your success.

May God empower all of you to succeed in all areas of your lives. You have called me blessed.
# TABLE OF CONTENTS

## CHAPTER ONE: CONTEXT AND PURPOSE OF THE STUDY

1.1 INTRODUCTION .................................................. 1

1.2 Formulating the Problem ....................................... 2

1.3 Context of the Study ........................................... 3

1.4 Motivation for the Research ................................... 5

1.5 Goals and Objectives for the Study ......................... 6

1.6 Critical Questions .............................................. 7

1.7 Research Methodology ......................................... 8

1.8 Underlying Assumptions ....................................... 10

1.9 Value of Findings ................................................ 11

1.10 Conceptual and Operational Definition of Concepts .... 11

1.11 Outline of the Research Report .............................. 12

1.12 Summary ........................................................ 14
CHAPTER TWO: THE PSYCHOSOCIAL AND SOCIO-ECONOMIC IMPACT OF HIV AND AIDS - A LITERATURE REVIEW

2.1 INTRODUCTION

2.2 The Demography of HIV & AIDS in South Africa

2.2.1 HIV & AIDS and antenatal figures

2.3 The Economic Implications of HIV & AIDS

2.4 The Challenges of HIV & AIDS to the Provision of Social Services.

2.5 HIV-infection in families

2.6 The Impact of HIV & AIDS on Children in South Africa

2.7 Summary

CHAPTER THREE: WOMEN AND HIV & AIDS - A LITERATURE REVIEW

3.1 INTRODUCTION

3.2 Gender Differences in HIV-Infection

3.2.1 Gender differences in the natural history of HIV-infection

3.2.2 Gender Differences in Clinical manifestations of HIV & AIDS

3.3 Women’s Gender-Specific Susceptibility to the HI-Virus
3.3.1 Socio-economic status of women and the HI- Virus 34

3.4 A Rights Based Approach to HIV & AIDS and the Protection/Empowerment of Women and Girls. 38

3.4.1 Women’s Right to Health 39

3.4.2 Standards on Violence against Women 40

3.4.3 Standards on Discrimination against Women 41

3.5 Summary 43

CHAPTER FOUR: THE REPRODUCTIVE DECISION - A LITERATURE REVIEW

4.1. INTRODUCTION 44

4.2 FACTORS INFLUENCING THE HIV-POSITIVE MOTHER’S DECISION NOT TO PROCREATE 45

4.2.1. Prenatal Transmission of HIV-Infection 47

4.2.2. Perinatal Transmission of HIV-Infection 47

4.2.3 Postnatal Transmission of HIV-Infection 48
4.3 PSYCHOSOCIAL FACTORS INFLUENCING THE HIV-POSITIVE MOTHER’S DECISION TO PROCREATE. 50

4.3.1 The influence of Cultural Beliefs on the HIV-Positive Mother’s Decision to Procreate 50

4.3.1.1 Reproduction and survival of the family name 51

4.3.1.2 Reproduction as a means of male dominance 51

4.3.2 The influence of Religious Beliefs on the HIV-Positive Mother’s Decision to Procreate 52

4.3.3 Intrapersonal motivating factors for reproducing offspring 53

4.3.3.1 Reproduction and identity issues 53

4.3.3.2 Desire to experience parenthood 53

4.3.4 The influence of Poverty on the HIV-Positive Mother’s Decision to Procreate 54

4.3.5 Media and Peer Pressure 55

4.3.5.1 Unrealistic perceptions about adult life and relationships perpetuated by the media, 55

4.3.5.2 Adolescents operate under a large number of misconceptions about sexual Issues 55

4.3.5.3 Adolescents believe that they are invincible 55
4.3.5.4 Other Reasons for teenage pregnancy 55

4.4 SUMMARY 56

CHAPTER FIVE: A DESCRIPTION OF IMPLEMENTATION OF RESEARCH METHODOLOGY EMPLOYED IN THIS RESEARCH PROJECT

5.1 INTRODUCTION 58

5.2 Research Questions 58

5.3 Research Approach and Design 59

5.4 Theoretical Framework 61

5.5 The Research Process 63

5.5.1 Stage One: Exploring the topic through the ethnographic field study 63

5.5.2 Stage two: Developing a Research Methodology 64

5.5.3 Stage Three: The Pilot Project 72

5.5.4 Stage Four: The Data Collecting Process 74

5.5.4.1 Focus group discussion sessions and semi-structured interviews 74

5.5.4.2 Data capturing and editing 76
5.6 Criteria for Judging Qualitative Research 77

5.7 Data Analysis 79

5.8 Limitations of the Study 80

5.9 Ethical Considerations 81

5.10 Summary 82

CHAPTER SIX: THE RESEARCH FINDINGS

6.1 INTRODUCTION 84

6.2 Presentation of Results 85

6.2.1 Exploring the Topic through the Ethnographic Field Study 85

6.2.1.1 Interviews with the anthropologist and traditional chief 87

6.2.1.2. Interviews with the nurses and social worker 93

6.2.2 The Pilot Project 104

6.2.2.1 Findings taken from pilot study 107

6.2.3 The data collected from the focus groups 111

6.2.3.1 The profile of the sample according to age 112
6.2.3.2 The profile of the sample according to socio-economic status 112

6.2.3.3 The profile of the sample according to highest level of education attained 114

6.2.3.4 The profile of the sample according to marital status 114

6.2.3.5 The profile of the sample according to the number of pregnancies/children after the diagnosis of HIV-positive status 115

6.2.4 Presentation of the sample for each focus group 116

6.2.4.1 Focus group one 116

6.2.4.2 Focus group two 117

6.2.4.3 Focus group three 118

6.2.4.4 Focus group four 119

6.2.4.5 Focus group five 120

6.2.4.6 Focus group six 121

6.2.5 Data capturing and editing 122

6.3 Discussion of Findings 127
6.3.1 Discussion of the Focus Group Data

6.3.1.1 Reasons for Taking the HIV Test

6.3.1.2 Thoughts and reactions prior and subsequent to the HIV test

6.3.1.3 Women’s account of the HIV testing process

6.3.1.4 Life after discovering their HIV-status

6.3.2 Discussion of Semi-Structured Interviews

6.3.2.1 The need for special counselling and preventive services for HIV-positive pregnant women and their families in antenatal clinics.

6.3.2.2 Feelings about the focus group experience

6.3.2.3 The impact of the focus group experience on the participant’s life

6.3.2.4 Sensitive topics which touched the participant during the discussion (topics they could not discuss in the group)

6.4 Summary of Findings

6.4.1 Research question one: What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?
6.4.2 Research question two: To what extent and in what nature are HIV-positive women informed about such risks? 152

6.4.3. Research question three: From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families? 153

6.5 Concluding Summary 154

CHAPTER SEVEN: CONCLUSIONS, SUMMARY, AND RECOMMENDATIONS

7.1 INTRODUCTION 156

7.2 The Rationale for and Context of the Study 156

7.3 Theoretical Framework 157

7.4 Objectives of the Research 158

7.5 Conclusion of the Study Based on the Research Methodology 160

7.6 Conclusions of the Study Based on the Research Findings 161

7.6.1 What are the Reasons behind HIV-Positive Women to Consciously Plan Parenthood despite the Risk of Vertical Transmission, the Infection or Re-Infection of a Partner, and the Risk of Hastening Disease progression? 161

7.6.2 To What Extent and In What Nature Are HIV-Positive Women Informed About Such Risks? 163
7.6.3 From The Perspective Of HIV-Positive Women Should Family Planning Antenatal Clinics Offer Specific Counselling To HIV-Positive Pregnant Women and their Families? What Should These Programmes Cover? 164

7.7 Summary of Identified Themes 165

7.8 Recommendations 165

7.8.1 Recommendations for Practice: Counselling Services Should Be Prioritised and Form an Integral Part Of The HIV & AIDS Treatment Regime 165

7.8.2 Recommendations for the Practitioners Dealing With HIV-Positive Pregnant Women in the Mthata Region; Specifically 166

7.8.3 Policy Recommendations 167

7.8.4 Recommendations for Future Research 168

7. 9 Limitations of the Study 168

7.9.1 Generalisability of the Study 168

7.9.2 Loss of Meaning 168

7.10 Summary and Final Note 169

LIST OF REFERENCES 171
ANNEXURES

Annexure 1: Semi-Structured Interviews for Exploring The Topic 184
Annexure 2: Interview Guide for the Focus Group Discussions 186
Annexure 3: Semi-Structured Interviews 187
Annexure 4: Copy of Letter Requesting Permission to Collect Data from Mthatha General Hospital 188
Annexure 5: Copy of letter of the Response from Mthatha General Hospital/Mthatha Hospital Complex 190
Annexure 6: Copy of Letter Requesting Permission to Collect Data from the KSD Municipal Clinics 191
Annexure 7: Copy of Letter of the Response from KSD Municipal Clinics 193

LIST OF TABLES

TABLE 1.1: HIV prevalence rates by mid 2006 4
TABLE 5.1: Selection of the Sample 68
TABLE 5.2: The Recruitment of the Participants of the Study 69
TABLE 5.3: Focus Group According to Clinics 71
TABLE 5.4: Codes used to Track Themes 76
TABLE 5.5: The criteria for Judging both Quantitative and Qualitative Research 77

TABLE 6.1: Demographic Information of Pilot Groups 105

TABLE 6.2: Group A & B for the Pilot Focus Group Findings 108

TABLE 6.3: Pertinent Demographics of the Sample Profile for the Six Focus Groups. 111

TABLE 6.4: Final List of Themes used when Analyzing Data 123

TABLE 6.5: Summary of Findings for Research Question One. 149
### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-Retroviral Therapy</td>
</tr>
<tr>
<td>ARVs</td>
<td>Anti-Retroviral Drugs</td>
</tr>
<tr>
<td>ASSA</td>
<td>Actuarial Society of South Africa</td>
</tr>
<tr>
<td>CEDAW</td>
<td>Convention on the Elimination of all forms of Discrimination Against Women</td>
</tr>
<tr>
<td>CGE</td>
<td>Commission on Gender Equality</td>
</tr>
<tr>
<td>CSG</td>
<td>Child Support Grant</td>
</tr>
<tr>
<td>DOH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>D4T</td>
<td>Stavudine</td>
</tr>
<tr>
<td>EDM</td>
<td>Ethnographic Decision Model</td>
</tr>
<tr>
<td>ELISA</td>
<td>antibody Enzyme-Linked Immuno Sorbent Assay</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HSRC</td>
<td>Human Science Research Council</td>
</tr>
<tr>
<td>IDC</td>
<td>Infectious Disease Clinic</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>KSD</td>
<td>King Sabatha Dalindyebo</td>
</tr>
<tr>
<td>NDSD</td>
<td>The National Department of Social Development</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organization</td>
</tr>
<tr>
<td>NPO</td>
<td>Non Profit Organization</td>
</tr>
<tr>
<td>NRF</td>
<td>National Research Foundation</td>
</tr>
<tr>
<td>NVP</td>
<td>Nevirapine</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living With HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission of HIV &amp; AIDS.</td>
</tr>
<tr>
<td>PTC</td>
<td>Post- Test- Counselling</td>
</tr>
<tr>
<td>SAHRC</td>
<td>South African Human Rights Commission</td>
</tr>
<tr>
<td>SRHI</td>
<td>Sexual Reproductive Health</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>TBVC</td>
<td>Transkei, Bophuthatswana, Venda, Ciskei</td>
</tr>
</tbody>
</table>
3TC : Lamivudine
UN : United Nations
UNAIDS : United Nations Joint Programme on HIV
UNFPA : United Nations Population Fund
VCT : Voluntary Counselling & Testing
WHO : World Health Organization
WSU : Walter Sisulu University
ZDV : Zidovudine
CHAPTER ONE
CONTEXT AND PURPOSE OF THE STUDY

1.1 INTRODUCTION

Gaffèn (2006) states that in the past decade, South Africa was considered to have the fifth highest occurrence of HIV & AIDS cases in the world. This figure can be attributed to the Government’s lack of leadership and confusion over the issue of HIV & AIDS, which led to a situation where mixed messages were sent to the general public. For example, the State advised people to condomize, be faithful, or abstain from sex in order to prevent HIV-infection; whilst at the same time stating that the statistics of HIV & AIDS were racist notions about African sexuality (Gaffèn, 2006).

Khumalo (2008) argued that the United Nations Joint Programme on HIV statistics state a different view. These statistics suggest that South Africa is one of the three countries in the Southern African continent where the prevalence of HIV has stabilized. This was confirmed by the Health Minister Manto Tshabalala - Msimang when presenting the Department’s budget vote in Parliament last year (June 2008). Tshabalala-Msimang stated that the prevalence of HIV & AIDS among pregnant women aged between fifteen and nineteen in South Africa has continued to decrease over the past two years. She further noted that the preliminary findings of the latest survey of HIV & AIDS prevalence among pregnant women attending public antenatal clinics reported a downward trend in the prevalence of HIV & AIDS. Zwane (2008) reports that the Minister informed Parliament stating that the 2007 survey shows that HIV & AIDS prevalence has decreased from an estimated 29.2 percent in 2006 to 28 percent in 2007. HIV prevalence in the fifteen to nineteen age group dropped from 13.7 percent in 2006 to 12.9 percent in 2007; while a decrease was observed in the twenty-five to twenty-nine year age group from 38.7 percent in 2006 to 37.9 percent in 2007. The HIV & AIDS prevalence rate in the twenty to twenty-four age group stabilized between 2006 and 2007. Taken together,
these figures suggest that the country has a trend of a decreasing prevalence overall and in the younger age group. This trend is in line with the predictions of the United Nations AIDS agency Spectrum model. In her speech, Tshabalala - Msimang attributed these encouraging trends to the intensive prevention campaigns that are beginning to make a difference in reducing HIV-infections; provision of treatment to those living with HIV & AIDS, with the Department of Health’s rollout of Anti-retroviral Drugs (ARVs) to more than 450 000 patients in more than 310 accredited sites across all nine provinces by the end of February 2008. In her closing remarks Tshabala-Msimang argued that the fact that South Africa accounts for 450 000 people out of the three million people on ARV treatment world wide by 2007 contradicted those who claimed the Government was not concerned about treatment (Zwane, 2008).

Khumalo (2008) argued that although the rate of the increase in HIV & AIDS prevalence has slowed down, the country is still to experience the devastating effects of the pandemic (such as orphaned children, child-headed households, and more households moving into absolute poverty due to the death of breadwinners). There are still too many people living with HIV & AIDS and too many still getting infected. According to the Department of Health’s National HIV & AIDS and Syphilis Antenatal HIV-Prevalence Survey, released in September 2006, the national average proportion of HIV-positive women attending antenatal clinics in 2004 was 29.5 percent.

1.2 FORMULATING THE PROBLEM

The "fundamental drivers" of the HIV & AIDS epidemic in South Africa are deep-rooted institutional problems of poverty, underdevelopment and the low status of women, including gender-based violence within the society (Khumalo, 2008). The immediate determinants of the spread of HIV & AIDS relate to behaviours such as unprotected sexual intercourse, multiple sexual partners, and biological factors such as vertical transmission. Vertical transmission as described by Khumalo (2008) is the passing on of HIV & AIDS from the mother to the baby either during pregnancy, birth, or through
breast-feeding. HIV & AIDS has a double impact on children, in that they may get infected with the virus and may also lose their parents to AIDS when they still need parental care. In light of the aforementioned aftermath left by the HIV & AIDS phenomenon, one would expect men and women to be cautious in their sexual behavioural and reproductive decisions; that they would decide not to have children if they are HIV-positive. But the high rate of HIV-positive pregnant women in South Africa depicted above shows that such decisions are not considered.

The reason why women reproduce even though they are aware of the risk of vertical transmission, and the possibility that they may die and leave their children orphaned and in need of care is of particular interest to the researcher. The goal of this research project was to explore and describe the reasons why HIV-infected women want to reproduce even though they are aware of the risk of vertical transmission and subsequent consequences that might cause them to die of AIDS, and leave a child behind who might be infected with the virus in need of care.

1.3 CONTEXT OF THE STUDY

The King Sabatha Dalindyebo (KSD) Municipality consists of Mthatha and Mqanduli. KSD forms part of the greater Oliver Reginald (OR) Tambo district municipality. Mthatha consists of ten urban locations, three semi-urban, two low income housing settlements, and three informal settlements. Mthatha has one comprehensive University called Walter Sisulu University, and two satellite Universities named the University of South Africa and Rhodes University.

Mthatha has many public and private schools, several sport grounds, one golf course, no stadium, and a few shopping centres. Tap water and proper sanitation is limited to urban settlements. The semi-urban and informal settlements use community stand pipes. Only the informal settlements do not have access to electricity. Fifty percent of the population is unemployed. There is consensus among the participants of the study that Mthatha is
characterized by high levels of crime, alcohol and drug abuse, domestic violence, child and elderly abuse. Most of the roads are tarred but have big potholes. According to the researcher’s observation Mthatha is a rural town which caters for quite a large number of surrounding villages.

The study took place within the Mthatha General Hospital and the KSD clinics. The Mthatha General Hospital has an antenatal clinic that services neighbourhoods surrounding it, such as Nduli, Fort Gale, Myezo, and Caravan Park. The three KSD municipality clinics from which data were collected included the Ngangelizwe, Civic Centre, and City Centre clinics. All three of these clinics render antenatal services to patients residing in the surrounding areas. For example, Ngangelizwe clinic caters for patients residing in Ngangelizwe, Mbuqe, and Khwezi. The Civic Centre clinic caters for patients residing in Ncambedlana, Northcrest, Hillcrest, and Maiden Farm and the City Centre clinic caters for patients who reside in the CBD (central business district) of Mthatha as well as surrounding suburbs.

A survey conducted in the Mthatha General Hospital by the Department of Health revealed that 47 percent of women attending the clinic were infected with HIV & AIDS (Department of Health Stats Schedule, 2006). The schedule also reported the Eastern Cape to be among the provinces that were disproportionately infected. According to Gafflen (2006) the HIV & AIDS prevalence rates by mid 2006 were as follows:

<table>
<thead>
<tr>
<th>HIV-infected women attending antenatal clinics</th>
<th>27.7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women aged 15 – 49</td>
<td>21.2%</td>
</tr>
<tr>
<td>Men aged 15 – 49</td>
<td>13.2%</td>
</tr>
<tr>
<td>Total population with HIV-infection</td>
<td>13%</td>
</tr>
</tbody>
</table>

| Number of Individuals                         |       |
Total Orphans | 225,618
---|---
Total AIDS orphans | 124,055

HIV staging:
- Asymptomatic Stage | 585,298
- Symptomatic Stage | 58,287
- On Antiretroviral Treatment (ART) | 21,371
- Discontinued ART | 1,866

(Source of table: Gaffen, 2006:33)

All antenatal clinics in Mthatha offer the Family Planning (prevention of pregnancy) services, Voluntary Counselling and Testing (VCT) and PMTCT for HIV-positive pregnant women. They educate women about the importance of knowing their status and the prevention of vertical transmission for those known to be infected with HIV & AIDS. Being a social worker and a lecturer in the area of Mthatha, who spent most of her career working with HIV & AIDS related cases; and a mother of a three year old and a person who had been born and raised in the area as ‘umXhosa’ (belonging to the Xhosa ethnic group) the researcher spent a lot of time observing and interacting with patients and clinic staff, exploring the reasons why HIV-positive women reproduced despite knowing the risks involved for their children and themselves. This exploration served as motivation for the research which is discussed in the next topic.

1.4 MOTIVATION FOR THE RESEARCH

In South Africa, a large number of people are infected with HIV & AIDS every day in spite of mass prevention campaigns. Young women fall pregnant despite the risk of contracting HIV & AIDS, undermining the attempts of the Government to mitigate the virus from spreading. The alarming incidence of HIV-positive women attending antenatal clinics suggests that many of the children who are born to these women are likely have basic needs compromised after their birth. Such as:
• Their mother’s health may be compromised.
• The risk of vertical transmission of HIV from mother-to-child increases.
• The risk of loosing biological parents before reaching adulthood is a reality.
• The compromised quality of life associated with families who struggle to manage the infection.

From the library and internet literature search made by the researcher there is little formal research on why these women choose pregnancy and giving birth in view of the bio-psycho-social risks that they and their offspring may endure as a result of their HIV-positive status. The high statistics of these pregnancies and births are incongruent with the services and resources that are developed to assist these young and developing families. More than ever before, health workers and people in other helping professions need to find ways to enable HIV-positive women to make sound choices regarding planned-parenthood.

The researcher, in her capacity as a social worker had experience of working with HIV-positive women who fell pregnant. She witnessed how some compromised their health and that of their babies together with the wellbeing of other family members. The researcher became interested to know the reasons why these women chose to reproduce in spite of all the dangers. She decided to empirically explore this phenomenon through participatory research. The researcher hoped that this study would act as a preliminary study for more in-depth studies that would help to inform strategic planning aimed at mitigating HIV & AIDS, as the current strategies in place appear not to be making adequate inroads into combating the pandemic.

1.5 GOALS AND OBJECTIVES FOR THE STUDY

Since there is little formal research on the reasons why HIV-positive women choose to procreate despite the risks, the main goal of this research project was to explore and
describe the reasons why HIV-infected women want to reproduce even though they are aware of the risk of vertical transmission and subsequent consequences that might cause them to die of AIDS, and leave a child who might be infected with the virus in need of care.

The objectives of the study were:

- To provide a locally specific perspective on the reasons why HIV-positive women procreated in spite of all the risks.
- To propose culturally specific interventions to reduce the incidence of vertical transmission from mother-to-child, disease progression within HIV-positive mothers, and cross infection of partners.
- To present a preliminary study that will generate hypotheses for more in depth studies that would help inform strategic planning aimed at mitigating HIV & AIDS.

1.6 CRITICAL QUESTIONS

According to Babbie & Mouton (2007) critical questions are essential for the consideration of the main topic. The critical questions of this study were formulated through the review of literature related to the topic with the aim to facilitate the process of realising the aforementioned goal. The critical questions were as follows:

1) What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?

2) To what extent and in what nature are HIV-positive women informed about such risks?

3) From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families?
1.6 RESEARCH METHODOLOGY

This study aimed to generate hypotheses for more in-depth studies on the topic, and thus followed a qualitative approach. According to Babbie & Mouton (2007) the purpose of qualitative research is to understand social life and the meaning people attach to it. Inherent to the qualitative approach the explorative, descriptive, contextual, and ethnographic strategies of enquiry were used. Bless & Higson-Smith (2000) state that the need for exploratory research usually arises out of lack of basic information on a new area of interest. The descriptive strategy of inquiry was used to describe that which was explored as posited by Neuman (2000). According to Hall (2006) ethnography engages covert and overt participatory observations which involve the researcher’s participation in the sample’s daily lives as much as possible. In covert participant observation the identity of the researcher is concealed, and in overt participant observation the identity of the researcher is revealed. In view of the fact that this study was interested in trying to establish whether there was a link between culture and the decision of HIV-positive women to procreate, an ethnographic field study was most appropriate. Therefore, the researcher studied HIV-positive women who planned pregnancies within the Xhosa culture through participatory observation. The study was guided by the Culture-Life Span Approach of Trommsdorff (2002). According to Trommsdorff (2002) culture offers options and restrictions for individuals during the developmental process. It assumes that culture provides a ‘shared meaning system’ that allows individuals belonging to a common culture opportunities to internalize certain cultural values and acquire specific adaptive competences relevant to the developmental stages. Therefore this study agrees with Trommsdorff. This study was concerned with discovering the developmental tasks of the adulthood stage within the Xhosa culture, and explored the extent of its influence on the decision made by HIV-positive women to procreate.

The study was conducted in four stages. The first stage was the exploration of the topic. During this stage, the researcher interacted with patients, a social worker, two nurses,
consulted an anthropologist and a traditional chief, and reviewed literature. The interviewed patients requested their names to remain anonymous. From these interactions, consultations, and readings, the researcher identified five themes which were used to construct an interview guide for focus group discussions. These were: ARVs; VCT; Xhosa culture and Christianity, including the importance of child-bearing, family values and beliefs systems; denial, stigma and discrimination, current status of health; ignorance and lack of knowledge. The second stage involved developing the research methodology. In keeping with the participatory paradigm that underpinned the study it was felt that focus group discussions would be most relevant. Focus group discussions are described by De Vos, Strydom, Fouche’, & Delport (2005) as carefully planned discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. The participants of the study did not reside in one locality and did not share a work place, therefore the most appropriate field sites for conducting the focus group discussions were the antenatal clinics. These were the Ngangelizwe, Civic Centre, City Centre clinics; and IDC. The researcher sampled forty-eight HIV-positive women from a sample frame of sixty-six women through the purposive sampling technique. Employing this non-probability sampling technique, the researcher purposefully handpicked participants who were information- rich because of their knowledge and ability to describe the phenomenon under study as posited by Babbie & Mouton (2007). All participants were members of the HIV & AIDS support groups that met at the clinics. The criteria used in the selection for inclusion in the study were, Xhosa pregnant women or women who had reproduced while HIV-positive in the age group of twenty to forty years. The forty-eight sampled women were grouped into eight focus groups according to age. The reason for clustering the focus groups according to age was that the study focused on human development tasks linked to particular stages in life.

The third stage was the pilot study. The focus group discussion questions contained within the interview guide were pilot tested. The interview guide is attached as annexure two. The researcher selected two pilot groups from the eight focus groups. The pilot focus groups were conducted to prepare the researcher about the process that needed to
be followed when facilitating the focus group discussions and to check whether the themes identified would yield relevant information for the research. The pilot study gave a clear guide of the number of sessions that were required, and the length of time that had to be allocated to each session.

The fourth and the last stage was the data collecting process. The data collecting process involved the focus group discussion meetings, semi-structured interviews, and data capturing. Each focus group had three meetings that were conducted over three consecutive days followed by two days of semi-structured interviews. The researcher recruited three nurses and one social worker to form part of the research team. These professionals were the co-ordinators of the support groups based in the clinics. The focus group discussion meetings were conducted with their assistance. Their role was to take process notes that were aimed to supplement the tape recorded information collected during the focus group discussion meetings.

After each session the data was transcribed and process notes were coded. Data analysis focused on reviewing patterns and themes that were identified. The findings were recorded and cross-checked with the research team and focus group participants. Recommendations were made that further research should investigate how the Xhosa culture can be generated to strengthen its vulnerability to the HIV pandemic in order to prevent and deal with its impact.

1.8 UNDERLYING ASSUMPTIONS

The researcher’s interactions with the professional nurses who were the key informants of the study resulted in the following assumptions being made:

- Family planning clinics have programmes in place to inform HIV-positive women about the health risks associated with planned-parenthood in their situation.
• The preventive approach that is at the core of South Africa’s HIV & AIDS strategy fails to recognise the cultural, psychosocial and political motivating factors that drive HIV-positive women to pursue planned-parenthood.

• Health workers situated in antenatal clinics do not have the capacity to provide relevant programmes to assist HIV-positive pregnant women to address the dynamic needs of HIV-positive women during their pregnancies.

1.9 VALUE OF FINDINGS

It was anticipated that the findings of this study would provide a better understanding of the constraints and challenges experienced by HIV-positive women in the Mthatha region. This will help the Government to:

• Develop an informed strategy on how to target young families at the beginning of their union or relationship in the fight against HIV & AIDS.

• Develop relevant programmes at Mthatha antenatal clinics to address the specific needs of HIV-positive pregnant women.

• Guide Provincial and National Government Departments in the development of policies, legislation and programmes to respond appropriately to the impact of HIV & AIDS on families within their socio-cultural context.

1.10 CONCEPTUAL AND OPERATIONAL DEFINITION OF CONCEPTS

Conceptual and operational definitions help to define what is being researched. According to Bless & Higson-Smith (2000) a conceptual definition is the definition of a concept by a set of other concepts, and an operational definition on the other hand, is based on the observable characteristics of an object or phenomenon and indicates what to
do or what to observe in order to identify these characteristics. Concepts central to this study that warrant clarification include:

- **HIV**: This is an abbreviation for “Human Immunodeficiency Virus”, which infects and destroys cells of the immune system causing a marked reduction in their numbers. This causes an individual to be susceptible to opportunistic infections and tumours leading to a diagnosis of AIDS, (Kalipeni, Craddock, Oppong & Gosh, 2004: 43)

- **AIDS** is an abbreviation for the concept, “Acquired Immune Deficiency Syndrome”, which Kalipeni et al. (2004) describes as a disease of the immune system that is characterized by a group of concurrent opportunistic infections resulting from an inadequate immune system.

- **Planned parenthood** is described by the Human Science Research Council (HSRC, 2009) as a cognitive process of thinking that involves contemplating the advantages and possible challenges of having a child.

- **Antenatal** means before birth (Kalipeni et al., 2004: 65)

### 1.11 OUTLINE OF THE RESEARCH REPORT

Chapter one of this report provided an introduction to the study, the problem formulation and motivation for the study, the context of the study, objectives of the study, theoretical framework, research methodology employed, assumptions, value of the study and finally the clarification of concepts central to the study.

Chapter two presents a review of literature that highlights the psychosocial and socio-economic impact and devastating effects that HIV & AIDS has on children, families,
communities, and society at large. These effects alert the reader to the intricate multi-dimensional issues that HIV-positive women have to contend with.

Chapter three of this report explores the specific nature of HIV-infection in women. It looks at gender differences in the natural history and clinical manifestations of HIV & AIDS. It concludes with a discussion about women’s rights and HIV & AIDS.

Chapter four reviews the various factors that influence HIV-positive women’s decision to procreate or not procreate. The factors discussed range from medical reasons (i.e. the transmission of HIV from the mother to the child) to societal factors that influence women to fulfil their role in society.

Chapter five, the research methodology used during the study is outlined and focuses on the research design, sampling strategies, and the data collection tools. It also elucidates on the limitations of the design and methodology used. The chapter concludes with a discussion of the ethical considerations.

Chapter six documents the data analysis process and discussions which highlights themes and sub-themes that emerged during data collection process related to the motivations of HIV-positive women to procreate.

Chapter seven of the report provides the conclusions that were arrived at as well as recommendations directed at practice and further research.
1.12 SUMMARY

In this chapter, the researcher demonstrated the extent to which South Africa is being affected by HIV & AIDS. The high levels of the prevalence of HIV & AIDS may be attributed to the governments’ delayed response to curtailing the pandemic. Today HIV & AIDS is one of the major social realities that challenge our country. The most probable people who suffer the most from HIV & AIDS are children who are left orphaned, vulnerable and in need of care. Some of these orphaned children are infected with the virus and are faced with the struggle to survive without their parents. Seeing the high rate at which HIV-positive women fall pregnant the researcher became interested to know the rationale behind this phenomenon. It was hoped that this would lead to innovative steps to mitigate the spread of HIV & AIDS and/or the development of empirically validated programmes to strengthen the ability of mothers to deal with their realities. The chapter provides an overview of the research used during the study.

The next chapter introduces the reader to literature relevant to the topic.
CHAPTER TWO

THE PSYCHOSOCIAL AND SOCIO-ECONOMIC IMPACT OF HIV AND AIDS: A LITERATURE REVIEW

2.1 INTRODUCTION

In order to conceive the research topic in a way that permits a clear formulation of the problem, theoretical highlights behind the study are necessary. These are obtained mainly from drawing together published information that is relevant to the topic. Bless & Higson-Smith (2000) refer to this process as a literature review. The review of literature aimed to formulate the research problem and shape the research questions. The research questions were not shaped by literature consulted only, but by the knowledge and perceptions of key informants in the study. The research questions of the study were:

1) What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?

2) To what extent and in what nature are HIV-positive women informed about such risks?

3) From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families?

Being a qualitative study, the researcher was interested in finding any current research that would help to develop a line of thought about why HIV-positive women choose to fall pregnant, as well as any information about unresolved conflicting studies undertaken that needed further exploration as attested by Neuman (2000). It soon became apparent that there was no evident line of thought regarding why HIV-positive women decided to fall pregnant once informed about their status. Secondly the scarcity of literature on HIV
& AIDS and planned-parenthood emphasized the need for such research to be undertaken.

South Africa as a nation is highly susceptible to the spread of HIV & AIDS and vulnerable to the impact of AIDS. In South Africa, currently the highest rates of infection are amongst people aged between twenty and forty-four, (Department of Health, Annual Antenatal Survey, 2006:12). Because the majority of South Africa’s population is located within this age group, HIV & AIDS has had a devastating effect on social and human development affecting the nation economically, socially, and politically. Barings (2004) advised that it would take some time for the economic impact to be felt, and careful and creative planning to manage the economic impact is essential. From the researcher’s experience of working in this field of HIV & AIDS the human development effects are more immediate and have already been felt by families. Illness, increased mortality, and loss in life expectancy are most visible in our communities. Because of the implications that the spread of HIV & AIDS has in our country one expects that planned parenthood will receive careful review. One anticipates that in the light of the economic implications of HIV & AIDS, and the burden it places on the social support system of HIV-positive people and the impact that it has on families, HIV-positive people will be dissuaded from choosing to fall pregnant.

In this chapter the following aspects will be presented:

- the demography of HIV & AIDS in South Africa
- the economic implications of HIV & AIDS
- the challenges of HIV & AIDS to the provision of social services
- the effect of HIV-infection in families.

In the light of the information presented one may question why HIV-positive people continue to procreate regardless. Each of the factors to be discussed provides clear evidence that planned parenthood should receive much more attention than has been given in the wake of the HIV & AIDS pandemic. The devastating effects that HIV &
AIDS have on children, their families, communities, and societies at large alert us to the intricate multi-dimensional issues that HIV-positive women unconsciously expose their families and off-spring to.

2.2 THE DEMOGRAPHY OF HIV & AIDS IN SOUTH AFRICA

South Africa was reported to have the fastest growing HIV & AIDS epidemic in the world (United Nations, 2004:5). The demographic work summarized by two reports prepared by Barings (2004) estimated that, since the onset of the epidemic, more than 500,000 South Africans have died of HIV & AIDS related causes. By 2010, this number is expected to grow by 20 percent which is more than 10 million deaths. The overall life expectancy in South Africa by 2008 was forecast to fall from its pre epidemic high of sixty-five years to forty years. Fortunately this prediction has not been realized. The extent of the epidemic and the ongoing vulnerability of the South African population to HIV-infection, like elsewhere in Africa, is directly related to issues of social equity, human rights and poverty. According to the World Bank (1997) both low income and unequal distribution of income are strongly associated with high HIV-infection rates. Rapid and fair distribution of economic growth will do much to slow the impact of HIV & AIDS epidemic as suggested by Barings (2004).

Barings’ analysis (2004) further suggests that semi-skilled and unskilled workers exhibit peak infection, nearly three times the rate for skilled workers. The result is that the homes of semi and unskilled workers, with their lower levels of social and economic security are most affected. The World Bank (1997) described the HIV & AIDS epidemic as having three phases, namely: the nascent phase, which is characterized by HIV & AIDS prevalence in all known sub-populations presumed to be vulnerable to HIV-infection; the concentrated phase, which is characterized by HIV & AIDS prevalence that is above five percent in one or more sub populations vulnerable to infection; the generalized phase, characterized by high levels of HIV-infection which is measured in women attending

2.2.1 HIV & AIDS and antenatal figures

The latest antenatal figures show that twenty two percent of pregnant women are infected, and that there is a differential spread across the provinces with KwaZulu/Natal being the worst affected and the Western Cape having the lowest infection rates (Department of Health Annual Antenatal Survey, 2007:12). According to Whiteside & Sunter (2005) the main mode of detecting infection rates in South Africa is the antenatal survey. Whiteside & Sunter (2005) recommended that caution should be observed with the figures provided by the survey because they tend to be skewed in the direction of poor women, who use public facilities and exclude the rates of infection in the other classes. Furthermore these statistics tend to be racially biased and they exclude the prevalence among sexually active, yet not pregnant women. It is therefore likely that these statistics underestimate the real rates of infection and that South Africa could have over twenty five percent of women infected with corresponding infection rates among men (Whiteside & Sunter, 2005: 56). This could mean in real terms that, up to twenty five percent of South African families are likely to face the challenge of trying to cope with and survive the effects of HIV-infection such as illness and death (AIDS Foundation SA, 2005: 65).

2.3 THE ECONOMIC IMPLICATIONS OF HIV & AIDS

There are several features of the HIV & AIDS epidemic that have substantial economic implications. The first feature is that HIV & AIDS tends to strike young adults, and according to the data presented in 2004 by Barings, most AIDS related deaths were likely to occur in the twenty-five to forty-five years age group (the active reproducing age group). AIDS does not only reduce life expectancy and the rate of population growth, but
also increases the burden on the working and retired age populations, who are required to care for the young and the sick. The second feature is that HIV & AIDS is very slow moving and the demographic projections employed by Barings estimate the median span between infection and death to be around eight and ten years. During much of that period, the person living with HIV & AIDS may experience relatively few symptoms, and employment and productivity may only be marginally affected. But people with HIV & AIDS that have depleted the CD4 cell count to below 200 are inclined to have declining labour productivity and incur increasing and substantial medical costs over the period. The loss of productive employment of people with HIV & AIDS has a direct impact on households. The fact is that there is no lasting unemployment support, or adequate social relief for single parents offered in our country. The third and last feature is that infection rates differ according to skill and class. As already mentioned semi-skilled and unskilled workers exhibit a peak infection rate that is nearly three times the rate for highly skilled workers. This implies that the poor tend to experience the scourge of the disease the most.

If the fundamental function of parenting is to provide for and socialize one’s children then one needs to question why HIV-positive people, who are poor and have limited access to resources continue to fall pregnant when the virus compromises their potential to fulfil these functions.

### 2.4 THE CHALLENGES OF HIV & AIDS TO THE PROVISION OF SOCIAL SERVICES

The National Department of Social Development (NDSD), as discussed in Crew (2002), recognized that previous services were inadequate and that radically different ways of providing services had to be developed. HIV & AIDS is too dramatic in its effects and its consequences to be incorporated into the existing services or the existing ways in which services are planned and developed (Crew, 2002:15). The NDSD’s response to this challenge was to put in place a number of programmes that would curb the effects the
HIV & AIDS epidemic and how it impacts on families. One of these programmes was the poverty relief programme. The Minister of Social Development announced that there would be extended poverty relief to increase the capacity of the Department to deal with HIV & AIDS and this would be achieved by collaborative partnerships with Non-profit Organizations, Faith Based Organizations, and Community Based Organizations (Crew, 2002: 16). A plethora of poverty alleviation programmes subsidised by the government emerged. Sadly these programmes do not appear to offer the relief HIV & AIDS infected and affected families need. The NDSD also recognized that the most vulnerable members of the South African society affected by HIV & AIDS were the aged, persons with disabilities and children. Despite this, the process that social relief applicants have to follow is so strenuous and protracted adding to their suffering. The application process prevents many from obtaining the social relief they are entitled to. It has even been verbalised that the policies that have been adopted by the South African Government contribute to HIV & AIDS as they fail to relieve the stressors that HIV-positive people have to cope with (Whiteside & Sunter, 2005: 59). For example, the placements of HIV & AIDS orphans in extended families increase the absolute levels of poverty within these families and thus compromise the life chances of all the children. In addition, failure to address discrimination, provide care, treatment, housing and employment all contribute to the spread of the disease (Arndt & Lewis, 2004:56).

Whiteside & Sunter (2005) concluded that implementing good policies at one level may do much to alleviate the situation and make the conditions under which people live more manageable. However, they may have little impact on some of the forces that drive this epidemic. They challenged the South African Government’s poor response to forces like violence against women; gender-based discrimination; early marriage; harmful traditional practices like circumcision, ‘ukuchaza’ (face-cutting), female genital mutilation or cutting etc; and wife inheritance amongst others, as practices that need to be carefully reviewed if the spread of HIV & AIDS is to be curtailed.
2.5 HIV-INFECTION IN FAMILIES

Desmond, Micheal, & Gow (2005) stated that HIV & AIDS does not only infect the individual because individuals rarely live in isolation. They explained that the family of a person who falls ill and dies is directly affected by HIV-infection. The family structure is likely to unravel as the family's available income is reduced, and savings are spent on survival care and the general quality of life of the members decline. There are two immediate effects as a result of a family member becoming HIV-positive: the standard of living of the family declines rapidly and dramatically; and the surviving family members, particularly children suffer as a result of having a decreased quality of life, lack of education, inadequate nutrition, poor health, and an uncertain future (Crew, 2002:34).

The illness and death of an individual affects the various systems to which he or she belongs. The household is one system that is possibly the worst affected by the HIV & AIDS epidemic. The characteristics of the virus, its concentration on particular groups, the mode of transmission and progression, and the stigma attached to HIV & AIDS seriously affects the psychosocial and economic welfare of households. As previously stated HIV & AIDS pandemic in South Africa is concentrated in the most productive segment of the population, the fifteen to forty-nine olds. According to Desmond et al. (2005) death within this group implies the loss of a productive household member, which generally results in loss of income and productive capacity as well as increased costs and changing expenditure patterns. The declining productivity of HIV-positive individuals is primarily and initially felt within the family. However, severe illness and subsequent death of those individuals have external effects. The loss of adults in their productive prime further reduces the capacity of communities to cope with the effects of orphaned and vulnerable children. The young ones often have to fend for themselves, thus forming child headed families, or they are taken care of by grandparents. Cornia (2002) states that the elderly are mostly in need of support themselves. The elderly rely on their children for support but when these children die, support ceases and the circumstances of the elderly decline dramatically.
What happens when the grandchildren come to live with them? When orphans come to reside in their grandparent’s household their capacity to offer material and emotional care is seriously stretched. Cornia (2002) concluded that HIV & AIDS deepens poverty and increases inequalities at every level, household, community, regional and sectoral. The epidemic undermines efforts at poverty reduction, income and asset distribution, and productivity for economic growth.

HIV & AIDS affects the major demographic processes of mortality and fertility. The direct effects on mortality arise from the deaths of adults and children. The United Nations is the body responsible for making global, regional and local projections of fertility and mortality rates. The United Nations (2004) explains that, in developing countries the population structure is generally described as a pyramid, reflecting the demographer’s traditional depiction of populations according to age group with men on one side of a central axis and women on the other. The shape of the pyramid is determined by birth and death rates. When both are high, the pyramid has a wide base and tapers off steadily with increasing age. If health improves and fertility falls, the pyramid becomes more of a column. HIV & AIDS has introduced a new shape of the pyramid called the population chimney. The base of the pyramid is narrower - as fewer babies are born and up to a third of babies are expected to die of maternally acquired HIV-infection. But the dramatic change comes when the populations of women in their twenties and men in their thirties shrink radically. As only those who have not been infected survive to older ages, the pyramid becomes a chimney.

Commenting on the new demographic population shape caused by the HIV pandemic Heywood (2003) stated that the world has never before experienced death rates of this magnitude amongst young adults of both sexes across all social strata. Heywood (2003) explained that a small number of adults - the group that traditionally provided care for both children and the elderly – are expected to support large numbers of old and young people. Many of these people will themselves be debilitated by HIV & AIDS related illnesses and may even require care from their children or elderly parents. The tables
appear to be turning. The middle age group twenty-four to forty years will no longer be the active providers of socio-economic support to children and the elderly. Instead their children and elderly will have to protect and care for them.

Recent analysis of family based data show clear increases in adult and child mortality rates, often occurring after many years of a declining death rate. "Because HIV & AIDS kills several members of a family, it destroys some families completely, with the result that some deaths are not captured in family surveys" (Heywood, 2003:44). These include families in which young people are cared for by adults other than their biological parents and the creation of 'dual families' for migrant labourers and the creation of new urban families that have no extended family networks or ties. No matter how families are structured, they carry the burden of the HIV-infection and the costs of care and death. This has a range of possible socio-economic impacts, particularly on poor rural families. These operate on a continuum from the HIV-infection of a family member, the illness and death to the ongoing demand for care of orphans and dependants (Heywood, 2003:44). In addition there are ongoing medical expenses, loss of employment, loss of income and thus decline in savings which implies far less money. In order for families to manage the burden of caring for their HIV-infected relatives they have to rearrange their roles.

In many families there is a division of labour to care for the ill family member/s. Partners may have to stop working and some children are taken out of school to take care for their sick parents and siblings. This leads to a loss in the earning potential of the family, increased debt and the increasing inability to purchase foodstuff, pay school fees, and buy basic clothes and household essentials. Available assets are sold and increasingly children enter the labour market prematurely in an unskilled capacity. Heywood (2003) states that there is an increasing decline in the ability to pay for services and this leads to the erection of outside shacks for tenants. Tenants are taken into the household in order to try to generate more income. This promotes serious overcrowding and breakdown of the sewage and water systems. There tends to be an increasing inability to maintain the houses and the properties leading to a rapid deterioration in the living conditions and an
escalating devaluation of properties (Heywood, 2003: 53). Evian (2000) also envisaged that the so-called “extended” families would be under increasing stress to meet the health, social and psychosocial needs of the children and other family members. The social cohesion of their communities and neighbourhoods as well as the families face disintegration. This leads to the potential for increasing levels of crime, vandalism and lawlessness. Clearly our society needs to find ways to arrest the debilitating effects of HIV & AIDS. One would assume that careful planned-parenthood would be taken more seriously than it appears to be at present.

According to Whiteside & Sunter (2005) HIV & AIDS impacts on households in three phases: infection and early illness; HIV & AIDS related acute illness and death; long term consequences. During the first two phases the costs of care gradually increase. The long terms costs are higher if the breadwinner is infected. The economic impact of HIV & AIDS at the household level is multi faceted once a member of the house-hold gets ill. A distinction can be made between an HIV & AIDS affected household in which the breadwinner dies and an HIV & AIDS afflicted household in which one or more members of the family dies. Members of the family may be forced to stop generating an income so as to care for the ill. The reduced income affects the families negatively, exacerbating the existing poverty level and the potential for increased deprivation. These families may be forced into patterns of migration, and the disintegration of the family unit has serious economic and social repercussions not for the family only but for the region as a whole. Poverty is a very common feature of South African households. Donahue (2000) argued that the ability to cope with the impact of HIV & AIDS, or other emergencies depends a great deal on the state of their resources before, during and after the crisis affects them. The impact of HIV & AIDS on a household or family follows a fairly predictable pattern. Initially the family is well able to cope with the HIV-infection of a family member, while this person is healthy and works and brings home an income. However, it is likely that the partner may be infected by HIV & AIDS and over time the household will experience the illness of one, if not two of the family members. An increase in medical expenses follows high absenteeism from work which results in loss of
employment and income. This leads to a reduction in foodstuffs purchased and the decline in family nutritional status. As attested by Donahue (2000) the three areas of impact on a household/family are: decreased revenue due to the loss of labour; increased expenditure in terms of medical care; the effects on dependent family members and children.

To conclude, uncertainty about the future for any family affected by HIV & AIDS is enormous. The shift from relative comfort to destitution, as household resources erode is likely to have a severe impact on the family as a whole and contributes to the already deteriorating situation of many vulnerable and poor families. The household income-earning capacity is affected negatively by the care needs of a person living with HIV & AIDS, exacerbating the already existing poverty level. One may question whether it is ethical or moral for HIV-positive people to procreate, given that until there is a cure for HIV & AIDS, they will compromise the quality of life for their offspring. Linking on to the discussion on the impact of HIV & AIDS on the family, the discussion in the next section of the chapter will focus on the impact of HIV & AIDS on children in South Africa.

2.6 THE IMPACT OF HIV AND AIDS ON CHILDREN IN SOUTH AFRICA

The following excerpt from a case study provided by Cuba (2007) alerts one to the multifaceted burden placed on a child caring for a relative living with AIDS. Sizwe looks after his dying mother and two sisters in a mud-block house in Mqanduli, KSD Municipality, Eastern Cape. Sizwe is a ten year old boy living in one of the richest countries in Africa, under one of the finest constitutions in the world, but he has no rights. He left school last year when his mother was sent home from hospital to die because her bed was needed by someone who might recover. He can’t go back to school because there is no money to buy food or to pay for school fees. Sizwe sends his sisters off to beg for maize-meal from a neighbour who sometimes helps out. He leaves his mother sleeping while he makes his third trip of the day to fetch water from the
standpipe. When he returns his sisters are waiting with a packet containing a cupful of maize-meal. Sizwe makes a fire while the older girl rocks the toddler to stop her crying. The mother sleeps between bouts of coughing. It is nearly time. Tomorrow he will visit the lady from the burial society to see if he can get help for the funeral. The story was narrated by Cuba (2007).

South Africa is home to approximately 17.7 million children (Budlender, Hall, & Rossa, 2005: 32). Even without HIV & AIDS, the interplay of factors such as the high level of poverty, unemployment, neglect, abuse, violence and drug dependence ensure that a large proportion of South Africa’s children live in difficult circumstances and can be classified as “vulnerable” and “in need of support” (Budlender et al., 2005: 32). According to Richter (1999) there are gaps in our understanding of the impact of HIV & AIDS on children in South Africa. However, no one disputes that HIV & AIDS has had, and will continue to have the effect of increasing the number of vulnerable children and of compounding the difficulties experienced by those who are already in need of assistance.

HIV & AIDS produces and compounds different forms of vulnerability among children. Firstly, children are made directly vulnerable by infection (mostly caused by mother-to-child- transmission) and related ill-health. Secondly, Budlender et al. (2005) explained that HIV & AIDS causes vulnerability among children by leaving them orphaned. “Based on calculations of the Actuarial Society of South Africa (ASSA), there are roughly 1 million children in South Africa who have lost a mother (maternal orphans) and around 2.13 million who have lost a father” (Giese, 2004: 2-3). As early as 1999 it was estimated that about half of all orphaned children had lost parents due to HIV & AIDS related mortality. Projections derived from the ASSA models predict that by 2015, in the absence of any major treatment or behaviour change, roughly 3.05 million children under eighteen years will be maternally orphaned and 4.51 million paternally orphaned the majority of such deaths will be AIDS related (Giese, 2004:4). The vulnerability associated orphanhood and the child’s needs for care and support services, including socio-economic and psychosocial, begin long before the death of parent(s). Some children who
are orphaned as a result of HIV & AIDS find themselves living completely without family support. They live on the streets or in institutions. Others live at least, for a period, in child-headed households (Budlender et al., 2005: 34). Their biggest challenge is persistent hunger, followed by a range of other poverty-related concerns including: the struggle to pay school-fees; lack of school uniforms; clothing; lack of money for transport and health care; inadequate housing; and insufficient warmth (Budlender et al., 2005: 34). A large proportion of children in child-headed households do not attend school. Lack of schooling reduces their chances of ever securing employment on the open labour market.

The majority of orphans are absorbed into families in their communities. Most live in informal kinship care placements. Others are formally fostered by relatives through children’s court enquiries. When placements are formalized the foster parents are entitled to some social relief in the form of foster care or child support grants. The foster care grant does not cater for sufficient resources to meet the expanding household’s basic needs. In many of these households the twin impact of HIV & AIDS and poverty creates a situation that is so desperate that strategies such as getting into debt, depending on neighbours for food and sending children out to work (sometimes as prostitutes) are employed simply to try and put food on the table. Hunger and malnutrition are constant threats and attendance at school is often a luxury, as posited by Meintjes, Budlender, Giese, & Johnson 2003; Giese & Meintjes (2003) and Giese (2004). The impact on relatives taking in orphans is lowered income and lowered food consumption. Pharoah (2004) stated that food consumption in households with orphaned children drops by forty-one percent. One of the coping mechanisms of caregivers is migration. This is the movement between kinship households for support, or moving from rural to urban areas to seek work or the help of relatives. Children are affected by this migration, as some are sent to help out in other households and others are encouraged to fend for themselves. Loss, separation, and bereavement result in orphans internalizing psychological conditions which include anxiety, depression, social isolation, survivor’s guilt, and low self-esteem (Pharoah, 2004: 15). This impact is evident in Mthatha where orphans who
lived in town while their parents were alive are relocated to live with relatives in rural areas. Life becomes difficult for these children who find themselves without parents and having to think seriously about their future early in life before they are developmentally equipped to do so. Some of these children are leased out for labour (to look after livestock) in rich families in the community. Some of them go to the big cities such as Johannesburg and Cape Town to seek employment. Others are overwhelmed by the situation and commit suicide.

Both law and morality demand that all vulnerable children in South Africa, including the growing number of children experiencing vulnerability due to HIV & AIDS are entitled to care and support services to ensure that their development is not compromised. There is a legal obligation on the State, imposed by the comprehensive cluster of child specific rights afforded children in Section 28 of the Constitution (Constitution of the Republic of South Africa, No 108 of 1996) and the Broader Children’s rights framework in South Africa to take measures to ensure assistance for vulnerable children. Children made vulnerable by HIV & AIDS have since 1998 been given a great deal of attention, relative to other categories of vulnerable children in the donor and domestic development debate, but yet not enough to guarantee them a good quality of life. Whilst the Government has made strides to absorb the blow of HIV & AIDS in our communities through policy formulation, one should ask, “is the responsibility for protecting children’s rights only that of policy makers, governmental, and national children’s rights groups? Or should parents not be challenged to consider whether they have the resources required to fulfil their responsibilities to their children until they are old enough to fend for themselves?”

With this pandemic, should planned parenthood not be given the spotlight it deserves?
2.7 SUMMARY

In this chapter South Africa was described to be characterized by high levels of HIV-infection. The measures used for such estimation were viewed to be biased because they were based on statistics from the public health antenatal clinics which are accessed by people from low-income populations thus leaving out those from the middle and upper income populations. HIV & AIDS was identified to strike young adults as statistics show that a majority of AIDS related deaths falls between the ages twenty-five to forty-five years. This age is considered to be the most productive years in the labour market, and people of this stage are in most cases breadwinners within their families. The impact of the death of the people in this age group affects both the economic status of the family as well as the country. The family is the most affected by HIV & AIDS particularly children, who sometimes act as care givers to their ailing parents. These children in most cases find themselves having to witness the death of their parents, suffer from social rejection, and in most cases have to fend for themselves.

In terms of the aid that is made available by the Government, such as the food security and social grants programmes, these were reported not to fully cater for the needs of those infected and affected by the pandemic. Families fall into abject poverty in spite of the programmes available. What inhibits the effectiveness of these programmes are the long processes that have to be followed before accessing them. This chapter therefore showed the detrimental impact of HIV & AIDS, psychological and social life of families in South Africa, as well as economic wellbeing of the family and country.

The next chapter discusses the compromised position of women in the HIV pandemic. It clearly shows their position in the natural history of HIV & AIDS, their susceptibility to the virus, and their commonly low socio-economic status. The chapter ends with a discussion of the rights of women.
CHAPTER THREE
WOMEN AND HIV & AIDS: A LITERATURE REVIEW

3.1 INTRODUCTION

When HIV & AIDS first presented itself in the 1980’s it appeared as a disease that affected homosexual and drug using men only (Paxton, Welbourn, & Kousalya, 2004: 23). But as the worldwide scope of the epidemic came to light it became apparent that heterosexual transmission of HIV & AIDS was the common cause of infection, and that, men and women were equally at risk. The fact that HIV & AIDS presented itself in men first, and became apparent in women at a later stage led to the under-representation of women in clinical trials of new therapies and literature of HIV & AIDS (Paxton et al. 2004: 23). In the 1990’s there was a wave of interest in the mother to baby transmission of the HI-Virus. However, several researchers were of the opinion that HIV-infection in women should not only focus on vertical transmission, as was the case, but should also focus on women’s gender-specific susceptibility to the virus, natural history of HIV & AIDS, clinical manifestations, and women’s rights (Masci, 1996: 342). This led to great developments in the literature on how HIV & AIDS affect women, specifically disease progression in women and the reasons why women are more susceptible to becoming infected.

The previous chapter alerted the reader to the multidimensional impact of HIV & AIDS on children and families. In the absence of locally specific studies about why HIV-positive women choose to proceed with planned-parenthood, this chapter will explore the specific nature of HIV-infection in women. It aims to reflect the position of women in South Africa within the context of HIV & AIDS and procreation. The chapter begins by examining women’s gender-specific susceptibility to the virus. It also looks at gender differences in the natural history of HIV & AIDS and clinical manifestations of HIV & AIDS. It concludes by discussing women’s rights with regards to HIV & AIDS, which
allows the reader to understand why HIV-positive women need special intervention and education when pregnant.

3.2 GENDER DIFFERENCES IN HIV-INFECTION

Women are biologically susceptible to HIV & AIDS (Masci, 1996:343). Their vulnerability is evident in the overall risk of male to female HIV & AIDS transmission during unprotected vaginal intercourse. Masci (1996) notes that the transmission of HIV & AIDS during unprotected vaginal intercourse is about 0.2 percent but this figure may vary among couples on the basis of host and viral factors. During sexual intercourse, the statistical probability of infection for women is higher than men, since men carry a higher viral load or concentration of HIV & AIDS in semen than is produced by the female's vaginal fluid. Moreover, the vagina offers a larger area of mucosal tissue subject to micro-injuries through which the virus can enter the blood stream. Women are more likely than men to contract HIV & AIDS through a single heterosexual encounter, (Paxton et al, 2004: 24). Literature reviewed for the purpose of this study reflected that gender differences were evident in the natural history and the clinical manifestations of HIV-infection.

3.2.1 Gender differences in the natural history of HIV-infection

The natural history of HIV-infection spans approximately ten years. For the first five to six years of infection the individual is asymptomatic or may have relatively minor manifestations of HIV-infection. For the last three to four years the immune system gradually becomes depressed. When the degree of the immune depression increases, the immunologic abnormalities, such as pneumonia, and tuberculosis (TB), culminate into life threatening opportunistic infections and malignancies recognized as AIDS (Brettle, 1992). Several attempts have been made to identify gender differences in the natural history of HIV-infection. Brettle’s (1992) research study presents a few gender differences in the survival after AIDS diagnosis stage. In the study Brettle (1992) states
that women have a poorer survival from AIDS compared to men. Brettle (1992) attributes this to women’s biological susceptibility to infection and/or re-infection, lack of sexual autonomy, and immune depression during pregnancy.

### 3.2.2 Gender Differences in Clinical manifestations of HIV & AIDS

Masci (1996) reports minor differences between genders in the clinical features of most AIDS defining opportunistic infections and other HIV & AIDS related syndromes. Kaposi sarcoma, genital tract neoplasm, HIV nephropathy, and mucosal candidiasis are reported to be relatively equally distributed amongst the different gender. Details for each of these AIDS defining opportunistic infections and HIV related syndromes are provided below.

(i) **Kaposi sarcoma** manifests as bluish-red small tumours that develop on feet and/or toes, and slowly increase in size and number. It is an HIV defining disorder in men, especially homosexual and bisexual men; and an AIDS defining disorder in women, especially for those who have had sexual contact with bisexual men.

(ii) **Genital neoplasm** is the abnormal and uncontrolled growth of sex organ tissue into tumours. There are two HIV-related immuno-deficiencies that characterise genital neoplasm. These include cervical neoplasm and cancer of the penis. The development of both types of genital neoplasm is associated with advanced HIV-related immuno-deficiency. Genital neoplasm is more common in women than men. Several research studies affirm that genital neoplasm behaves more aggressively on patients with severely depressed immune systems (Fanning, 1997: 48).

(iii) **HIV nephropathy** is the disease of kidneys, for example renal failure. It mainly affects Black males, and its rate in other HIV-infected patients, including women, is currently not known (Fanning, 1997:47).

(iv) **Mucosal candidiasis** is a yeast-like fungus present in the mucus membranes and affects the mouth, intestinal tract, vagina, respiratory tract, and skin. Although vaginal
candidiasis is a common infection among HIV non-infected women it often symbolizes the onset of CD4 lymphocyte depletion in HIV-infected women. The difference is that vaginal candidiasis reoccurs more frequently in HIV-infected women. HIV-infected women are at higher risk, than men, of oral and oesophageal candidiasis later in the natural history of HIV-infection.

In summary, several HIV-related disorders have a clear predilection for men than women and for women than men. For example, kaposi sarcoma and HIV nephropathy were discovered to be more common in men, and genital neoplasm and mucosal candidiasis appeared more common in women. Fanning (1997) stated that other aspects of HIV-infection may differ between genders, but specific data are either incomplete or unavailable to permit definite conclusions in this regard. We can nevertheless conclude that women are more susceptible to HIV. There are specific risks: they have poorer survival with a higher risk of genital tract neoplasm, mucosal candidiasis, and more rapid progression of the virus (Fanning, 1997).

3.3 WOMEN’S GENDER-SPECIFIC SUSCEPTIBILITY TO THE HI-VIRUS

While many women have taken action to help counsel each other and prevent the further spread of HIV, they find themselves not only having to combat biological factors but entrenched social norms and human rights factors as well. Multiple factors associated with women’s subordinate position increase the risk of HIV-infection (Amaro, 2005). Among them are illiteracy and poverty, lack of sexual autonomy, rape by intimate partners or strangers, multiple sexual partners, trafficking for sexual exploitation, genital mutilation and other harmful practices, prostitution, and child marriage (Amaro, 2005). For many women the most common risk factor they face is living with an HIV-positive husband or partner. Other risk factors include the level of violence to which women are subjected to and harmful traditional practices such as virginity testing and genital
mutilation; and socio-economic factors which limit women’s capacity to protect themselves (Levin, 1993: 50).

3.3.1 Socio-economic status of women and the HI-Virus

In countries where gender inequality is large, women’s risk of contracting the disease increases. Violence is a key factor in increasing women’s risk of contracting the virus. The study of Amaro (2005) suggested that the first sexual experience of a girl is often forced. Apart from the girl having no choice in the sexual encounter, the forced nature of the sexual act may induce and injure the mucosal tissue, increasing the chances of the virus entering the girl’s blood stream.

Condoms are not a realistic option for women who live in countries such as South Africa where families and communities are patriarchal. It is also an especially contentious issue, particularly for married couples, as women have limited influence and bargaining power over condom use (Levin, 1993). Levin (1993:56) also stated that, “Women do not have powers to refuse unprotected sex even when their partners are unfaithful to them”. Despite these limitations, there is no alternative prevention for them. Microbicides, a clear gel that a woman can use before intercourse, is still undergoing testing and findings have not been disseminated (Soandso, 2002: 22). Female condoms are scarcely available in public clinics.

Novelo (1995) highlighted that the complex interaction between the economic marginalization of women, the increase in the number of female headed households, and the deterioration of the current economic situation places women in a precarious position. There is a general belief that to request your partner to use a condom or to express a desire for condom use is socially unacceptable. Women, because of their inferior social status are unable to communicate their desire for condom use. In a study conducted by Flaskerud and Nyamathi (2000) the position of women in patriarchal society, as mentioned previously, was found to be seriously disadvantageous in terms of condom
use. Their study of Latino women discovered that only twenty-three percent used condoms. Those who did not use condoms mentioned cultural, religious, and sexual factors that prohibited them from using condoms. In fact most women in the study were under the misconception that condoms were used by prostitutes. Others believed that sexual intercourse should only be associated with reproduction. This study has relevance for the Mthatha context. A similar study was carried out at Mthatha General Hospital in 1992, with women who were attending antenatal clinics to test their knowledge, attitudes and beliefs about HIV & AIDS. It was found that only 16 percent were using condoms for protection against the risk of HIV-infection, 43 percent claimed that they were willing to use condoms but their partners were not (Amok, Mthwesi & Buga, 2002).

According to Elya (2003) poverty also increases the rate of HIV & AIDS. In South Africa, the majority of women earn only seventy percent of what men earn. This negatively impacts on their attaining self-sufficiency. Poverty rates are much higher for women than men, with sixty percent of female headed versus thirty-one percent of male-headed households, falling below the poverty line (Elya, 2003: 22). Women's vulnerability often forces them into sexual relationships that they otherwise would not engage in and gives men more leverage for taking on multiple wives. In addition, the HIV & AIDS situation in South Africa has been exacerbated by men’s migration to cities for mining and other job opportunities. Men’s separation from their wives and their proximity to other women who know nothing about their lifestyle put the rural women at greater risk of contracting the virus.

For many women, financial, material, or socially-determined dependence on men means that they cannot control when, with whom, and in what circumstances they have sex, nor can they make demands on men to minimize risky behaviour (Panos, 2003: 43). Absolute and relative poverty can pressure women to exchange sex for food or other material favours in order to ensure daily survival for the woman and her family. The United Nations Secretary General’s Task Force on HIV & AIDS in Southern Africa (2003)
stated clearly that poverty and HIV-infection are deeply intertwined. As the burden of caring for the sick, the dying and the orphaned forces millions of African women deeper into poverty and batters their energy and self-esteem, so it increases the pressure to resort to high risk, transactional sex. That is, sex in exchange for money or goods or sex with older men who offer the illusion of material security. And as more women and girls take to the streets as their only means of survival, the need to confront gender inequality becomes unavoidable.

Avert (2001) stated that sex workers are exposed to a relatively high risk of contracting HIV & AIDS. They work in an informal often illegal sector of society in which they occupy a low status and marginalized position. They frequently have little control over working conditions and in particular are exposed to primary mode of transmission of HIV & AIDS, which is sexual intercourse. Their capacity to negotiate condom use or to look after their health in other ways is limited. They are subject to violence by those who control or manage them, as well as violence by clients (Gwele, 2006:22).

Gwele (2006) conducted research on the connection between HIV & AIDS and poverty. Gwele (2006) stated that many women who migrate from rural to urban areas become sex workers. Gwele’s (2006) study also indicated that poverty was associated with the increased risk of HIV-infection, and that orphaned girls from poor households are vulnerable to HIV-infection because they succumb to having sexual relations with older men in exchange for financial support, and are vulnerable to sexual exploitation by relatives. HIV & AIDS was found to have a negative impact on women, because of their social and biological status, thus minimizing the control they have over their bodies (Avert, 2001). They were discovered to lack knowledge about HIV & AIDS and seldom reported using condoms (Abdol, Abdol & Nkonokazi, 2001: 35). Abdol et al., (2001) also argued that many women did not perceive themselves to be at risk of infection, and regarded condom use as a sign of promiscuity, a notion promoted by their partners, and something that met with their partners’ strong disapproval. According to the Joint Monitoring Committee’s Report on the Improvement of the Equality of Life and Status of
Women (2002:8) the role played by men in the spread of HIV & AIDS was defined by a belief that having sex with a virgin could cleanse them off HIV & AIDS. The Love-Life study conducted in 2002 revealed that one in four young South Africans did not know that this was a myth. The Joint Monitoring Committee’s Report on the Improvement of the Equality of Life and Status of Women (2002) therefore, concluded that it was men who were raping infants, children, young and old women in the hope of being cured. Men took the initiative and decision about where, when and how sexual intercourse should take place. As a result of the nature of their patriarchal communities, men tended to have more than one sexual partner. Abstinence and monogamy were seen as unnatural. Men were expected to prove themselves by engaging in sexual encounters frequently.

Friedman et al., (2006) in their study on the impact of male sexuality on women and children’s health, argued that male sexuality was having a profoundly negative impact on the wellbeing of women and children. They identified two predominant problem areas, which have reached grave proportions. These problems are sexually transmitted diseases and the effects of sexual violence. Friedman et al., (2006: 88) continued stating that, “While men are central to these problems, they are often excluded from the proposed solutions”. Traditionally, sexual and reproductive health (SRH) services including family planning have focused almost exclusively on women. Yet many observers have emphasized that the knowledge, attitude, behaviours and health of men plays a critical role in determining the reproductive health of women. Men hold decision making power over matters as basic as sexual relations, when or whether to have a child and health seeking behaviour. Entrenched patriarchy, male dominance, transactional sex and inequality in sexual relations place women at risk of unwanted pregnancy and infection (Friedman et al, 2006: 88). It was found that men do not utilize public health services as much as women, and to a great extent reproductive services are made inhospitable for men (Friedman et al, 2006: 88). The lack of men’s participation in reproductive health services, family planning, antenatal and postnatal consultations means that they do not benefit from any information given by health providers regarding sexuality or their role in it. Research has also shown that men do not seek treatment including ARVs at
appropriate stages of the HIV-infection (Friedman et al., 2006: 88). Friedman et al., (2006) therefore concluded that there is a strong rationale to involve men in supportive roles in issues that impact on sexual and reproductive health. There is also an urgent need for men to use such sexual and reproductive health services in a much more active manner than has traditionally been the case. One therefore can discern that in a context where a woman has little power to protect herself from unsafe sexual practices and unwanted pregnancy she may also not be able to take some decisions related to avoiding pregnancy when having a HIV-positive status. Because of the power invested in men in this society it is difficult for women even when they have been informed about health risk issues associated with sexual behaviour to protect themselves.

3.4 A RIGHTS BASED APPROACH TO HIV & AIDS AND THE PROTECTION/EMPOWERMENT OF WOMEN AND GIRLS

This approach operates from the premise that respect for human rights forms a coherent basis for programmes to address the pandemic and that the abuses of human rights contribute to the spread of the virus and undermines attempts to combat it. As the Canadian Legal Network (2004:7) puts it, “When human rights are not promoted and protected, it is harder to prevent HIV & AIDS transmission.”

A number of International Human Rights standards, including those agreed to by Governments are relevant to protecting women’s rights in the context of HIV & AIDS, both in terms of the prevention of HIV & AIDS and the response to it (Canadian Legal Network 2004:8 ). International Human Rights Law requires governments to take a range of measures to protect the right of all to the highest attainable standard of health, also known as the right to health, and the right to freedom from discrimination among others.

There are other rights which are also important when talking about HIV & AIDS, such as rights to information, to education, to work, to find a family, to enjoy the benefits of
scientific knowledge and other rights (Canadian Legal Network, 2004: 12). The relevance of human rights standards to HIV & AIDS prevention, treatment, and support have been elaborated upon by international consultations on the subject, and independent experts within the United Nations human rights system (Canadian Legal Network, 2004:15). The Bill of Rights contained in the Constitution of the Republic of South Africa No 108 of 1996, give all women the right to equality. The Equality Clause says that no person may be discriminated against on a number of grounds, such as their gender. The creation of the Commission on Gender Equality (CGE) and the South African Human Rights Commission (SAHRC) set up under the Constitution, are meant as watchdogs to ensure that women are not discriminated against, and are afforded equal status to men in South Africa. Discussion in this section is limited to the women’s right to health, standards on violence against women, and standards on discrimination against women.

3.4.1 Women’s Right to Health

The right to health for everyone was promulgated as a core value of the Constitution of the World Health Organization at its establishment in 1946 (WHO, 2006). The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being. This right was later articulated in a number of international treaties. The International Covenant on Economic, Social and Cultural Rights in Article 12 required countries to recognize the right for everyone to the enjoyment of the highest attainable standards of physical and mental health (Jackson, 2007).

Governments, such as South Africa have also made important political commitments to secure the right to health of women, through different laws and policies, such as the Constitutional Law (Woolman, Roux, & Bishop, 2008); Common Law; statute laws like the Health Act No 63 of 1977; and Health Policies and charters, for example, the
National Patients’ Rights Charter (National Department of Health, 2002). The National Patients’ Rights Charter (National Department of Health, 2002) for example, says that all health care workers like nurses and doctors, must treat all patients with human dignity, respect, courtesy, patience and tolerance. Some of the rights of patients are: the right to have a healthy and safe environment; to take part in making decisions about their treatment; to get basic health care at government health facilities, such as emergency care, counselling, information; to make a proper choice about health services; to enjoy confidentiality and privacy about their medical treatment; to give informed consent to medical treatment; to refuse medical treatment; to get a second opinion from another doctor; to have ongoing medical care; to complain about poor health services by health care workers (National Department of Health, 2002).

In light of these standards, one would expect HIV-positive women to be fully informed about the health risks involved in planned pregnancy. The key informants in the research study indicated that even when these rights are honoured by the health system the immense power that Xhosa male partners have over their women appear to negate the information and health options afforded to them (Amaro, 2005: 440). Evidence of this experience tells the researcher that the implementation of these policies is harder to enforce. This was highlighted in the preceding section about the entrenched patriarchy and male dominance over women’s rights.

3.4.2 Standards on Violence against Women

The Declaration on the Elimination of Violence against Women (1994) called for countries to condemn violence against women and not invoke any custom, tradition or religious consideration which compromises their obligations with respect to its elimination. The Declaration suggested that States should pursue by all appropriate means and without delay a policy of eliminating violence against women. The South African Government translated the Declaration’s call by passing the Domestic Violence Act 116 of 1998 and initiating campaigns against violence directed at women and children. The Act protects women from various kinds of abuse such as: physical violence,
threats of physical violence; emotional abuse; economic abuse (including situations where a partner refuses to provide money for food and shelter, and where he tries to destroy or remove property that is jointly owned); sexual abuse or threats of sexual abuse; harassment; stalking; damage to property. The Act allows any woman who is abused to apply for an interdict or bring a criminal charge against the abuser. It has thus created better protection for women who are in abusive relationships.

The anthropologist who was the key informant in the study concurred that despite these initiatives acts of violence against women remain unacceptably high. Too few women are aware of their rights and have no idea how to access help.

3.4.3 Standards on Discrimination against Women

The United Nations Special Rapporteur on the Right of Everyone to the Highest Attainable Standard of Health (2004) emphasized the effect of discrimination on gender when reflecting upon women’s rights to sexual and reproductive health. The Special Rapporteur (2004) stated that discrimination based on gender reduces women’s ability to protect themselves from HIV-infection and to respond to the consequences of HIV-infection. The vulnerability of women and girls to HIV & AIDS is compounded by other human rights issues, such as inadequate access to information, education and services necessary to ensure sexual health; sexual violence; harmful traditional or customary practices affecting the health of women and children (such as early and forced marriage); lack of legal capacity and equality in areas such as marriage and divorce. The Convention on the Elimination of all Forms of Discrimination against Women (1997, Article 5(a):128) called on countries “To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women; and to modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women”. The Bill of Rights contained in the
Constitution of the Republic of South Africa No 108 of 1996, gives all women the right to equality. The Equality Clause says that no person may be discriminated against on a number of grounds, including matters such as their sex and gender. The creation of the Commission on Gender Equality (CGE) and the South African Human Rights Commission (SAHRC) were set up under the constitution to act as watchdogs to make sure that women are not discriminated against. These emphasize the importance of equality between men and women in South Africa.

Clear evidence exist that discrimination against women and children places women and children at risk, especially in relation to HIV & AIDS. While national and international authorities recognize and are committed to protecting women and children from discrimination, the positive impact of their developed policies is yet to be felt. It would seem that discriminatory practices against women continue to marginalize them. Such marginalization increases their susceptibility to HIV & AIDS. This according to the anthropologist who is the key informant in the study is the reality of women in the Mthatha region.

It remains unclear exactly what steps are being taken to counteract gender based discrimination at the level of service providers. The references consulted failed to provide practical suggestions as to how these harmful attitudes can be changed at a community level. Changing these attitudes will better ensure that HIV-positive pregnant women’s health rights are protected. Finally, the references fail to suggest how policies and human rights issues can be translated into practical guidelines for assisting HIV-positive women to make decisions regarding reproduction.
3.5 SUMMARY

In summary, the HIV & AIDS pandemic is increasingly viewed as a strongly gendered health, development, and human rights issue. Whilst HIV & AIDS is a preventable disease, millions of people are living with the virus and the proportion of women affected is increasing. Physiologically women are at greater risk of contracting the HI-Virus than their male counterparts. Alarmingly, women have been found to have a poor survival rate, a higher risk of genital tract neoplasm and mucosal candidiasis and the virus progresses more rapidly in their system than in males. This chapter emphasized that violence against women and other forms of gender-based discrimination increase women’s likelihood of contracting HIV & AIDS. Gender-based discrimination hinders women’s access to prevention methods and to treatment.

The next chapter examines literature studies on the reproductive decision by HIV-positive women.
CHAPTER FOUR
THE REPRODUCTIVE DECISION: A LITERATURE REVIEW

4.1. INTRODUCTION

According to Cooper (2006) most HIV-positive women are in the reproductive age, which results in many desiring to start families or add more children to the ones they already have. Delvaux & Nöstlinger (2007) therefore advocate the empowerment of HIV-positive women to make informed choices relating to their reproductive lives. They continue to explain that uninformed reproductive decisions taken may cause HIV-positive women to ignore their specific health condition and their socio-economic situations, thereby increasing their vulnerability to the serious risks associated with procreating while HIV-positive. The most serious risk being the conception of a baby in the most conventional way, i.e. normal sexual intercourse. This act of engaging in unprotected sexual intercourse increases the woman’s vulnerability to infection, the infection of an uninfected partner, or the re-infection of both the woman and her partner. Once conception occurs the risk of disease progression on the mother and vertical transmission on the baby is posed. After the baby is born there is a likelihood of the child becoming an orphan later on in life.

According to Cooper (2006) there are several alternatives an HIV-positive woman has in relation to the reproductive decision. The first alternative which offers one hundred percent protection to the mother and baby from the risks associated with procreating while HIV-positive is to choose not to procreate. The second alternative is centered-around the conception of the baby. This may be performed through the natural sexual intercourse, or artificial insemination. Artificial insemination is a procedure where a sperm sample is inserted into the uterine cavity by means of a tiny flexible plastic tube (Mohr, 2001). The third alternative is centered-around the delivery of the baby. This may be natural birth through the birth canal or a caesarian section. The natural way of
conceiving and giving birth pose a higher risk of HIV transmission (Hude, 2006:32). The fourth alternative concerns those women who fall pregnant without having planned the pregnancy, and then discover while pregnant that they are HIV-positive. Such women have an option to abort their pregnancies before three months into gestation.

This chapter reviews literature that portrays two major themes regarding to the HIV-positive woman’s decision to procreate. These are medical factors pertaining to the mother to child transmission of HIV & AIDS, and social factors pertaining to the woman fulfilling her role in society. This chapter reviews studies which enlighten us on these issues.

4.2 FACTORS INFLUENCING THE HIV-POSITIVE MOTHER’S DECISION NOT TO PROCREATE

One of the routes of transmission of the HI-Virus is called “vertical transmission”, which is the transmission of the virus from the mother to the baby. This is the main reason why some HIV-positive women refrain from procreating. There are three routes of vertical transmission. They include:

- **Prenatal** also referred to as “antepartum”, “antenatal” or “intrauterine transmission”. In this instance, the HI- Virus is transmitted from mother-to-child during pregnancy and the transmission occurs within the womb.

- **Perinatal** or “intrapartum transmission” of the HI-Virus is the transmission that occurs at birth or during delivery.

- **Postnatal** or “postpartum transmission,” is when the HI- Virus is transmitted from the mother to the child through breastfeeding (Kalipeni et al., 2004:45).
It is estimated that only thirty-five percent of transmission occurs intrauterine, with sixty-five percent of HIV transmission occurring at delivery and/or postpartum (Termmerman, 1993:292). Johnstone & McCallum (1994) are of the view that most transmission occurs at the time of delivery. However Hishid (1992) in an earlier study documented two forms of the HI-Virus, namely: HIV-type 1 and HIV-type 2. The major difference between these forms of HIV is the level of infectivity. HIV-type 1 was reported to be three times more infectious than HIV-type 2, and the natural history of HIV-type 2 is longer than HIV-type 1. For example individuals infected with HIV-type 2 are asymptomatic for much longer, and do not develop high levels of the virus in the blood for 15 to 20 years after infection. Individuals infected with HIV-type 1 on the other hand remain asymptomatic for approximately five years. Hishid (1992) concluded that HIV-type 2 was not easily transmitted during the lengthy asymptomatic phase of infection due to the very low levels of the virus, while HIV-type 1 was easily transmitted even during the asymptomatic phase.

To date studies show that between twenty-three percent and forty-two percent of babies born to African mothers infected with HIV-type 1 become infected through one of the above-mentioned routes (Hishid, 1992). HIV-type 1 is predominant in Africa, Europe, Asia, and America, while HIV-type 2 is predominant in West Africa and in a few parts of Europe. One can conclude that if a woman is HIV-positive and has type HIV-type 1 then the risk of passing the virus to her baby is high especially if she delivers the baby naturally. A significant number of babies born to African mothers are infected with HIV-type 1 (Hishid, 1992).

The following subtopics provide in depth discussions on the various routes of HIV transmission.
4.2.1. Prenatal Transmission of HIV-Infection

There is evidence that the foetus of a HIV-positive mother may become infected during pregnancy. Research conducted by Masci (1996) indicates that HIV & AIDS has a significant impact on the pregnancies of HIV-positive women before they go into labour. Masci’s (1996) research revealed that foetal infection has been documented to occur as early as eight weeks of pregnancy, during the first and second trimester. The biological mechanisms of transmission, however, were not understood at the time of the study. It was believed that the virus could cross the placental barrier and infect the foetus.

Prenatal HIV transmission is reported to cause growth failure to about seventy-five percent or more of HIV-infected infants (Masci, 1996: 263). Masci (1996) explains that the growth failure results in specific deformities at birth, such as a prominent forehead, flat nasal bridge, and patulous lips. Through his research Masci (1996) also discovered that pregnancy accelerates the progression of HIV-infection. He found that pregnancy is associated with immunologic reductions in both HIV-infected and non-infected women. This raised a theoretical possibility that the natural history of HIV-infection could be accelerated in pregnant HIV-positive women. The difference between HIV-positive and HIV-negative pregnant women is the persistent CD4 cell depletion after delivery in HIV-positive women and the recovery of the depleted immunity in HIV-negative women, after delivery.

4.2.2. Perinatal Transmission of HIV-Infection

Transplacental infections were thought to occur shortly before or at the time of delivery. This means that labour and delivery were believed to be the period when the foetus was at greatest risk of becoming infected (International Planned Parenthood Federation, 1990). The Federation (1990) proved this in its 148 sets of twins study. The evidence
showed that the first born twin was more likely to be infected than the second born twin. This demonstrated that birth was more likely to be the time of transmission, with twin one being the first to encounter the vagina in his journey through the birth canal. Another plausible indicator of intrapartum transmission was the lower rate of HIV-infection in infants delivered through caesarean section than those delivered vaginally. Shepherd (1994) suggested that prematurity was also associated with a higher risk of intrapartum transmission. Other factors associated with increased perinatal HIV transmission were Sexually Transmitted Infections (STI’s) during pregnancy and haemorrhage during labour. These increase the viral load in the genital tract (International Planned Parenthood Federation, 1990). The findings of this early research have not changed.

A significant pregnancy outcome for HIV-positive women identified by Termmerman, K’Odud, Plumme, Ndinya-Achola, & Piot (1992) was the increased risk of pre-term delivery. They attributed this risk to the infectious disease in the mother, such as tuberculosis (TB) and malaria, and low nutritional status. Based on the evidence presented by the results of their case-study in Nairobi-Kenya, it seemed plausible that HIV-infection in women who were asymptomatic and not significantly immunocompromised experienced no major effects on pregnancy outcome (Termmerman et al., 1992: 44).

4.2.3 Postnatal Transmission of HIV-Infection

Newell (1995) identified the transmission of HIV through breastfeeding in situations where the mother acquired infection shortly after birth. Newell (1995) attributed this to the high risk of infection in mothers with primary infection after birth, and thus estimated that the risk of HIV transmission by HIV-positive mothers through breastfeeding, in such cases, was about twenty-nine percent. In cases where the mother was infected with HIV before the pregnancy, the infant’s additional risk of contracting HIV from breastfeeding was estimated at fourteen percent. Newell (1995) reported an anticipated lower risk of
infection of children who had been breastfed by mothers with an established HIV-infection at the time of delivery. This anticipation was based on the assumption that babies born to HIV-positive women were maternal IgG antibody carriers. These antibodies were believed to perform a protective function on the infants. For example, within the first four days after delivery 72 percent of HIV-positive women in a Haitian study had HIV-DNA in their breast milk. After twelve months the rate of HIV-DNA detectable in breast milk decreased in half of the women, and for the other women it remained the same. The decreasing prevalence of HIV-DNA reflected normal decrease in breast milk cells during lactation and the association with the transmission of infectious HI- Virus remained to be explored (Gordon, Ruff, & Halsey, 1990: 56).

Based on the above discussion the World Health Organisation (WHO, 2001) concluded that HIV-positive pregnant women based in areas where the main cause of death in infancy was not infectious disease, and infant mortality rate was low, should be advised to use safer alternatives to breastfeeding, such as bottle feeding or feeding with a spoon. However HIV-positive pregnant women from areas where infectious diseases and malnutrition were the main cause of infant deaths with high infant mortality rates should be advised to breastfeed.

The Centres for Disease Control (1999) suggested that HIV-negative women and women of unknown status should continue breastfeeding. However, a woman known to have HIV-infection should be informed about the risk of HIV transmission through breastfeeding and educated about other possible feeding options, so that she can make her own decision about whether to breastfeed or to use commercial infant formula. This will be further expanded upon at a later stage in this chapter.

Although the data on the mechanism of vertical transmission of HIV-infection is inconclusive, this section established that vertical transmission poses fatal risks for both mother and baby. This section also highlighted the factors which indicate how planned parenthood in HIV-positive women poses risks to the mother as well as her baby if the
mother has HIV-type 1 and the baby is delivered through the vaginal canal, or is born premature or the mother has STI during pregnancy, or haemorrhages during labour. In this instance, the risk of vertical transmission of HIV from mother to baby is increased. That is why abortions and stillborns of HIV-infected infants are greater (Masci, 1996). These infants experience growth failure and an increase in deformities (Masci, 1996).

There is much debate about how HIV-positive women should feed their babies. There is some evidence that the HI- Virus can be vertically transmitted from mother to infant through breastfeeding.

4.3 PSYCHOSOCIAL FACTORS INFLUENCING THE HIV-POSITIVE MOTHER’S DECISION TO PROCREATE

There are several psychosocial factors that influence the decision to procreate. They range from religious and cultural beliefs, poverty and peer pressure. Each of these will be elaborated upon.

4.3.1 The influence of Cultural Beliefs on the HIV-Positive Mother’s Decision to Procreate

Patriarchal cultures place a heavy premium on encouraging reproduction for the purpose of continuity of families and the survival of the family name. Reproduction may also be used as a means of asserting dominance over women (Smith, 2006). These motivators for reproduction will be briefly reviewed.
4.3.1.1 Reproduction and survival of the family name

An HIV-positive woman may decide to have children to conform to cultural norms. Traditionally, cultural norms require one to have a family comprising of a woman, man and children. Christopher (1996) argued that patriarchal cultures do not recognize marriages with no children. The Xhosa culture is no exception. It expects young Xhosa adults to fulfill a parental role (Smith, 2006). Because reproduction is such a socially sanctioned practice in situations where a woman is infertile, the man or spouse is expected to choose a second wife, referred to as ‘isithemvu’, in order to bear children. This is custom for the sake of the survival of the family name through generations. This was illustrated in the television soap opera, ‘Isidingo’ (SABC- 3, 2004), where a Mosotho boy named Parsons Matabane grew up to become a young man, and married an HIV-positive woman named Nandipa. Nandipa and Parsons made the reproductive decision not to have children. Parsons’ father, Zebedia Matabane was not happy with the decision because it had deleterious implications for his family’s survival. He believed that this would mean the end to the Matabane lineage. He and Parsons were the only male survivors in the entire Matabane clan. Zebedia felt that Parsons had the responsibility to bear more sons to ensure the survival of the lineage. Zebedia took it upon himself to ensure that the Matabane lineage survived through the next generation by taking a second wife to bear him a son. This reflects the importance of children to Africans across cultures, because although Zebedia was a Mosotho man, a Xhosa man would have done the same.

4.3.1.2 Reproduction as a means of male dominance

Christopher (1996) pointed out that pregnancy may sometimes be used as a means to control a woman, especially where there is violence in a relationship. In such relationships women do not have a say in contraception use. They depend on the decision of a man, which may be based on gender role scripting. Being female casts a woman into
the role of the bearer of children. Patriarchal societies such as the Xhosas socialize men to view women and children as their possessions. Women are expected to submit to their husbands especially on issues concerning sexual intercourse. Some tribes that are closely related to the Xhosa tribe, such as the Pondo, take it as a norm for a man to have an extramarital affair. This affair is usually not hidden, and the wife knows and accepts her husband’s mistress referred to as ‘inkazana’. The roles of women in such communities are taken merely as child-bearers, child careers, home makers and ‘sex objects’. Women are there to satisfy men’s needs. Indigenous communities are cautious of accommodating change brought about by industrialization and urbanization. Although they may know of HIV and its transmission they negate or ignore the use of condoms stating that it is contrary to custom. Westernized or first world practices are regarded with much suspicion especially because of social disintegration of indigenous cultures caused by colonialization (Christopher, 1996).

4.3.2 The influence of Religious Beliefs on the HIV-Positive Mother’s Decision to Procreate

Christopher (1996) and Hankins (1996) were of the same opinion that religion influences reproductive decisions. Most religions view pregnancy as the will of a Higher Power and ‘that the sole purpose of Humanity was to reproduce and fill up the earth’ (Genesis, 1:28 in the Good News Bible, 2000: 4). People with strong religious beliefs tend not to believe in contraception and condemn abortion considering this practice as murder. Some religious sectors which follow Christian ideologies such as the Catholic faith strongly reject the promotion of condom use. The concern of the Catholics in making condoms available is that it promotes early sexual activity among adolescents and extra-marital sexual activity among adults. Both these behaviours are condemned as immoral and contrary to God’s will and societal expectations. Byamugisha (2000: 55) confirms the aforementioned as follows, “In many countries young people are denied access to education about HIV & AIDS including safe behavioural skills. Others are unable to buy
condoms or attend STI clinics. This is usually because adults believe such education and services will encourage young people to engage in sexual activity. Many people believe that those who promote condom use to prevent HIV-infections and STIs are promoting sexual intercourse outside marriage and among adolescents”. Several religions believe in the natural methods of contraception. In order to space children, and avoid falling pregnant the couple abstain from sex when breastfeeding, and during ovulation, or use the withdrawal method during copulation. Judging by statistics that indicate that the age of sexually active people is getting lower and the incidence of babies born out of wedlock and unplanned is getting higher, it appears as though religious teachings about sexuality are failing (Hankins, 1996).

4.3.3 Intraperpersonal motivating factors for reproducing offspring
Hankins (1996) explained that the reproductive decision could also be tied to several intraperpersonal factors, such as;

4.3.3.1 Reproduction and identity issues: For some, an individual’s identity as a man or woman is bound up with his/her ability to have children. Procreation is regarded as a way of proving one’s worth.

4.3.3.2 Desire to experience parenthood: This is the desire experienced by women who have no children that influences an HIV-positive woman to have a child despite the risk of prenatal transmission. Smith (2006) referred to this desire as natural maternal and paternal drives. This desire can be witnessed by observing the extreme efforts that barren parents go to, to become parents. Such efforts may include resorting to artificial insemination and more advanced artificial reproductive technologies, visits to traditional healers, alternative healers, and following old wives remedies.
Shepherd (1994) who is the author of the book ‘HIV-infection in pregnancy’ stressed that HIV-positive women experience this strong desire to have children too. She mentioned several other reasons why HIV-positive women decide to procreate. These include the mother’s current good health, anti-abortion feelings, and knowledge of other women with HIV who have healthy children. According to Christopher (1996) a baby or a child, across cultures, represents a new beginning and new hope. A child may provide parents with hope for a life that they wanted to live. Children confer adult status, carry on the family name, are insurance for old age, ensure immortality, keep a marriage and relationship together, prevent boredom and loneliness, satisfy the need to define role in life, and provide stability. These are powerful motivating reasons for couples to have children.

4.3.4 The influence of Poverty on the HIV-Positive Mother’s Decision to Procreate

In South Africa, poverty influences adolescent females to fall pregnant (Makhiwane & Udjo, 2006). In situations of severe poverty people in South Africa are desperate to access social grants. These authors state that some women fall pregnant in order to benefit from child care grants. Teenagers living in destitute areas of South Africa have fallen pregnant to access the child support grant amounting to R240 (Hall, 2009). It has also been reported that people willingly infected themselves with HIV so as to access disability grants (Makhiwane & Udjo, 2006). When interviewed, these people state, “HIV & AIDS will not kill us today but hunger will”. In response to this the Government changed the criteria for eligibility for the disability grant so that only those whose CD4 count was 200 and below were eligible (Hall, 2009).
4.3.5 Media and Peer Pressure

Some teenagers do not plan to fall pregnant but find themselves dealing with the harsh reality of an unplanned pregnancy. These unplanned pregnancies are often a result of myths and common misconceptions about sexual practices that are projected by peers and the media. Some of the myths and misconceptions are:

4.3.5.1 Unrealistic perceptions about adult life and relationships perpetuated by the media, such as; "girls who wear sexy & revealing clothing will be popular with men and will have plenty of boyfriends and dates. Sex is no big deal, it is expected on dates. Attractiveness guarantees love from the opposite sex," (Caissy, 1996:67 &68).

4.3.5.2 Adolescents operate under a large number of misconceptions about sexual issues: Smith (2006) stated that teenagers believe that pregnancy cannot occur in the middle of a menstrual cycle, and that it only occurs when people want to be pregnant. Such misconceptions originate from inadequate sex knowledge imparted by families. South Africans, particularly Black ethnic groups, are not accustomed to talking about sex. Within many Black ethnic groups sex is viewed as a private and taboo subject. Ignorance has led to increased teenage pregnancy and HIV-infection. Attempts to address this problem are seen through efforts to provide sex education in schools as well as programmes directed by organizations such as Thetha Junction and Love Life.

4.3.5.3 Adolescents believe that they are invincible: Caissy (1996) stated that adolescents are very idealistic. When warned about the consequences of adult behaviour such as sex they feel invincible and believe that nothing bad will happen to them.

4.3.5.4 Other Reasons for teenage pregnancy:

There are a host of other reasons such as intra-familial sexual abuse, sexual abuse by family friends, and neighbours, being an orphan, and sex work at a very young age. These put children in vulnerable positions where they are exploited by older men who
take care of their financial needs in exchange for sexual favours. The first part of this chapter revealed that there are several factors which indicate that planned-parenthood in HIV-positive women poses risks to the mother as well as the baby. Furthermore the literature alerted the reader to the risks of mother-to-child transmission of HIV during breast-feeding. Clearly psychosocial factors mentioned in the literature such as, religious and cultural beliefs are significant to this study. Some factors such as reproduction as a form of male dominance, a strong desire to experience parenthood and, poverty, peer pressure could be relevant to the research participants in the study. What remains unclear is just how great these influences actually are among HIV-positive women in the Mthatha region.

4.4 SUMMARY

The literature reviewed has shown various factors that come into play when one is faced with the decision to either procreate or not procreate. Whether this decision is made consciously or not is one of the focus questions of this study.

The major factor that influences the HIV-positive mother’s decision not to procreate is the vertical transmission of HIV. This transmission is thought to occur in three modes. These include the pre-natal (during pregnancy), peri-natal (during labour), and postnatal (through breastfeeding) modes of HIV transmission from the mother to the baby. Most transmission is viewed to occur during labour. HIV-infection in Africa is said to be characterized by the HIV-type 1 infections. HIV-type 1 is believed to pose a higher risk of HIV vertical transmission than HIV-type 2. The factors that influence the HIV-positive mother’s decision to procreate revolve around cultural and religious beliefs, intrapersonal factors, poverty, and the media and peer pressure. Xhosa culture was discovered to promote reproduction so that the family name survived through generations, and perpetuated and instilled male dominance. Religion esteems reproduction as the will of a ‘higher power’. Certain religious groups are against condom use and abortion, for
example Roman Catholics. Condoms are viewed to promote sexual activity among adolescents and extra-marital affairs. Abortion is viewed as murder. The intrapersonal motivating factors for reproduction included proving individual identity and self worth which are tied to the ability to have children and the desire to experience parenthood. Poverty causes adolescent girls to fall pregnant in order to gain access to the child support grant and intentionally with HIV to gain access to the disability grant. Media and peer pressure portray and promote misconceptions about sexual activity to adolescents, and this in cases results in teenagers engaging in sex and thus falling pregnant.

The next chapter presents the research methodology employed in this research.
CHAPTER FIVE
A DESCRIPTION OF THE IMPLEMENTATION OF RESEARCH METHODOLOGY EMPLOYED IN THIS RESEARCH PROJECT

5.1 INTRODUCTION

This chapter documents how the research methodology was employed in this research study. The chapter begins with an outline of the research questions and proceeds to discuss topics such as: research approach and design; theoretical framework; the research process; sampling methods, method of data collection, data analysis, and criteria for judging qualitative research; the ethics considered during the study; the limitations experienced in the study.

The study set out to explore the motivations of a sample of women from the Mthatha region. These women were HIV-positive and had made a conscious decision to procreate despite their HIV-status. The sample also included women who discovered their HIV-positive status during pregnancy and chose to carry their babies to term instead of the alternative to abort them. The exploration of the motivations of women was done through focus group discussions with members from four support groups organized and facilitated by the IDC, and the Ngangelizwe, Civic Centre, and City Centre Clinics.

5.2 RESEARCH QUESTIONS

The researcher was interested in finding answers to the following three questions:

1) What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?
2) To what extent and in what nature are HIV-positive women informed about such risks?
3) From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families?

5.3 RESEARCH APPROACH AND DESIGN

The study was conducted from a qualitative approach. Within this approach the explorative, descriptive, contextual, and ethnographic research designs or strategies of inquiry were employed. In the introductory chapter it was stated that this study did not have hypotheses but aimed to generate them. Trochim (2006) affirmed that studies such as this one are qualitative in nature, seek to develop hypotheses and have special value for investigating complex and sensitive issues, such as God and religion, human sexuality, death penalty and many other topics. Trochim (2006) attributed value to the ability of the qualitative approach to achieve a deep understanding of how people think about such issues. This study seeks to investigate the decision of HIV-positive women to procreate despite the risks of vertical transmission, infection or re-infection of a partner, and disease progression. HIV & AIDS is a sensitive topic that is treated confidentially and HIV-positive people are protected by human rights laws globally. According to Denzin & Lincoln (2000) the goal of qualitative research is defined by describing and understanding through exploration rather than explanation and prediction of human behaviour.

The literature reviewed for this study generated very few studies on the topic rendering it a relatively new subject of interest. Babbie and Mouton (2007) suggested that the purpose of a research endeavour focussing on a relative new topic is exploration. In addition, they explained that exploratory studies are most typically done in order to satisfy the curiosity and desire for better understanding; to determine priorities for future research; and to develop new hypotheses about an existing phenomenon. The major purpose of this study, as mentioned earlier in the objectives of this study, was to develop hypotheses for further
and more in depth studies in order to generate new theories on HIV & AIDS and planned parent-hood.

A research design can be thought of as the structure of research, which acts as the glue that holds all the elements in a research project together (Trochim, 2006). Qualitative research designs share the following features: a detailed engagement with the object of study; the selection of a small number of cases for study; an openness to multiple sources of data; and flexible design features that allow the researcher to adapt and make changes to the study where and when necessary (Babbie, & Mouton, 2007:279). The five design types of qualitative research are phenomenology, grounded theory methods, ethnographic studies, case studies, and life history methods. This study used the ethnographic study research design because it focused on linking behaviour to culture.

Spradley (1979) defined ethnography as the work of describing culture in an attempt to understand other people’s way of life from their native point of view. This definition is still relevant today because it clearly describes the nature and essence of ethnography. Ethnographic fieldwork then involves the disciplined study of what the world is like to people who have learned to see, hear, speak, think, and act in ways that are different. In the case of this study ethnographic fieldwork involved the disciplined study of what the world is like for Xhosa HIV-positive pregnant women from the Mthatha region who made a conscious decision to have babies despite the risks of vertical transmission, infection or re-infection of a partner, and disease progression. Ethnography, therefore, means learning from people rather than studying people. Babbie & Mouton (2007) argued that although the term “ethnography” has its origins in cultural anthropology it has been taken up by many social scientists to undertake studies in ethnographic field sites such as clinics, schools, cult groups, and so on. Ethnography therefore has subsequently lost its field of origin. The researcher used ethnography to undertake her study in clinics, and has thus not used cultural anthropology as a theoretical framework.
The clinics she identified as the ethnographic field sites were comprised of; IDC, Ngangelizwe, Civic Centre, and City Centre Clinics.

As stated before, the researcher wanted to explore the reasons why women who are HIV-positive deliberately decide to become pregnant and why the ones who find out that they are HIV-positive during pregnancy opt to carry their babies to term instead of abortion. In view of the fact that there seems to be a dearth of indigenous qualitative-generated research on the topic the researcher employed an explorative research design. This mode of inquiry is used to explore a new topic or learn more about issues where little is known (Neuman, 2000:20). The descriptive design was employed to provide a detailed description of what was explored (Neuman, 2000: 20). The contextual design was used because the researcher wanted to investigate the phenomenon in a specific context (i.e. the researcher wanted to investigate the decisions of women who are HIV-positive to procreate and women who chose to continue with their pregnancies in spite of learning about their HIV-positive status).

5.4 THEORETICAL FRAMEWORK

The theoretical framework for the study was the Culture Life Span Approach authored by Trommsdorff (2002). This approach suggests that culture provides a “shared meaning system” that allows individuals belonging to a common culture opportunities to internalize certain cultural values and acquire specific adaptive competences relevant to developmental stages. The framework assumed that there are five developmental stages, which can not only be defined by chronological age but by functional, psychological, social, and biological age. The framework also assumed that the beginning and end of developmental stages in certain cultures is marked by gender specific rituals. The Xhosa culture life cycle development stages are defined by the gender specific biological age, with the beginning of each stage marked by gender specific rituals. The traditional chief and anthropologist explained that the beginning of the childhood stage is marked by the ritual called ‘imbeleka’ (a sheep or goat is sacrificed in order to introduce a child to the
ancestors). The stage ‘ukufikisa’ puberty is marked by the onset of menstruation and
development of breasts in girls, and the development of an erection, beard and deep voice
in boys. The young adulthood stage is marked by the initiation ritual called ‘intonjane’
for girls (a cow or goat is sacrificed to the ancestors on behalf of the girl in order for the
ancestors to prepare a good path as the young woman assumes the responsibilities
attached to being a woman) and ‘ukwaluka’ for boys (this is termed circumcision and is
the preparation of boys to be men. It is a transmission from boyhood to manhood. A goat
is sacrificed to the ancestors so that they can prepare a path as the young men assume the
responsibilities attached to being men). Old age is marked by having a grandchild or
retirement from work. In each stage there are particular developmental tasks that a person
has to fulfil.

Because most procreation occurs between the ages twenty to forty years this study was
based on the adulthood stage. According to the Xhosa culture young men and women in
the adulthood stage are expected to establish families by either getting married and
bearing children, or by bearing children without getting married (although this option is
allowed it is discouraged), thus assuming a parental role (Lamla, 2007 ). This approach is
based on the premise that culture provides options and restrictions for individuals during
the developmental process. Social pressure is exerted on those who violate cultural values
and norms and individual choices become secondary to community and cultural identity
(Brisil, 1993:78).

This study concerned itself with discovering the developmental tasks of the adulthood
stage within the Xhosa culture. This study also explored the Xhosa cultural influence on
the decision made by HIV-positive women to procreate. These are discussed at length in
chapter seven.
5.5 THE RESEARCH PROCESS

The research was conducted in four stages: exploration of the topic; the development of the research methodology; pilot study; and the data collecting process. The exploratory approach and ethnographic field study were significant tools of validation for the researcher’s observations and assumptions.

5.5.1 Stage One: Exploring the topic through the ethnographic field study

In ethnographic research participants are full collaborators. They are included in negotiating the content and direction of the research process. Ethnographic research requires a researcher to engage with participants in a social situation, by living among them; acquiring the language of those being studied; observing from within and conducting semi-structured interviews making a record of events and analyzing them (Boeree, 2007). Being a social worker and lecturer in the area of Mthatha, who had spent most of her career working with HIV & AIDS related cases and also a mother of a three year old and a person who had been born and raised in the area as “umXhosa”, that is, a Xhosa, the researcher observed that the HIV & AIDS pandemic had not changed the reproductive patterns within the Mthatha community. Young couples continued to have children despite their HIV-positive status. To negotiate the content and direction of the research the researcher interacted with HIV-positive pregnant women both professionally and socially. The researcher had informal discussions with HIV-positive women from the Ngangelizwe clinic as well as HIV-positive students from Walter Sisulu University (WSU) who had given birth after having been diagnosed with HIV. The researcher also interacted with two nurses and one social worker who were based in the clinics, as well as an anthropologist based at WSU, and the chief of Viegiesville in Mthatha. The professionals and traditional chief were considered to be the key informants of the study. These people were enlisted, using the purposive sampling method, and were approached
because of their expert knowledge in the fields of HIV & AIDS, family planning, and the Xhosa culture. The interaction was in the form of overt participant observation and semi-structured interviews. Field notes were taken to record the data during the semi-structured interviews. From the field notes the criteria HIV-positive women used when making the decision to procreate was identified. These criteria were later used as themes (or codes) to facilitate data analysis. Codes are keywords, themes, or phrases that may or may not correspond to actual terms in the text being analyzed (Creswell, 2003:88). The discovered themes were ARVs; VCT; Xhosa culture and Christianity, including the importance of child bearing, family values and beliefs systems; denial, stigma and discrimination, current status of health; ignorance and lack of knowledge. Exploring the topic was regarded as the preliminary stage of the data collecting process.

This stage of the research process developed insight and understanding into the reasons why HIV-positive Xhosa women planned pregnancies despite their HIV-status. These interviews further aided question development for the focus group discussions.

5.5.2 Stage two: Developing a Research Methodology

This stage involved deciding on the data collection methods, designing a research tool, sampling, formation of pilot and focus groups, and recruiting and training the research team.

(i) The data collecting methods

As explained earlier, the research design of this study was the ethnographic field study, and therefore the methods of data collection decided upon were from that premise. According to Denzin, & Lincoln (2003) ethnographic research is a combination of participant observation and semi-structured interviews. Participant observation is a form of observation where the researcher is simultaneously a member of the group that is being
studied and the researcher who is conducting the study. Babbie & Mouton (2007:56) referred to this approach as “covert participant observation” and stated that the covert approach to participant observation is devoid of ethical procedures and thus negates people’s human rights. Another approach to participant observation is termed overt participant observation. In this approach the identity of the researcher is revealed. This study used both covert and overt observation. Semi-structured interviews are viewed as guided conversation (Denzin & Lincoln, 2003: 53). According to Babbie & Mouton (2007) a semi-structured interview is an interaction between the interviewer and a participant in which the interviewer has a general plan of inquiry but not a specific set of questions that must be asked using particular words in a particular order. The research study used focus group discussions as well. Focus group discussions can be thought of as a semi-structured interview with several people at the same time (Denzin & Lincoln, 2003: 54). Focus groups are fundamentally a way of listening to people and learning from them. Babbie & Mouton (2007) described focus group discussions as a collective rather than an individualistic research method that focuses on the multi-vocality of the participants’ attitudes, experiences, and beliefs. It must be noted that not all people are comfortable discussing topics on a one-to-one basis. Those intimidated by one-to-one semi-structured interviews were afforded an opportunity to express their views, daily experiences, feeling, attitudes, hopes, and dreams in the presence of others who could share and relate to their experience through focus group discussions. Focus group interviews obtained views of group members simultaneously which led to a cross pollination of ideas. Data were, therefore, collected using the participant observation, semi-structured interviews, and focus group discussions. Participatory observation was used to explore the topic and establish the sample frame. The semi-structured interviews were also used to explore the topic, recruit the sample, and to debrief participants after the focus group discussions.
(ii) Designing the research tool

The most suitable research tool for semi-structured interviews and focus group discussions was the interview guide. The purpose of the interview guide was to provide an overall direction for the interviews and discussions. Separate interview guides were developed for the semi-structured interviews and focus group discussions. The interview guides for the semi-structured interviews were designed to explore the topic with input from the anthropologist, traditional chief, social worker and two nurses, and to elicit the individual experiences and attitudes of participants after the focus group discussions. The interview guides designed for the data collecting process were guided by the themes identified through the key informant interviews. The interview guides provided the researcher with topics and issues that were to be covered during the semi-structured interviews and focus group discussion. The interview guides were loosely structured and did not suggest potential responses (Sherraden, 2001:21). The interview guides proceeded logically from one topic to another and from general to more specific. They were pre-tested during the pilot study to structure the questions so that they were clear and stimulated discussion. The actual copies of the interview guides are appended (See Appendix A and B).

(iii) The sampling process

According to David and Sutton (2004) sampling is the process of deciding who will participate in the study. For this study good sampling implied a well-defined target population that was adequately chosen. There are two fundamental methods of sampling. These are probability sampling and non-probability sampling. The distinguishing factor between the two is that non probability sampling does not involve the random selection of the participants, while, probability sampling does. Non-probability sampling is used in situations where there is no standardized list of the population being studied and there is no way the researcher can formulate one. Like in the case of this study, there was no list of all HIV-positive women who deliberately procreated, and there was no way in which
the researcher could establish such a list. The researcher therefore used a non-probability sampling method to sample the target population. Amongst the various types of non-probability sampling methods the researcher used purposive sampling. Purposive sampling allowed the researcher to select the sample on the basis of her own knowledge of the target population and the nature of the research purpose (Babbie & Mouton, 2007:166). The purpose of this study was to explore the reasons for HIV-positive women to consciously procreate despite the risks of vertical transmission, re-infection, and disease progression. Babbie & Mouton (2007) recommended that a researcher could use a subset of a larger population in which many members of the subset are easily identified, but the enumeration of all of them would be nearly impossible. Based on this suggestion the researcher used HIV & AIDS support groups attached to the primary health care clinics in the Mthatha region as a subset of a larger population of HIV-positive people. These support groups were coordinated and facilitated by clinics of the Department of Health. As mentioned earlier sampling was done in four clinics that rendered HIV & AIDS care services. These were the IDC, Ngangelizwe, Civic Centre, and City Centre.

A target population is defined by Bless & Higson-Smith (1995) as the set of elements that the research focuses upon. The target population in which the researcher was interested had to possess the following characteristics:

- HIV-positive pregnant women, and women who had given birth to babies after their HIV-status had been diagnosed
- These women had to be Xhosa speaking, and be attending clinics in the Mthatha region
- They had to be in the “adulthood stage” as classified by Trommsdorff (2002), between the ages twenty and forty years.

The sampling process began with establishing or setting up the sampling frame of the target population from the support groups. The sampling frame was developed by identifying individuals from the target population who displayed characteristics listed above. The researcher chose to work with existing support groups whose members were comfortable to talk about their experience of being HIV-positive and pregnant within the
Xhosa cultural context in Mthatha region. According to Babbie & Mouton (2007) the process of developing a sampling frame can follow a participant observation exercise. Participant observation needed to be unobtrusive and ethical to give participants in the study an opportunity to talk about their experiences whilst benefiting from support groups simultaneously. It was hoped that through this study valuable information would be attained in order to develop relevant services for these women. The researcher therefore used both covert and overt participant observation by covertly participating with the support groups under study, and then later on sharing her interest in conducting research on the experiences of the support group members. The researcher participated in the support groups by co-facilitating three meetings for each support group. The aim was to build rapport. Each of the four clinics had two support groups, one for the PMTCT programme and the other for empowering PLWHIV. The PMTCT support groups provided services to HIV-positive pregnant women, and the PLWHIV support groups provided services to any HIV-positive men and women. The total number of PLWHIV support group members for all clinics was 115, and the total number of all PMTCT support group members for all clinics was twenty-nine. Out of 115 members from the PLWHIV support groups thirty-seven were identified and selected to form part of the sample frame. While all twenty-nine of the PMTCT support group members were identified and selected to form part of the sample frame. As mentioned earlier, the identification and selection of the sample frame was based on the characteristics of the target population and the purpose of the study. The sample frame therefore had the total of sixty-six members. Table 5.1, that follows displays the selection of the sample frame more clearly:
Table 5.1: Selection of the sample frame

<table>
<thead>
<tr>
<th>ETHNOGRAPHIC FIELD</th>
<th>TOTAL POPULATION OF SUPPORT GROUPS</th>
<th>SAMPLE FRAME</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLINICS</td>
<td>PLWH IV</td>
<td>PMTCT</td>
</tr>
<tr>
<td>IDC</td>
<td>35</td>
<td>10</td>
</tr>
<tr>
<td>Ngangelizwe</td>
<td>30</td>
<td>8</td>
</tr>
<tr>
<td>Civic Centre</td>
<td>27</td>
<td>6</td>
</tr>
<tr>
<td>City Centre</td>
<td>23</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>115</td>
<td>29</td>
</tr>
</tbody>
</table>

The sampling process culminated with the recruitment of participants for the study. This exercise was conducted in order to help the sample frame to understand the implications of their participation in this study: to establish whether they were interested and willing to participate in the study. The researcher met informally with each candidate using semi-structured interviews. During the interviews the researcher explained the purpose of the study, and the rights of the candidates to voluntary participation, informed consent, confidentiality, and anonymity. These rights are discussed in detail towards the end of this chapter. The researcher’s expectations of the data collection process were also explained, and the candidate’s expectations as participants in the study were explored.

Out of the total membership of sixty-six on the sample frame, forty-eight agreed to participate in the study and eighteen declined. The researcher did not explore the reasons why the candidates did not wish to participate but assumed that they did not have the time available to engage in the study. Out of the twenty-nine members of the PMTCT sample frame fourteen agreed to participate and fifteen declined. From the PLWHIV sample frame three declined and thirty-four agreed to participate in the study. A large number of
the participants declined the request to participate in the study and the view of the key informants was that when these women are faced with the infection they go into denial. Table 5.2 shows more clearly the recruitment of the participants in the study.

<table>
<thead>
<tr>
<th>WILLINGNESS TO PARTICIPATE</th>
<th>PMTCT</th>
<th>PLWA</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreed</td>
<td>14</td>
<td>34</td>
<td>48</td>
</tr>
<tr>
<td>Disagreed</td>
<td>15</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>37</td>
<td>66</td>
</tr>
</tbody>
</table>

(iv) Formation of pilot and focus groups

The formation of focus groups involved assembling the sample into homogenous groups of six to twenty participants, including age, economic status, gender, ethnicity, and health status (David & Sutton, 2004:56). The researcher therefore grouped the sampled participants into groups of six in order to, maintain the principle of homogeneity, maximize the comfort of the respondents, and make it easier to control the volume of data collected. The total number of focus groups formed was eight. The main criteria used for group classification was age. This was the case because all participants were women, Xhosa speaking, HIV-positive, and of the same economic status. Three focus groups were formed in the IDC and were categorized by age to include: group one consisted of members between the ages of twenty to twenty-five; group two consisted of members between the ages twenty-six to thirty; and group three consisted of members between the ages thirty-six to forty. One focus group (group four) was formed in the Civic Centre Clinic and was categorized by age to include members between the ages twenty-six to thirty. Two focus groups were formed in the City Centre Clinic and were categorized by age. Group five consisted of members between the ages twenty to twenty-five; and group
six consisted of members between the ages twenty-six to thirty. Two focus groups were formed in Ngangelizwe Clinic and were categorized by age. These included group seven consisting of members between the ages twenty to twenty-five; and group eight consisting of the age group thirty to thirty-five. Table 5.3 displays the formed focus groups more clearly.

Table 5.3: Focus groups according to clinics

<table>
<thead>
<tr>
<th>Name of clinic</th>
<th>Name of group</th>
<th>Category by age</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDC</td>
<td>Group one</td>
<td>20 – 25</td>
</tr>
<tr>
<td></td>
<td>Group two</td>
<td>26 – 30</td>
</tr>
<tr>
<td></td>
<td>Group three</td>
<td>36 – 40</td>
</tr>
<tr>
<td>Civic Centre clinic</td>
<td>Group four</td>
<td>26 – 30</td>
</tr>
<tr>
<td>City Centre clinic</td>
<td>Group five</td>
<td>20 – 25</td>
</tr>
<tr>
<td></td>
<td>Group six</td>
<td>26 – 30</td>
</tr>
<tr>
<td>Ngangelizwe clinic</td>
<td>Group seven</td>
<td>20 – 25</td>
</tr>
<tr>
<td></td>
<td>Group eight</td>
<td>30 – 35</td>
</tr>
</tbody>
</table>

(v) Recruitment and training of the research team

After the focus groups were formed, the researcher mobilized a team to help to record the discussions of the focus groups. The researcher recruited the co-ordinators of the PLWHIV and PMTCT support groups. These were two nurses and one social worker who were chosen because they were known to the sample and had good rapport with the members and they were bound by their professional ethics to maintain confidentiality, and could follow up cases that needed attention after the research had been conducted. Each clinic had one co-ordinator for both the PLWHIV and PMTCT support groups, with
the exception of Civic and City centre clinics whose support groups were co-ordinated by one nurse who rotated between the two clinics. The co-ordinators and the researcher formed the research team. The role of the researcher in the focus group discussions was to facilitate the group discussions. The role of the support group co-ordinators on the other hand was to record and take notes of the focus group discussions. In preparation for the focus group discussions the research team was trained on how to conduct a focus group discussion. Topics covered during the training included functions of the facilitator and functions of the recorder. The functions of the facilitator involved: ways to encourage discussion, encourage involvement; build rapport; empathize; avoid being placed as an expert; control the rhythm of the session in an unobtrusive way; summarize the discussion at the end of the session. The functions of the recorder involved capturing information such as: the date, time, place; names and characteristics of participants; general description of the group dynamics, level of participation, presence of a dominant participant, and level of interest; opinions of participants. The recorders were encouraged to record as much as possible about the process of the meetings including a summary of what was said. The words of the group members were captured verbatim when transcribing the tape recoded data. Transcribing was anticipated to include key statements; expressing emotional sentiments, such as reluctance, strong feelings attached to certain opinions; vocabulary used, and spontaneous relevant discussions during breaks or after the meeting had been closed. The training was offered by a Sociologist from Walter Sisulu University.

5.5.3 Stage Three: The Pilot Project

The researcher conducted a pilot study before the focus group meetings. The term pilot study refers to a mini version of a full-scale study and is also called a feasibility study (Winter, 2001:1). The pilot study was conducted to provide a trial run of the process of the focus group discussions and test the prepared topics for the focus group meetings. Baker (1994) stated that conducting a pilot study provides advance warning about where the main research project could fail, where research protocols may not be followed, and
whether proposed methods or instruments are inappropriate or too complicated. It increases the likelihood of success in the main study (Teijlingen & Rennie, 2001:1). De Vos et al., (2005) state that pilot testing focus group questions is difficult, in that, questions used are hard to separate from the context of the environment of the focus group. Because of this challenge the researcher selected two focus groups from the recruited eight, and used them as pilot groups. As already specified the pilot groups were recruited from the Ngangelizwe clinic, where the researcher worked as a social worker.

The focus group meetings were conducted in the clinic hall, which offered privacy and few disturbances. The researcher arrived an hour before the focus group meetings commenced to prepare the hall. The seating arrangement was circular so that eye contact could be maintained between members in order to encourage communication and interaction, as well as create a relaxed and intimate climate to foster group cohesion. On day one the research team met with focus group seven. The team consisted of the researcher as the facilitator and nurse as the recorder. The first meeting was dedicated to introductions. The facilitator introduced herself and the nurse, explained the purpose of the meeting, indicated the nature of the information required and how that information will be used, asked for permission to tape record the meetings, and requested the participants to use their clan names instead of their first names to maintain anonymity. The first meeting was also dedicated to build rapport through the sharing of experiences about the participants' testing for HIV & AIDS, touching on pre-and-post test counselling and how they disclosed their statuses to their loved ones. The session took two hours which is in line with Oniel's (2008) prescription that a focus group meeting can take plus minus one and a half to two hours. When evaluating this meeting the researcher noticed that the participants were inhibited to share experiences and remedied this by introducing an ice-breaker in the second meeting. The ice-breaker was in the form of a song.

The researcher faced a challenge of some participants not coming for the second meeting. She phoned those participants and discovered that they had a problem with transport fare. She then postponed the second meeting for the following week. The researcher
fundraised for the transport fare from the local businesses around Mthatha. Businesses like Spar, Spargs, Shoprite, and Kie Cash and Carry donated transport fare and refreshments for the focus group meetings. The second meeting had full attendance and the participants interacted more freely because of the refreshments offered before the meeting and the ice breaking song. The refreshments also acted as an ice breaker because during refreshment time the research team and the participants mingled. The second session focused on discussing the reasons for participants’ procreating in their state of health, their source of strength, the impact child bearing had on their health, their fears, and their future plans. This meeting discussed the effects of HIV-infection on the family. This session also took two hours. The third meeting was dedicated to evaluation and termination. This session lasted one and a half hours. Contact with the focus group participants did not end with the third meeting. The researcher conducted post-focus group semi-structured interviews, because ethically, it was important to elicit the individual experiences and attitudes of the participants that arose from the group discussion. These interviews were essential in informing the participants about the relevant agencies where they could access reliable support after termination. These semi-structured interviews were conducted by the researcher over a period of two days. The whole focus group discussion process took five days. The researcher followed the same process with focus group eight, and the meetings and semi-structured interviews were successful. The results of the pilot study were used to derive themes, and were not published because this was an experimental study designed to test the process that had to be followed for the research project.

5.5.4 Stage Four: The Data Collecting Process

This stage involved the focus group discussion meetings, semi-structured interviews, and data capturing.
5.5.4.1 Focus group discussion sessions and semi-structured interviews

Focus groups one to six were used for the study. The process that was established through the pilot study was used for all focus groups. The focus group meeting in IDC, Civic Centre and City Centre were conducted in the halls situated within the premises of the clinics. The halls were chosen as the best venues because of their location, that is, they were situated in a private and quiet environment. Preparation for each meeting was done two hours before the meeting because the research team had to set up the seating arrangement, as well as prepare the refreshments. The seating arrangement was circular in order to encourage communication and interaction, and create a relaxed and intimate climate to foster group cohesion. The refreshments acted as an icebreaker together with the song that was sung when opening the focus group meeting.

The research team worked with one group at a time until all the groups had an opportunity to engage in focus group discussions. Each focus group had three meetings held over three consecutive days followed by two days of semi-structured interviews. During the first session the facilitator introduced herself and then the co-facilitator/research recorder. The facilitator explained the purpose of the focus group session, the kind of information needed, and how the information would be used.

Permission to use a tape recorder was sought. Cooperation from the participants to keep everything discussed in the sessions confidential was requested. The researcher also explained that participants could ask for clarification at any time. She then requested the participants to introduce themselves using clan names instead of their first names in order to maintain anonymity in the recorded data. The discussion began with the participant’s sharing of their experiences concerning testing for HIV & AIDS. They were expected to first state the reasons why they tested and the process of pre-and-post test counselling. The last topic for discussion in the first session was life after diagnosis. The participants shared their experiences in disclosing their statuses including the reactions of their partners, families, and relatives. The second meeting explored the reasons why the
participants procreated in spite of their HIV-positive status; discussed their sources of support; impact of childbearing on their health; their fears; their sources of strength; their future plans. This meeting culminated with a discussion of the effects of HIV-infection on the family. The third meeting was dedicated to evaluating the whole focus group experience and the termination process of the focus group discussions. As discussed earlier, contact with the participants did not end after the focus groups terminated but after the semi-structured interviews. During sessions the facilitator encouraged involvement, empathized, and avoided playing the expert role. At the end of each session the researcher summarized the main issues brought up, checked whether members agreed, and asked for additional comments. The facilitator thanked the participants for their valuable contributions.

5.5.4.2 Data capturing and editing

Data was captured for each session through field notes and tape recorder. During the pilot study and focus group discussions the recorders tape recorded the discussion and kept notes of the whole proceedings as well as emotional reactions and important aspects of group discussion. After each session the recorded information and field notes were coded into themes. The themes identified through the pilot study and focus group discussion were combined with the themes identified through the key informant interviews. The results included the theme VCT being amended and recorded as PTC. This was due to the fact that PTC was the part of VCT that was most relevant to the study. The theme ‘Xhosa culture and Christianity’ was broken down into two independent themes because the two concepts contained in the theme were applied independently of each other. The sub-theme ‘importance of children’ was excluded because it was discovered to be contained in the sub-themes ‘family, individual, and couple values and belief systems’. The theme ‘ignorance’ was also excluded because it was a contribution from the key informants that was not supported by the empirically collected data. This decision was taken in light of the fact that this study sought to learn from the people and not to study them. ‘Denial’
was identified to be the sub-theme of ‘stigma and discrimination’. An additional theme ‘fear’ was identified. The final themes of the study that were analyzed were: ARVs; PTC; Xhosa culture using family, individual, and couple values and belief systems as sub-themes; Christianity; fear; stigma and discrimination with denial as a sub-theme; and the current state of good health. Table 5.4 displays the codes used to track themes.

Table 5.4: Codes used to track themes

<table>
<thead>
<tr>
<th>IDENTIFIED THEME</th>
<th>MARKED THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Anti-retroviral Drugs</td>
<td>ARV</td>
</tr>
<tr>
<td>2. Post Test Counselling</td>
<td>PTC</td>
</tr>
<tr>
<td>3. Xhosa Culture</td>
<td>XHC</td>
</tr>
<tr>
<td>3.1 Family Values and Beliefs</td>
<td>FVB</td>
</tr>
<tr>
<td>3.2 Individual Values and Beliefs</td>
<td>IVB</td>
</tr>
<tr>
<td>3.3 Couple Values and Beliefs</td>
<td>CVB</td>
</tr>
<tr>
<td>4. Christianity</td>
<td>CHR</td>
</tr>
<tr>
<td>5. Fear</td>
<td>FEA</td>
</tr>
<tr>
<td>6. Stigma and Discrimination</td>
<td>SAD</td>
</tr>
<tr>
<td>6.1 Denial</td>
<td>DEN</td>
</tr>
<tr>
<td>7. Current State of Health</td>
<td>CSH</td>
</tr>
</tbody>
</table>

5.6 CRITERIA FOR JUDGING QUALITATIVE RESEARCH

Trochim (2006) suggests four criteria for judging the soundness of qualitative research. These are credibility, transferability, dependability, and confirmability. Trochim (2006) states that the criteria for judging qualitative research are analogous to the criteria for judging quantitative research, that is, validity and reliability. The table below displays this analogy clearly:
Table 5.5: The criteria for judging both quantitative and qualitative research.

<table>
<thead>
<tr>
<th>Criteria for Judging Quantitative Research</th>
<th>Criteria for Judging Qualitative Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Validity</td>
<td>Credibility</td>
</tr>
<tr>
<td>External Validity</td>
<td>Transferability</td>
</tr>
<tr>
<td>Reliability</td>
<td>Dependability</td>
</tr>
<tr>
<td>Objectivity</td>
<td>Confirmability</td>
</tr>
</tbody>
</table>

Source: Trochim (2006)

According to Babbie & Mouton (2007) credibility poses the question, “does it ring true, that is, is there compatibility between the constructed realities that exist in the minds of the participants and those that are attributed to them?” In this study credibility was achieved through persistent observation (Babbie & Mouton, 2007). This involves a process of constant and provisional analysis of the responses of the participants to the research questions in order to obtain accurate interpretations. The participants volunteered to share the information and they largely determined what was spoken about. The responses of the participants in this study were derived through focus group discussions. These discussions were conducted with eight groups of HIV-positive women who procreated in spite of the associated risks. Interpretations therefore were developed through constant analysis of each focus group discussion. Since the interpretations were sought for repeatedly from eight focus group discussions covering the same topics the researcher deemed them accurate.
Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts or setting (Trochim, 2006). To ensure transferability the researcher must describe the research context thoroughly and the assumptions that were made central to the research (Trochim, 2006). The researcher purposely selected the field sites and the participants through purposive sampling so as to maximize and the range of specific information that could be obtained from and about that context. The context of this study is described thoroughly in chapter one, as well as the assumptions that were made central to it. This study, however, was limited to the opinions of a small sample of women in the Mthatha region and this made it not to be transferable.

According to Trochim (2006) dependability emphasizes the need for the researcher to account for the ever-changing context within which research occurs. In addition, the researcher is responsible for describing the changes that occur in the setting and how these changes affected the way the researcher approached the study. This study collected data on several levels. From the key informants, focus group discussions, and semi-structured interviews. The co-facilitators who were part of the research team helped collect data. Changes that occurred in the setting of this study were explained during the pilot study section, where the researcher had to change the venue for the focus group discussions, and fundraise for taxi fare for the participants as well as the refreshments. This meant that the information gathered was dependable.

Confirmability refers to the degree to which the results could be corroborated by others (Trochim, 2006). It can be enhanced by documenting the procedures for checking and rechecking data throughout the study. These are the procedures used to develop the study. This chapter was dedicated solely to explaining the procedures used and by which data could be checked and rechecked.

The credibility, dependability, and confirmability of this study have been proven to have been met with the exception of transferability which could not be ensured. The next
section gives an overview of the data analysis process which will be discussed at length in chapter six.

5.7 DATA ANALYSIS

The type of data that was analyzed was qualitative data. Qualitative data refers to text, which is, any form of written material obtained through data collecting techniques. Qualitative data analysis focuses on finding meaning in text through coding. Denzin & Lincoln (2003) describe coding as the heart and soul of the whole text analysis; and Creswell (2003) defined codes as keywords, themes, or phrases that may or may not correspond to actual terms of the text being analyzed. The fundamental tasks associated with the coding process included building code books, marking texts, and building contextual models. There are various approaches to coding which facilitate the process of model building. These are grounded theory, schema analysis, analytic induction and the ethnographic decision model (EDM). This study has used the EDM to facilitate the process of model building. The EDM is a qualitative, causal analysis that explores and predicts behavioural choices under specific circumstances (Denzin & Lincoln, 2003:287). This approach was chosen because the study sought to explore the people’s choice to procreate despite the risk of vertical transmission and disease progression. The step by step description of data analysis will be discussed in the next chapter.

5.8 LIMITATIONS OF THE STUDY

As already mentioned, this study was a qualitative exploratory study through which the researcher examined the motivations and expectations of HIV-positive women who plan pregnancy despite their own status. Limitations associated with this method of research, which were experienced in the study involved:
• **Generallsability of the study:** The fact that the study relied on opinions and experiences of the locally specific participants; the sampling method used relied on the researcher’s judgement; and the small sample size suggest that the results of the study may not be applicable to all HIV-positive women who plan pregnancies. The researcher used triangulation of data sources by including patients from different clinics and conducting focus group discussions with different age groups in an attempt to make the findings as representative as possible given the nature and scope of the study.

• **Loss of meaning:** Inaccuracy in capturing the exact meaning to the information shared during the focus group discussion may have occurred. It is however hoped that the fact that the research team shared the same mother tongue with the participants kept loss of meaning to a minimum. The triangulation of data collection methods, namely focus group discussions, semi-structured interviews with key informants and research participants using a research team were all attempts to obtain truth value, neutrality and consistency of data.

### 5.9 ETHICAL CONSIDERATIONS

Miller & Brewer (2003) defined ethics as the science of morality and explained that one who engages in it determines the values for the regulation of human behaviour. They continue to explain that ethics of social research are about creating a mutually respectful, win-win relationship in which participants are pleased to respond candidly, and valid results are obtained. The researcher had to consider research ethics within all stages of the research process: from the design of the study; the recruitment of participants; to their treatment during the research process; and the consequences of their participation. The key ethics that the researcher considered included:

> **Voluntary Participation:** This ethic is considered the central norm governing the relationship between the researcher and participant. Voluntary participation means
that an individual partakes in research on his or her free will. When selecting the sample the researcher informed the participants that participation was voluntary and no one was forced, and that they could withdraw from the study if they felt the need to.

➢ **Anonymity and Confidentiality:** When collecting data confidentiality is recommended as an addition to anonymity. Because the researcher had direct contact with all participants and was able to recognize each one of them she assured them that their identity would be kept anonymous, and that the information given would be treated confidentially. Confidentiality meant that the interview data would be used for the stated purpose of the research and that no other person would have access to it. The research team was composed of qualified professionals bound by their professional codes of conduct.

➢ **Informed Consent:** This ethic is considered an integral part of data collection. Informed consent means that the participants are informed of the purpose and the whole process of the research, and its significance to them and the entire society. The participants were informed that the study was a preliminary study to explore the motivations of women who planned parenthood despite their HIV-status. This preliminary study would provide insight to the life experiences of HIV-positive women and could lead to more in depth studies that would inform policies and antenatal practices for HIV- infected pregnant women.

➢ **Self Determination and Non-judgmentalism:** The participants were informed about self-determination, which is the right to stop participating at any time in the research process. They were also informed that the research team would respect their options and shared life experiences, and would not judge them. These ethics were communicated within the research team and adherence was stressed.
5.10 SUMMARY

This chapter served to provide a detailed account of the rationale for the selection and the sequence for the implementation of the research methodology. The research plan was constructed in such a way that the study would proceed according to ethical and empirical principles.

The study was conducted from a qualitative approach and within this approach explorative, descriptive, contextual, and ethnographic research designs or strategies of inquiry were employed. It was guided by the culture life span approach. As an ethnographic field study, it involved participant observation, focus group discussions, and semi-structured interviews as the main methods of data collection. The data collecting instrument used was the interview guide, and the sampling technique used was the non-probability purposive sampling. The sampling frame was drawn from the support groups attached to IDC, Civic Centre, City Centre, and Ngangelizwe primary health care clinics. The selected sample was grouped into eight focus groups. Each focus group had six members. Two focus groups from the eight were used to pilot the study. The remaining six were used for data collection. Semi-structured interviews were used after the focus group discussions. Data collection was done by a research team consisting of the researcher, two nurses and one social worker. Data was captured through tape recording and note taking. Data was edited and analyzed through the Ethnographic Decision Model (EDM). The study was judged for credibility, transferability, dependability, and confirmability, and was found to be sound on all four criteria. Ethics considered were voluntary participation, confidentiality, informed consent, self-determination and non-judgementalism.

The next chapter provides an overview of the research findings.
CHAPTER SIX
THE RESEARCH FINDINGS

6. 1 INTRODUCTION

This chapter is divided into four sections. The first section presents the results of the four stages of the research process. These stages are: the exploration of the topic through the ethnographic field study; development of a research methodology; the pilot study; and data collection process. In each of these stages the results obtained are presented according to the interview guides, sample profiles, and identified themes. The study had three sets of interview guides. The guides were for interviews with the key informants, focus group discussions, and semi-structured interviews. Sample profiles are displayed for the two focus pilot groups, the total sample and each focus group. The presented results are linked to the following three research questions of the study in an attempt to answer them:

1) What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?
2) To what extent and in what nature are HIV-positive women informed about such risks?
3) From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families?

The second section provides a discussion of the findings according to the focus group and semi-structured interviews. The third section examines the findings by clarifying the reasons why HIV-positive women procreate in spite of the associated risks. The fourth and last section finalises the chapter by deducing concluding interpretations.
Data analysis was done according to the EDM. The EDM is often referred to as a decision tree or flowchart which represents an aggregate decision process and comprises a series of “if then” statements that link criteria to the behaviour of interest (Denzin & Lincoln, 2003:287). The coding process involved identifying themes, marking texts, building codebooks, and conceptual models.

6.2 PRESENTATION OF RESULTS

6.2.1 Exploring the Topic through the Ethnographic Field Study

This stage was the first stage of the research process and focused on negotiating the content and direction of the research study.

The process of data analysis according to the EDM began by informally reflecting upon the decisions that were made by HIV-positive women in relation to procreation and identifying the alternatives that were available to them. This was done by noting the researcher’s and key informants’ observations about the reasons why HIV-positive women procreate in spite of the associated risks. These observations were used to develop a clear formulation of the research questions. The review of literature on the “reproductive decision” also shaped this part of the research process. The literature review chapter, “the reproductive decision”, stated the alternatives available to HIV-positive pregnant women as, the decision not to procreate and, in cases where women discovered their HIV-positive status while pregnant, to abort the pregnancy (see chapter four’s introduction). Very little information was found on the reasons why HIV-positive women choose to procreate once they have discovered their HIV-status and the search of literature by the researcher resulted in a situation where there was no documented information found at all about the motivations for Xhosa HIV-positive women to fall pregnant in spite of an HIV-positive status.
The results obtained in this stage were derived from covert and overt observations by the researcher, which were in the form of informal conversations and semi-structured key informants interviews. As already mentioned, the researcher was a social worker by profession working at Ngangelizwe clinic with HIV & AIDS related cases and a lecturer in the social work department at WSU. The researcher’s covert observation was that women with known HIV-positive status consciously plan to fall pregnant and those who discovered that they were HIV-positive while pregnant opted for carrying their babies to term. With these observations in mind the researcher often pondered the reasons why HIV-positive women did so in view of the risks of vertical transmission, disease progression, and the infection or re-infection of the partner. She also wondered if these women purposefully disregarded the risks that were involved in making these choices and if enough was being done to sensitize them about the associated implications of bearing children with the HI-Virus.

During informal contacts with researcher’s colleagues, students and clients during meetings at the health clinics and social gatherings there appeared to be a general consensus that the numbers of HIV-positive women attending the antenatal clinics were high. It was highlighted that some women returned with a second pregnancy despite having been told during the previous pregnancy that they were HIV-positive. At times there was frustration expressed about what impact their decisions would have on the community as a whole, as clearly these women were not taking heed of what they had been told about HIV & AIDS and were putting themselves and their unborn babies at risk. The researcher felt that it was important to meet with several key people who were active in the community to try to consolidate their views on the topic. A couple of semi-structured interviews with significant key informants were arranged. These interviews were planned to assist the researcher to identify some of the possible criteria HIV-positive women used when taking the decision to procreate despite their status so that these topics would be dealt with in the focus group discussions. These key informants were all known to the researcher who had informally discussed the topic with them on several occasions as indicated earlier.
Interviews were arranged with two nurses, one social worker, an anthropologist who was working at the University, and a traditional chief from a rural village in the KSD district municipality. The interviews lasted one hour with each key informant. The researcher personally approached each of the key informants and requested them to share their professional views on the topic. When they agreed to participate in this process appointments were made. The nurses and social worker were interviewed in the researcher’s office at Ngangelizwe clinic, the anthropologist was interviewed in his office in WSU, and the traditional chief was interviewed at his home in Viegiesville.

The results of the key informant’s interviews are presented according to the interview guide questions for the anthropologist and traditional chief, and the professional nurses and social worker (See appendix 1 (a) and (b)). In the next section the information obtained from the anthropologist and traditional chief will be presented.

6.2.1.1 Interviews with the anthropologist and traditional chief:

The anthropologist is a Xhosa man in his early sixties. He is a retired anthropologist whose main field of interest was “HIV & AIDS and culture”. The traditional chief is a Xhosa man in his mid forties. He has been the chief of a rural village in KSD for twelve years. The village is one of the rural villages of Mthatha and is part of the greater OR Tambo district municipality. As the leader of the village he felt obligated to involve himself in the protection of his people by participating in initiatives taken to fight HIV & AIDS. The anthropologist and traditional chiefs’ responses to the interview guide questions are presented concurrently below. The interview guide questions are displayed as statements as follows:
(a). Their understanding of the importance of child-bearing in the Xhosa Culture.

The anthropologist responded that the need for child-bearing was universally in-born and natural. Human beings at a particular stage in life experience a natural desire to bear children. This natural desire is in most cases influenced by cultural prescripts that dictate to its members what is expected of them at a particular stage in life. In relation to child-bearing the Xhosa culture has distinct adulthood developmental stages for men (ubudoda) and women (ubufazi). ‘Ubudoda’ (manhood) is defined by attending the initiation school and graduating as a man on completion thereof. The young man is only recognized as ‘indoda’ (a man) once he has performed the developmental tasks relevant to the manhood stage. These tasks involve selecting and securing a wife and bearing children. ‘Umfana’ (young man) enjoys a much lesser status than that of being a man. A male moves from being a young man to manhood when he fulfils the associated developmental tasks. ‘Ubufazi’ (womanhood) is achieved when a woman achieves the two developmental tasks of getting married and bearing children. Nowadays, females who bear children out of wedlock are accommodated into ubufazi (womanhood). Should a man or a woman not perform the developmental task of having children then he or she will not have the status of an adult man or a woman bestowed upon him or her by traditional members of the community. Trommsdorff (2002) stated that two of the main developmental tasks of adulthood are establishing a family and assuming a parental role. From the anthropologist’s explanations it can be seen that these developmental tasks are most relevant in the Xhosa culture. Those who deviate from these norms are stigmatised, treated differently from those who comply with the norm and forfeit the social privileges associated with adulthood.

The chief stressed the importance of children within the Xhosa culture. He emphasised that child-bearing was essential for the survival of the Xhosa nation through generations. Xhosa culture places the responsibility for ensuring the survival of the culture on its young adults. The continuity of culture can only be guaranteed by placing restrictions on those who deviate from the norm. Such restrictions may include verbal condemnations,
being ostracised, not taking opinions of deviators seriously, and excluding them from social events. This is consistent with Trommsdorff’s (2002) view that each culture shapes both options and restrictions available to people. In the Xhosa culture young adults are not given an option of whether to take a partner, or remain single. Neither are they given choices as to whether they should have children or not. Digression from these two important developmental tasks is clearly restricted.

(b) The role that Xhosa men play in the decision to procreate

The anthropologist explained the importance of being recognised as ‘indoda’ (a man) in the Xhosa culture. “Each ‘mfana’ does all that he can to get this recognition. This means he marries a wife and bears children with her”. He went on to say that a lot of power is invested in men in the Xhosa culture. The man is considered to be the head of the family. He is the one who makes all the important decisions. The wife is expected to submit to the wishes and desires of her husband. The anthropologist emphasised the significant role played by men in making a decision around procreation. He pointed out, “Even if the wife does not consider it as a good idea, if her husband desires to have a baby, she has to submit or face societal rejection”. The study of Friedman et al., (2006) affirmed this notion. Their study on the impact of male sexuality on women and children’s health argued that men hold decision making power over matters involving basic sexual relations. This decision making includes when and whether to have a child, as well as whether or not to engage in health seeking behaviours. The anthropologist observed that entrenched patriarchy, male dominance, transactional sex and inequality in sexual relations continue to place women at risk of unwanted pregnancies and infections. This observation was highlighted in an example he gave of a woman who when asked to explain why she had a child while HIV-positive shared the following, “I had no choice in the matter. It was either that I bear a son for my husband or he finds another woman to do it for him. I chose to bear the son because I could not afford to lose him. He supports me with the little money he gets from the small gardening jobs he does”. This quotation highlights another intrinsic dimension relevant to this discussion. This refers to the fact
that Xhosa culture places great importance on a woman bearing a son and not just a child. According to the traditional chief emphasis on bearing a son relates to the need to fulfil the male’s deeply rooted desire for an heir. He argued that the survival of the Xhosa nation depends on male children reaching adulthood, marrying and bearing children, particularly sons. This is because lineage depends upon their sons rather than their daughters. The sons carry the family name and remain the custodians of their culture. A Xhosa girl child may marry a Zulu man and then be expected to conform and perform the customs of the Zulus. Once a woman weds she becomes part of her husband’s family. She even loses the family name that she was born into and assumes a new family name, taken from her husband’s family. The nation would perish without the blessings of sons. Since men, therefore, are custodians to the culture (Smith, 2006: 47), it is their responsibility to ensure that they are survived by at least one male child. When the researcher probed as to what happens in situations where the couple only had girl children, the traditional chief explained that a man has two options. Firstly he can find a concubine to bear his son. Secondly he can choose to deviate from the norm and deal with the condemnation associated with cultural restrictions (Smith, 2006: 47).

(c) Perceptions of the HIV & AIDS pandemic on the Xhosa nation

The anthropologist viewed the impact of HIV & AIDS on the Xhosa nation as devastating. He stated that, “This disease has killed families, from parents to children. It is causing a lot of damage and will continue to do so until South Africans do something about it as a nation. The Xhosa society needs to revisit its norms and customs concerning sexual matters”. The specific areas that he felt needed to be readdressed were: the education of children about sex and love; changing sexual habits and attitudes; encouraging monogamy; urging people, particularly men to refrain from having multiple sexual partners. He noted, “During the time of our fore-fathers sex was practised only within marriage. It was taboo to engage in sexual relations out of wedlock. Sex was very private it was not displayed for youngsters to see. Men and women of that time respected themselves. The moral fibre was still very strong. Our culture does not hold strongly to
the Xhosa customs and rituals as it did in the past”. He went on to explain that the evident weakening of the Xhosa culture could be attributed to industrialization and apartheid. During the apartheid era young men were expected to seek jobs in the industrial cities and leave their wives behind. At that time Transkei, Bophuthatswana, Venda, and Ciskei (TBVC states) were reservoirs for cheap labour as the Government believed in the separate development of races.

In the City these young men would work for a year and return home in December for Christmas to be with their wives and would go back in the New Year. This pattern continued until retirement age. The anthropologist hypothesized that the young men who went to the cities seeking employment normally found female partners, who were probably working in the kitchens, and would have sexual relations with them and have children. Once in the cities the men mixed with other ethnic groups and were thus influenced by those cultures. Children at home would be left without father figures to socialize them into proper moral standards. The digital age has also influenced the Xhosa culture. Every child has access to television which promotes negative sexual behaviour. The kissing and undressing on the television promotes promiscuity and premature sexual behaviour. The anthropologist suggested that Xhosa culture be evaluated and reconstructed to have the moral standards necessary to build the Nation.

In keeping with this line of thought, the traditional chief observed that men are no longer as responsible as they were in the olden days. He explained, “In those days men were providers and protectors of their families but today a man is not ashamed to be provided for by a woman, while he sits down and does nothing. I think this goes back to the way most of our children are raised and are expected to be at home all times unless the child is at school or is sent by an adult. But most boys are not taught to do household chores because that will not be part of the role they will play later on as men. They are given freedom to wander the streets. They have nothing to do and are of course more prone to like street life rather than school. Most boys here in the village tend to drop out of school. In all fairness, both girls and boys should be socialized equally. Similar rules should be
imposed equally on both girls and boys so that they become independent, responsible, and productive citizens of tomorrow. Parents should provide boys and girls the same protection, guidance, and love they deserve as children”.

(d) The impact of HIV & AIDS on the Xhosa society, families and individuals

The anthropologist observed that people were dying in multitudes. He stated, “There are families which have been completely wiped out. Children suffer because they are left alone with no parents to nurture them. The extended families are overstretched by the number of orphans they have to care for. Grandmothers are left with the burden of caring for these children”. The traditional chief elaborated on the same topic stating: “Some of the children do not experience a day of peace free from pain from the day they are born until they die due to HIV-infection.” He described the impact as “very bad”. The traditional chief narrated a story of a baby girl born in 2006 by a mother who was HIV-positive. This was a teenage mother who, apparently, tested HIV-positive while pregnant. She never attended the antenatal clinic again and delivered her child at home. The mother died a year later leaving an HIV-positive sickly child. The baby is now two years old and has developed TB meningitis. The child at the time of the interview was classified as being in clinical stage four, according to the WHO – HIV – staging (2005). This is the stage that is regarded as the full blown AIDS stage. This is the final stage of HIV-infection and is characterized by a critically low level of the CD4 cell count of 200 and below. The low levels of the CD4 cell count manifest into a range of opportunistic infections such as the toxoplasmosis of the brain, candidiasis of the esophagus, trachea, bronchi or lungs, and kaposi sarcoma. A person who has full blown AIDS is described to be bedridden for more than fifty percent of the day for more than a month and experiences the HIV wasting syndrome, that is, weight loss of more than ten percent of body mass. In children this stage is characterized by recurrent severe bacterial infections such as bone or joint infection and meningitis.
(e) General Comments

The traditional chief ended the interview with the following closing remarks, “As a Xhosa nation we need to improve some customs in our culture that are not helping to build the nation. Particularly customs that favour men, such as, the acceptance of the infidelity of married men. We need to teach our boy children responsibility and love so that when they become men they can act just. We need to protect them as we protect our girl children and teach them to take care of their bodies as is done with girls. That is the only way we can win the fight against HIV & AIDS.” The traditional chief recommended that the Xhosa nation unite against AIDS and concentrate on developing unity. Such actions would drive out stigma and discrimination associated with HIV & AIDS.

In the following section of this chapter the research results that emerged from the interviews with the nurses and social worker are presented.

6.2.1.2. Interviews with the nurses and social worker

Two nurses and one social worker were interviewed. These were Xhosa women who lived and worked in the Mthatha region. The nurses were in the middle adulthood stage, the early and late forties, and the social worker was in her mid twenties, which is the early adulthood stage. The nurses had practiced as professional nurses for more than fifteen years and had worked in the field of HIV & AIDS for three years. The social worker had practiced as a professional social worker for five years in the hospice movement. The responses provided by these professional women in the semi-structured interviews have been combined in this next section due to the similarities of their opinions.
(a) Factors involved in planning a pregnancy

The first nurse informed the researcher that planning a healthy pregnancy involves three factors that need to be considered: physical fitness, and the social and economic environment of the couple. Physical fitness involves taking the age of the mother into consideration. Is the mother at the right reproductive age namely between twenty and forty years, or is she underage? The general health status of the couple also needs to be taken into consideration. The health practitioner considers any known ailments the couple suffer from, and the extent to which these could affect the unborn baby. Such consideration enables them to assist the couple to plan ways to protect the baby from harmful effects.

The social worker added that the social environment involves assessing the quality of the relationship between the couple. One hopes that the couple will consider whether their relationship is strong enough for them to be able to love and nurture the child until he or she reaches adulthood. They also have to weigh up the financial affordability of having children. One hopes that they will have enough money and resources to take care of all the needs of the child such as food, clothing, shelter, medication, schooling, and intellectual stimulation. Even though these are critical factors that the couple have to attend to before deciding to become parents, practitioners do not have a right to intervene or challenge couples to think of these issues as professional values dictate the clients have a right to self determination. Their rights are protected by the Constitution of the Republic of South Africa (No 108 of 1996), and by professional ethics.

(b) The impact and risks posed by pregnancy on HIV-positive mothers

Both professional nurses reported that pregnancy naturally lowers the immune system even when HIV & AIDS is not involved. Pregnancy in a HIV-positive woman can actually promote disease progression and necessitate the pregnant woman to commence ARV treatment earlier than if she was not pregnant. The adverse effects of ARVs are
often very unpleasant for pregnant women to endure and results in a higher incidence of non compliance in taking the ARVs which further compromises their health. The most serious risk needing consideration in this area is the greater likelihood of the mother-to-child-transmission of HIV & AIDS. This is constant with the literature review on the reproductive decision that documents three routes of vertical transmission. Mother-to-child infection can happen intrauterine (within the womb), intra partum (at birth), and postnatal (after birth). Termmerman (1993) estimates that thirty-five percent of HIV & AIDS transmission occurs intrauterine, and sixty-five percent of HIV-infection occurs at birth and postnatal.

(c) Available assistance to HIV-positive mothers

This group of key informants identified five main interventions available to HIV-positive pregnant women living in the Mthatha region. They were: access to ARVs; special antenatal monitoring; referral to prevention of mother-to-child-transmission support groups; postnatal monitoring of mother and baby; and psychosocial support (from some antenatal clinics). Each of these services is expounded upon below:

- **Access to ARVs**

The second professional nurse explained that in order to prevent the mother-to-child-transmission of HIV & AIDS, pregnant women are exposed to two sets of combination antiretroviral regimens. The first combination comprises Zidovudine (ZDV) and Nevirapine (NVP). HIV-positive pregnant women with a CD4 cell count above 200 are given ZDV at twenty-eight weeks of gestation, and during labour these women also receive a single dose of NVP. Their babies only receive a single dose of NVP at birth. These women are allowed to discontinue ZDV one week after delivery. The second combination comprises ZDV and Lamivudine (in short form it is 3TC). This therapy is given to HIV-positive women with a CD4 cell count that is below 200 at twenty-eight weeks of gestation. Their babies receive a single dose of NVP at birth. These women do not stop taking ARVs. They continue taking them for as long as they live. A week after
delivery their treatment is changed from ZDV + 3TC to d4T (Stavudine) + 3TC + Nevirapine (WHO, 2005).

- **Special monitoring at antenatal clinics**

The second professional nurse expounded on the process involved in routine clinic checks. Women are expected to visit the clinic once a month until the twenty-eighth week of their pregnancies. From their thirty-fourth to their thirty-sixth weeks of pregnancy they visit the clinic fortnightly. Thereafter, they are expected to visit weekly until delivery. These visits are essential for the monitoring of fetus growth. This monitoring involves routine screening tests for conditions that may affect the baby. Routine testing for high blood pressure and urine is done during each visit. High blood pressure and the presence of protein in urine pose danger to both the mother and baby. Screening tests undertaken include tests for Hepatitis B, HIV & AIDS, and anemia. For HIV-positive women additional routine assessment for opportunistic infections and STIs are also carried out for early identification and management of opportunistic illnesses. Women on Anti-Retroviral Therapy (ART) are monitored for side effects.

The first professional nurse described the rate of antenatal care attendance by community members of the KSD municipality, “twenty percent of HIV-positive women are estimated not to attend the antenatal clinics. Most of them are reported to stay at home while pregnant and only seek antenatal services during labour. Some give birth at home. Such women put their health, their babies, and family members who assist in the delivery of the baby at risk. More importantly these women put themselves and their babies at risk of developing conditions that may prove fatal if not attended to early. Such conditions as haemorrhages, hypertension, pregnancy related sepsis, organ dysfunction or failure, and pre-eclampsia. The attendance of the women who are registered at the antenatal clinic remain regular until their babies are born.”
• Prevention of mother-to-child-transmission support groups

The social worker explained the role played by the support groups that are specially designed to assist HIV-positive pregnant women to cope with their situation as follows, "HIV-positive pregnant women are referred to the PMTCT support groups by nurses or VCT counsellors. These support groups meet once a week. The aims and objectives of the support groups are to provide support to the members, opportunities to strengthen their coping mechanisms, increase their emotional support and offer specific guidance and information relevant to HIV-positive expectant mothers. The groups are facilitated by the clinic volunteers who are supervised by either professional social workers or nurses. Specific information on ART, especially prevention of mother-to-child-transmission of HIV, management of pregnancy and giving birth, and caring for the baby after birth are also provided".

These groups are purely support oriented as they are member centred. The members share their experiences, information with one another and offer one another advice. The leader, who is usually a volunteer PLWHIV, plays a facilitative role and promotes the development of helping relationships amongst the group members. Topics covered include: expressing feelings associated with being HIV-positive; sharing coping strategies, living life positively (embracing life); strengthening spirituality; the prevention of mother-to-child transmission of HIV. The groups are co-ordinated by the clinics in partnership with community Non-Profit Organizations, and are funded by the Departments of Health and Social Development. The funding usually provides for basic catering to the amount of one thousand rand a month for each support group. This amount supplies tea, coffee, juice and sandwiches. Attendance of these groups by members tends to be good. The professional nurses raised concern about their inability to attract more women to join these groups.
• Post natal care to mother and baby

The nurses informed the researcher that HIV-positive women receive group counseling within the PMTCT support groups on infant feeding options to enable them to make informed choices on the infant feeding option that is most suited for their circumstances. The two nurses recommended two infant feeding options, exclusive breastfeeding or exclusive formula feeding for the first six months of life, and there after the introduction of the baby to semi-solid foods through spoon feeding. The WHO (2001) recommends exclusive breastfeeding to mothers who perceive cultural, social, or financial barriers to choosing and executing exclusive formula feeding. These barriers involve firstly, the fear of stigma and discrimination; secondly, inadequate knowledge, skills and thirdly other resources to prepare formula milk. Families should have adequate finances to purchase, prepare and use formula feeding, and access to things such as fuel, clean water and equipment. There should be a continuous sustainable uninterrupted supply of all ingredients and commodities needed to safely implement the feeding option, for as long as the infant needs it. Finally adequate hygiene is necessary to prepare formula milk, such as feeding infant with clean hands using clean utensils, preferably use of feeding cups.

• Psychosocial support services at antenatal clinics

Where antenatal clinics provide social work services, women who have problems adjusting to their medical condition receive counselling. Those women who do not have a source of income and do not have adequate food are given food parcels from funds provided by the Social Relief of Distress Programme. Women who do not have identity documents are also assisted to apply for necessary documents in preparation for their applications for birth certificates after the birth of their babies. Women whose CD4 counts are below 200 are assisted to apply for financial support in the form of the State Disability Grant. Two clinics from the four that formed part of the field site for the study offered these services. These were the IDC and Ngangelizwe clinic. Each of these clinics
had one social worker. The services offered were not considered by this professional group to be adequate. They complained that there were insufficient food parcels for the number of patients requiring food relief. Their biggest criticism was that antenatal services focussed on mothers and not fathers. Their frustrations can be understood when considering Friedman et al’s (2006) opinion that it is fathers who have the decision making power invested in them when it comes to matters related to procreation and basic health seeking behaviour. The key informants acknowledged that the few services offered to patients were meaningful and made some difference in their lives. The social worker emphasized, “We are not saying nothing is being done. All we are saying is it is not enough. A lot more still needs to be done. We need to get men to be actively involved in the campaigns to fight HIV & AIDS. We need them to share pregnancy with their partners so as to strengthen their bond. We want both parents to be exposed to the information shared in the support groups”.

(d) The impact of HIV & AIDS on families, especially children

The social worker stated that HIV& AIDS affects the couple, children, and extended family. The couple’s sex life becomes affected because they are forced to use protection (condoms) to prevent re-infection. There is resistance from men to using condoms. They believe in “flesh on flesh” for it to be a real fulfilling sexual encounter. The couple also faces the challenge of disclosure to their children and extended family. Now and again there are health issues that need to be attended to such as recurrent fevers, sore throats, pneumonia, TB, unexplained loss of energy etc. The family may need, after sometime, to seek external assistance caring for the ailing family member. In situations where there is no extended family, children become the primary carers of a dying parent. They may have the responsibility of burying a parent or both parents, and may be left alone with no one to look after them once the parent passes on. “We usually have cases of single parents who do not have any extended family to support them, who when they become ill, depend on their children to care for them”. The social worker explained and provided
an example of the patient who was in the PLWHIV support group who had two children. "The first born was an eleven year old boy and the last born was a nine year old girl. These children assumed a great deal of responsibility for caring for her as her health deteriorated. Hospice, in partnership with the clinic, offered some assistance. The volunteers from Hospice and the clinic took turns to nurse the lady when she became bedridden. There was no food for the children and so the clinic and Hospice had to help the children with food parcels. When the mother died the poor children had no one to care for them. No one in the community wanted to volunteer to foster the children because of the disease their mother had died of. The children were placed in SOS children’s home, where they received bereavement counselling and were assigned to a house mother. Those children are doing quite well. They are thirteen and fifteen years old now and are still attending school”.

An observation made by the second professional nurse with regards to the impact of HIV & AIDS on families was that it brings so much sorrow to our society. There are some families where these professional nurses virtually cared for all the members, from the parents to the children. People in such families die one by one. A case example is a family where the parents were HIV-positive and their two teenage children were also HIV-positive. Only one ten year old child was HIV- negative. The father died in 2003, and the family had to deal with the loss of their father as well as loss of income. The mother was not working at the time. She sought employment and found a position as a domestic worker. Shortly after getting the job she fell terribly sick and died from TB meningitis. She died in June 2004. The children were left alone and became one of the child headed families in the neighbourhood. Two years passed and the second born fell sick and died from kaposi sarcoma. The first born who was also HIV-positive could not take the trauma and a month after the funeral of her younger sister overdosed on her ARVs and died. The last born, who at the time of the study was thirteen years, was left alone with no relative willing to take her in. She was placed in SOS children’s village. The professional nurse concluded, “HIV & AIDS has brought nothing but sorrow!”.
The first professional nurse remarked, “We pray to God for a break through in finding a vaccine and a cure. The one’s who procreate while HIV-positive do not know the amount of sorrow they will bring one day. It breaks my heart as a Christian to see so much pain and suffering!”

(e) **Projection of the future of children born to HIV-positive women in light of the risks involved**

The picture the key informants painted of the children born to HIV-positive women was bleak. They listed several unpleasant consequences that affect their lives. Firstly, they believed that these children were at greater risk of contracting HIV. Those who contract HIV do not thrive as well as HIV-negative children do. Some do not thrive at all and die before they reach two years of age. Others tend to have a slow growth rate although they may live up to twelve years of age. Children in these families who are fortunate to escape HIV-infection still suffer as they have to face the death of their parents when they are still young. They have the awful experience of being orphaned. Most are taken in by extended family members as foster children. Here they are often moved around to different family members who struggle with the financial burden of caring for them. In some cases family members agree to have these children live with them not because of their interest in their well being but only to gain access to the Foster Care allowance awarded by the Government. Some live on their own without any adult guardian, and others are institutionalized. Most orphaned children drop out of school because of their compromised living conditions. Some are even driven to become street children, prostitutes, juvenile delinquents, etc.

(f) **Possible motivating factors for HIV-positive women to plan pregnancies despite their status.**

This group of professional women identified three reasons why HIV-positive women plan pregnancies despite the risks to themselves, their unborn babies and their families.
These included: the need to satisfy the natural desire to be a mother; using pregnancy as a tool to strengthen a marriage or relationship; sheer lack of knowledge and or disregard of the risks. The second professional nurse shared her own life experience, “As a woman naturally one desires to at a particular stage in life have her own baby. You see I am forty-seven years old and I do not have children not because I don’t want to but because I have only one not so effective fallopian tube. The other one that was effective was removed when I had an ectopic pregnancy. I yearn to have a baby of my own. I want to carry my baby in my womb, deliver, and hold her. There is a child I foster but it’s not the same as having my own child. I am yearning inside. I imagine how it must feel for HIV-positive women who can bear children but do not because of HIV. I don’t condemn the HIV-positive women who bear children because I know how it feels not to have a child of your own”. The social worker added, “I have counselled many women who had told me that they fell pregnant in order to strengthen their marriages or relationships. Most these women usually came back to tell me that their partners were still with them and their relationships were stronger as a result. Others however were not so fortunate because their relationships did not improve. Some women fell pregnant not knowing that HIV could be transmitted to the baby. They only learned about it when they came to the antenatal clinic already pregnant. Women who fell in this category were those that did not attend support groups when referred by the VCT counsellors. The last group of women knew that HIV & AIDS could be transmitted to the baby but chose to disregard all the risks for reasons known to them”.

(g) The availability of counselling services to families affected and infected by HIV & AIDS

The primary type of counselling available to HIV-positive pregnant women in Mthatha was VCT offered to everyone who desired to know their HIV-status. Counselling services are offered by a network of NPO’s within the community, such as Hope World Wide, Siyanqoba, and Themba. All clinics in the region of the Department of Health offered VCT services. One major problem was the scarcity of professionally trained
personnel on HIV & AIDS to assist women with the reproductive decision and offer abortion counselling. The scarcity is attributed to the stigma attached to HIV & AIDS which results in very few professionals seeking training in the field. Abortion on the other hand is taboo to both Xhosa culture and Christianity (which is the predominant religion in the region). Local professionals are sceptical about involving themselves with such cases and this has resulted in a gross shortage of abortion counselling services in this region.

(h) General Comments

The social worker made these recommendations, “As professionals we can not make decisions for our patients. The best we can do is to help them make informed decisions. The decision to procreate is not done by women alone. Their partners influence this decision. If we only inform women, can we say as practitioners that we have helped our patients to make informed decisions? I don’t think so. I believe that decisions that are taken by two people require both parties to be informed. I think it is high time we involve men in our services, so that we can say the decision taken to procreate is an informed decision.” The first professional nurse highlighted that, “There is a need for a vigorous fight against the stigma and discrimination toward HIV & AIDS. We refer so many patients diagnosed with HIV & AIDS to support groups but, to my estimation, only half of those patients go to them. I once asked a patient for the reason she never attended to my referral and she said, and her exact words were, ‘It is enough for me to know that I have this disease, but I do not want the whole world to know. Everybody in Ngangelizwe knows that people who go into that hall have AIDS’. Some people do not seek help early because they do not want to associate themselves nor be associated with HIV & AIDS. This community still needs a lot of HIV & AIDS education. I therefore would love to see more people enrol in this programme, because it does not only focus on health issues but social ones as well.”
From this overt participant observation exercise the researcher was able to identify several criteria HIV-positive women used to influence their decision to procreate. As indicated in chapter five the criteria included: Xhosa culture and Christianity, which can be further subdivided into sub-themes, importance of child-bearing, family values and belief system, individual values and belief system, couple value and belief systems; ARVs; VCT; denial, stigma and discrimination; current status of health; ignorance and lack of knowledge. These criteria would later be used as themes for the purpose of developing questions for focus group discussions and the analysis of findings in the research process.

6.2.2 The Pilot Project

As explained during the chapter on methodology, eight focus groups of six members in each were formed from the sample population. Two of the eight groups were used for the pilot project. The experience of running the pilot focus groups together with the pilot semi-structured interviews, as well as the findings from informal discussions and key informant interviews refined the research process for the formal part of the study. The information gained from these two groups has been separated from the formal research data because the pilot study was used to test the interview guide and the process planned for the focus group discussions. During the pilot focus group discussions, the group members were given an opportunity to explore their reasons for choosing to have babies despite their HIV-positive status. Their discussions enabled the research team to discover additional themes to augment the code list identified by the key informants.

The semi-structured interviews gave the participants an opportunity to deal with unfinished business that arose from the focus group discussions, provided them with an opportunity to share things that they might not have felt comfortable sharing in a group context, and ensured that the participants could access reliable support after termination. These issues will be expanded upon later in this section.
This section of the discussion focuses on tabulating the pilot sample profile for the study. As mentioned in the research methodology chapter, a sample of twelve HIV-positive women was selected from a sample frame of forty-eight. The demographic details captured included: age; economic status for each participant according to the total monthly income generated per house-hold; highest standard of education; marital status; the number of pregnancies after the HIV & AIDS diagnosis. The sample profiles for the two focus pilot groups (seven and eight) are tabled below.

Table 6.1: Demographic information of pilot groups.

<table>
<thead>
<tr>
<th>AGE CATEGORY</th>
<th>GROUP 7</th>
<th>GROUP 8</th>
<th>TOTAL</th>
<th>HIGHEST LEVEL OF EDUCATION</th>
<th>GROUP 7</th>
<th>GROUP 8</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 – 25</td>
<td>6</td>
<td>0</td>
<td>6</td>
<td>GRADE 8</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>26 – 30</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>GRADE 10</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>31 – 35</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>GRADE 12</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>6</td>
<td>6</td>
<td>12</td>
<td>TOTAL</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>ECONOMIC STATUS</td>
<td>MARITAL STATUS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>----------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CATEGORY</td>
<td>GROUP 7</td>
<td>GROUP 8</td>
<td>TOTAL</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R50 – R200</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R201 – R500</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R501 – R1000</td>
<td>2</td>
<td>5</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R1001 – R2000</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R2001 – R2500</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>6</td>
<td>6</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>GROUP 7</th>
<th>GROUP 8</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>SINGLE</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>MARRIED</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>COHABITATING</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>DIVORCED</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>WIDOWED</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

**NUMBER OF PREGNANCIES AFTER HIV-POSITIVE DIAGNOSIS**

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>GROUP 7</th>
<th>GROUP 8</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>ONE</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>TWO</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>THREE</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

Based on the information in the table above, pilot focus group seven consisted of six Xhosa HIV-positive women who were between the ages of twenty to twenty-five years. This is considered as the “reproductive age”, according to Trommsdorff (2002). One of the women had a total monthly income of R50 – R200, three of the women had a monthly income of R201 – R500, and two had a monthly income of R501 – R1000. Four of the women stated their highest educational qualification as grade eight, whilst one had a grade ten. The last one in this group had grade twelve. Three of the women were married, two were living with their partners, and one was single. When it came to planning further
pregnancies after learning of their HIV-positive status, four women in the group went on to have another two pregnancies and the remaining two women had one pregnancy after learning of their HIV-status. According to the information provided in the table above, pilot focus group eight consisted of six Xhosa HIV-positive women. Their ages were between thirty-one and thirty-five years. All the women in this group had a total monthly income of R2001 – R500. Five of the women had grade ten, and one had grade twelve as the highest level of education obtained. Three women in the group were cohabiting with their partners, two were widows, and one was married. Lastly, two women had one pregnancy after learning of the positive HIV & AIDS diagnosis, three had two pregnancies, and one woman had three pregnancies.

In summary the women who participated in the pilot study were mostly women in committed relationships, who were mostly unemployed, and between the ages of twenty and thirty-five years old. It was evident that most of them had had two or three additional pregnancies after discovering their positive HIV-status. The themes that emerged during the pilot study are discussed together with the themes that emerged during the focus group discussion in the next section.

6.2.2.1 Findings taken from pilot study

The information gathered during the pilot study is presented as preliminary answers to the research questions.

(a) Reasons why HIV-positive women procreate despite the risk of vertical transmission, disease progression, and infection or re-infection of a partner.

The pilot study yielded two distinct groups of HIV-positive women. It is important to acknowledge the differences of these groups to better understand the topic. The first group (group A) comprised those women who discovered their HIV-positive status while pregnant and the second group (group B) comprised women with known HIV-positive status but decided to procreate. A clear description of these groups is tabled below:
Table 6.2: Group A & B of the Pilot Focus Group Findings

### Group A and B of the Pilot Focus Group Findings

<table>
<thead>
<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 - 25</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>26 - 30</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>31 - 35</td>
<td>0</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2</strong></td>
<td><strong>10</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 8</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Grade 10</td>
<td>2</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Grade 12</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2</strong></td>
<td><strong>10</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

### Economic Status

<table>
<thead>
<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>R50 - R200</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>R201 - R500</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>R501 - R1000</td>
<td>0</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>R1001 - R2000</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>R2001 - R2500</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2</strong></td>
<td><strong>10</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

### Marital Status

<table>
<thead>
<tr>
<th>Category</th>
<th>Group A</th>
<th>Group B</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Married</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Divorced</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2</strong></td>
<td><strong>10</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>
From the table above group A consisted of two women out of the twelve who formed the focus group pilot sample. This group accounted for seventeen percent of the pilot sample. Both women were in the age group twenty to twenty-five years which Trommsdorff (2002) categorises as the reproductive age. The total monthly income of each of these women fell within the categories of R50 – R200 and R201 – R500 respectively. Both women attained grade ten as their highest standard of education. They were both cohabiting and had one pregnancy after the diagnosis of HIV & AIDS. These women procreated because they discovered their HIV-positive status while pregnant and according to them, did not see themselves as having another alternative because abortion was taboo to them in terms of their Xhosa culture and Christian religion. According to Naidoo & Sehoto (2002) abortion is not favoured by the Xhosa culture because the death of a foetus is regarded as a serious obstacle to the soul’s aspirations. Their decision was strengthened by the availability of ARV treatment to prevent vertical transmission.

Group B consisted of ten women out of the twelve that formed the focus group pilot sample. Four of these women belonged to the age group twenty to twenty-five years; and six of these women belonged to the age group thirty-one to thirty-five years. Two women had a total monthly income between R201 – R500; seven women had a monthly income between R501 – R1000; and one woman had a monthly income of R2001 – R2500. One woman attained grade eight; seven women attained grade ten; and two women attained grade twelve as their highest standard of education. Four of the women were married;
three women were cohabiting; two women were widowed; and one woman was single. Two women had one pregnancy; seven women had two pregnancies; and one woman had three pregnancies after the diagnosis of HIV & AIDS. These women planned pregnancies knowing their HIV-status and the associated risks because they wanted to: strengthen the bond with their partners, fulfil their wifely duties, and fulfil the deep desire to be a mother.

(b) The extent to which HIV-positive women are informed about such risks

A lot of relevant information was shared with participants when they went for post-test counselling. This information covered the following topics: promoting responsible sexual and preventive behaviours, encouraging disclosure and seeking support from others; encouraging early management of opportunistic infections; facilitating access to mother-to-child intervention; referral to support groups; and contraceptive advice. Although this information shared during the post-test counselling session was important, timing was reported to be the problem. The participants felt that they were bombarded with a lot of information at the time of receiving bad news. There was no follow-up after that session. Most of them reported not remembering half of what was said during the session. The knowledge they had about the post-test counselling was imparted to them by an NGO that offered the support group members training. The NGO was called Hope World Wide.

(c) Whether family planning antenatal clinics should offer specific counselling to HIV-positive pregnant women and their families

The participants noticed a gap in the services offered at the clinics, particularly in relation to post-test counselling. They were of the opinion that counselling and preventive programmes to HIV-positive pregnant women and their families would bridge that gap. The research questions to the study proved to be relevant to the study, which was to explore the reasons why HIV-positive women plan pregnancies despite the risks of vertical transmission, disease progression, and infection or re-infection of the partner.
The pilot study tested, revised, and confirmed the process for data collection. It was decided that the process used in pilot focus group eight would be carried through all focus group discussions.

The next stage presents the analysis of the findings of the six focus group discussions that formed the formal part of this research process.

6.2.3 The Data Collected from the Focus Groups

This section presents a sample of thirty-six focus group members according to their age, economic status, the highest level of education attained, marital status, and number of pregnancies they had after receiving their HIV-positive diagnosis. A table displaying a combined sample profile for the six focus groups is presented and then discussed.

Table 6.3: Pertinent Demographics of the Sample Profile for the Six Focus Groups

<table>
<thead>
<tr>
<th>AGE</th>
<th>ECONOMIC STATUS</th>
<th>HIGHEST LEVEL OF EDUCATION OBTAINED</th>
<th>MARITAL STATUS</th>
<th>NUMBER OF PREGNANCIES AFTER HIV POSITIVE DIAGNOSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Stats of Sample</td>
<td>Category</td>
<td>Stats of Sample</td>
<td>Category</td>
</tr>
<tr>
<td>20-25</td>
<td>12</td>
<td>R50 – R200</td>
<td>4</td>
<td>Grade Eight</td>
</tr>
<tr>
<td>26-30</td>
<td>18</td>
<td>R201 – R500</td>
<td>7</td>
<td>Grade Ten</td>
</tr>
<tr>
<td>31-35</td>
<td>R501 – R1000</td>
<td>17</td>
<td>Grade Twelve</td>
<td>13</td>
</tr>
<tr>
<td>36-40</td>
<td>6</td>
<td>R1001 – R2000</td>
<td>7</td>
<td>Divorce</td>
</tr>
</tbody>
</table>
6.2.3.1 The profile of the sample according to age

Thirty of the thirty-six participants in the study were under the age of thirty. According to the family lifecycle model of Trommsdorff (2002) the ages twenty to thirty years are the most reproductive. There were twelve participants in the twenty to twenty-five year old category and eighteen in the twenty-six to thirty year old category, respectively. There were no participants in the thirty-one to thirty-five age groups and six in the thirty-six to forty years age group, which is to be expected because we assume that the fertility declines as women progress towards middle adulthood. A noticeable outcome was that there were no women in the sample who were younger than twenty years in this study. Panday & Makiwane (2008) point out that most pregnancies within this age group of twenty years and under are unplanned and unwanted. In the light of this these young women try to conceal their pregnancies, try to deny them altogether and do not engage easily in antenatal services. The main reasons for the non-involvement of younger women in the study according to the researcher’s perspective are related both to developmental and social issues. Developmentally one expects teenage mothers to want immediate gratification rather than engaging in preparation for their futures. According to Bizaare (2007) factors that inhibit their engagement in antenatal services include denial of the reality of what is happening, mistrust in service providers, poor concrete thinking skills (in other words an inability to focus on the future consequences), fear of the consequences of disclosure, poor understanding of the multiplicity of their situation, substance abuse, chaotic life-styles, and lack of family support.

6.2.3.2 The profile of the sample according to socio-economic status

The sample profile confirms that the majority of people who used the government antenatal clinics (the general public sector) in this region were struggling financially as eighty-one percent of the sample had a monthly income of less than R1000. According to
South Africa.info (2008) the minimum desirable level of income (poverty line) in South Africa using the absolute approach is R322 per person per month. The absolute approach to poverty measures the goods and services required to meet a set of absolute minimum living standards in monetary terms, unvarying over time and across the various basic needs (Oosthuizen, 2008). The participants who fell below a monthly income of R1000 and less had a minimum of five family members and a maximum of twelve family members living in their households, as most of them lived as extended families. This translates into R322 multiplied by five to twelve people. One would therefore expect them to have at least R1610 for families of five members and R3867 for families of twelve. This suggests that seventy-eight percent of the sample did not have the minimum desirable level of income and therefore could not meet the absolute minimum living standards. The remaining twenty-two percent of the sample with an income between R1001 – R2500 had participants that were below the absolute poverty line and participants that were above. Those that fell below the absolute poverty line (nineteen percent) had large households of seven to nine members and an income below R2000. Such house-holds required a minimum of R2254 and a maximum of R2898 absolute minimum living standards. Three percent of the sample was above the absolute minimum living standard but fell below the relative minimum living standard. Relative minimum living standards take into account a given society’s characteristics and attempts to identify those individuals whose standards of living are unacceptably low relative to the rest of society (South Africa.info, 2008). For example, a person earning R2500 cannot afford to get a loan to purchase decent housing, or buy a car, or get medical insurance. This sample profile therefore tells us that most of these women might not have access to medical coverage, which means that they had to rely on the services offered by local health centres.
6.2.3.3 The profile of the sample according to highest level of education attained

The sample profile depicts that the most frequent category within this study was grade ten as sixteen participants of the group fell within this category. Thirteen participants attained grade twelve. Seven participants stated that grade eight was the highest level of education that they had achieved. Clearly, even the grade twelve education did not appear to offer this group many career opportunities as the only work that they reported as securing with this educational achievement was sales, and even then only nine of the group of fifteen had been successful in finding employment.

6.2.3.4 The profile of the sample according to marital status

The majority of the sample, that is twenty participants, were in serious and committed relationships. This conclusion was reached because fifteen were married and five were cohabiting with their partners. Thirteen had lost their partners either through death (nine participants) or divorce (four participants). Three of the participants described their status as single. The number of widowed women in this study was significantly high (nine participants) and this may be relevant when one considers that this study focussed on HIV & AIDS issues. These widows disclosed that their spouses died due to AIDS. Mangcitshana in focus group six when explaining her reason for testing for HIV stated, “I tested because my husband fell extremely sick, he was vomiting and had diarrhoea that could not be treated. The doctors advised him to test for HIV which he did, and the results were unfortunately positive. He did not live long. He passed away a week after the test, leaving me three months pregnant. I knew that I was HIV-positive even before testing. When I took the test it was only to confirm my fears.” What is relevant is that thirteen women did not have a partner to fall back on when having to make the decision to reproduce.
6.2.3.5 The profile of the sample according to the number of pregnancies/children after the diagnosis of HIV-positive status

Sixteen women had one child and eleven participants had two children. A quarter of the group went on to have three children after discovering their HIV-positive status. Clearly, the HIV-status did not deter twenty participants from continuing to procreate. This information should be considered against the backdrop of information provided by the professional nurse and social worker who clearly stated that even though some women were informed about the risks involved in reproducing for themselves and their offspring they still chose pregnancy and ignored the professional warnings issued.

In summary then, the sample profile portrayed that, the women who faced the dilemma of whether to procreate or not were mostly between twenty and thirty years, the key reproductive age. The demographics presented suggest that this group failed to consider their health status as a potential risk for the unborn offspring. Whilst the majority were in committed relationships (fifty-six percent), a high number was not in any relationship because of death, divorce or being unmarried and single. More than a third of the women (thirty-six percent) who participated in the study had been in a committed relationship with the biological father of their babies but had lost the partner as a result of divorce or death. As pointed out, the majority were still involved with the biological partner. This may suggest that their partners may have had some involvement and influence over their decisions to procreate.

The high rate of low income earners among the sample (eighty-one percent) suggested that the Xhosa women who consciously decided to proceed with their pregnancies or who had fallen pregnant despite knowing their status had not taken the affordability of having a child into consideration. This conforms with the evidence provided by the anthropologist and traditional chief who stressed that Xhosa people place tremendous emphasis on the significance of child bearing in their culture.
Most of the women had been exposed to the South Africa’s basic school leaving levels of education, grade ten and twelve. This makes one question whether these women gave any careful and conscious consideration to the reproductive decision. One assumes that people with those levels of education ought to be equipped with basic literacy and reasoning skills to allow themselves to stay abreast of the basic developments in the HIV & AIDS field. For several years HIV & AIDS education has been mainstreamed in South African schools. Only nineteen percent of this group had not completed a recognised school leaving qualification. It became evident that the HIV-positive women in this study had more than one child after the diagnosis of HIV & AIDS. In some instances members continued to have up to three children whilst HIV-positive. This makes one question whether Xhosa culture exerts such strong pressure on women to procreate that they are willing to sacrifice not only their own health but that of their offspring too. This challenges us to seriously contemplate the importance that child bearing plays within this community.

The following sub-section presents the sample profile for each focus group laying out a basis for the discussion of the findings from the questions asked through the focus group interview guide.

6.2.4 Presentation of the sample for each focus group

6.2.4.1 Focus group one

Focus group one was composed of six Xhosa HIV-positive women who were between the ages of twenty to twenty-five years. The economic status of the women included two women with a total monthly income of between R201 and R500; and four women with a monthly income between R501 to R1000. Three women stated grade ten as their highest standard of education, while two had grade twelve, and one had grade eight. Two women were married, another two were living together with their partners, and one was single.
Only one woman in the group was divorced. Three women had only one pregnancy after the diagnosis of HIV & AIDS, and the remaining three women had two pregnancies. Half of the group discovered their status while pregnant, and therefore opted to carry their babies to term due to their Christian belief that abortion was murder. Two of these women were married and at the time of discovering their statuses were “omakoti” (newly wed). These women still enjoyed the support of their husbands. One group member who was single had no support from her partner but relied heavily on her family. The remaining half of the group continued to have babies in spite of their HIV-positive status, each having two children already. Two of these women were cohabiting and therefore attributed their reason for procreating to strengthening the bond with their partners. This cohabiting group of women also enjoyed the support from their partners. The one woman who was divorced chose to have her children despite of her HIV-positive status. She explained that she wanted to avoid being victimised by her husband as a result of not bearing children. She had failed to disclose her HIV-positive status to her husband after testing and he found out about it later and blamed her for bringing the disease into the family. The three women who had more than one pregnancy while HIV-positive reported that their state of health was affected by the pregnancies. They emphasised that a healthy lifestyle was advocated for HIV-positive people but that this was harder to execute than it seemed. An HIV-positive person, more specifically pregnant person needs adequate resources to achieve this, which they did not believe they had.

6.2.4.2 Focus group two

This focus group consisted of six Xhosa HIV-positive women whose ages fell between the twenty-six and thirty year range. Their economic status included three women with the total monthly income between R50 and R200; one woman with a total monthly income between R201 and R500; and two women with a total monthly income between R501 and R1000. The highest level of education that was attained by three of the women was grade twelve. Two women had attained grade ten, and one woman attained grade eight. According to the marital status category four women were married, one was living
with her partner, and another one was divorced. Three of the women had one child, two had two children, and one woman had three children after being diagnosed with HIV & AIDS.

What was evident in this group was the fact that four women out of the six discovered their HIV-positive status when pregnant and three continued to procreate despite this. One of the group members even went on to have two more children. This woman reported that the pregnancies did not have a negative effect on her health because her CD4 count always recovered after child birth. She ascribed this to her managing to lead a healthy life-style that was characterised by practicing safe sex using condoms when not trying to fall pregnant, eating a balanced diet, and living a joyful life. She was fortunate to have a supportive partner whom she described as her “pillar of strength and the source of her joy”. The story narrated by the divorced woman, revealed that she married knowing that she was HIV-positive. She never disclosed her status to her husband at all. During the marriage she bore him two children, whilst still withholding her status from him. The husband discovered the truth when she fell terribly sick and had to seek Hospice for assistance as a patient. The husband was devastated and could not deal with the betrayal. He filed for a divorce. This woman now is on ARVs and doing relatively well.

6.2.4.3 Focus group three

This focus group consisted of Xhosa HIV-positive women who were between the ages of thirty-six and forty years. Their economic status included two women with a total monthly income between R201 and R500 and four women with a total monthly income between R501 and R1000. Three women attained grade twelve, two women grade ten, and one woman grade eight. In terms of their marital status, four women were married, one woman was living with her partner, and another was divorced. After being diagnosed with HIV & AIDS four participants procreated one child, one participant had two children, and one other participant procreated three children.
Four of the women discovered their HIV-positive statuses as “omakoti” (newly weds). They went to test for the HI-Virus because their husbands fell very sick shortly after they married. On testing for HIV & AIDS they learned that they too were positive. These women chose to procreate in spite of their HIV-positive status because they wanted to avoid being singled out as different. The four women had only one pregnancy while HIV-positive but stated that they still intended to have one or two additional children. The divorced woman had three pregnancies, and the cohabiting woman had two pregnancies. These two women had children in spite of their HIV-positive status because they wanted to fulfil their inner desire to have their own biological children. These women stated that they started procreating at the age of thirty –three, frustrated by not having had children by that age. They felt that their biological clock was ticking and they did not want to miss out on motherhood.

6.2.4.4 Focus group four

Focus group four consisted of six Xhosa HIV-positive women who were between the ages of twenty-six to thirty years. The economic status of the women included one woman with an income of between R50 and R200; two women with a monthly income of between R201 and R500; and three women with a monthly income of between R1001 and R2000. Four of the women had achieved grade ten, and two noted grade twelve as their highest level of education. Two women were widowed, another two were single, and one was living with her partner, and the last member was divorced. Three women had two children, two had three children, and one woman had one child after learning of their HIV-status.

The one woman who was married discovered her HIV-positive status while pregnant. There was nothing different to this woman’s situation from her fellow participants. Like the other women, she resigned herself to her status. Two single women shared that they had three children after the diagnosis of their HIV-positive status. They shared that they had fallen pregnant because of their ‘inability’ to negotiate condom use with their
partners. One would think that it would be easier for single women to negotiate condom use than women in committed relationships. This clearly shows women’s compromised position in sexual matters, as they were not empowered to protect themselves from HIV & AIDS transmission. As Flaskerud & Nyamathi (2000) state the position of women in patriarchal societies, such as South Africa is seriously disadvantageous when it comes to condom use. Cultural, religious, and sexual factors were reported to prohibit condom use.

Not a single woman ever mentioned female condoms. According to these women HIV & AIDS prevention is the responsibility of men. The remaining three women procreated in spite of their HIV-positive status out of a sense of obligation to perform their wifely duties.

6.2.4.5 Focus group five

This group consisted of six Xhosa HIV-positive women who were between the ages of twenty to twenty-five years. Their economic status may be described as follows: three women had a monthly income of between R501 and R1000; two between R1001 and R2000; one between R2001 and R2500. The distribution of the levels of education attained was as follows: two had completed grade twelve, two grade ten, and two grade eight. In terms of their marital status two women were married, one was living with her partner, and three women were widowed. Three of the women had three children, two had one child, and one had two children after learning of their positive HIV-status.

Two of the six women were married and discovered their HIV-positive status while pregnant. One of the women who was cohabiting had two pregnancies after the diagnosis of HIV-infection. The remaining three women (who were widowed) had three pregnancies after the diagnosis of HIV-infection. What is exceptional about this group is that all the members were below twenty-five years of age. Sixty-six percent of this group were widowed having three children. This seems to be a very young age to have to shoulder the responsibility of raising children alone. The members emphasised how they
had to grapple with the impact of the HI-Virus. They felt overwhelmed by having to manage so many issues at such an early age.

6.2.4.6 Focus group six

Focus group six consisted of six Xhosa HIV-positive women who were between the ages of twenty-six to thirty years. In terms of monthly income four had an income between R5001 and R1000, and two between R1001 and R2000. Two of the women had attained grade eight, three grade ten, and one grade twelve. Two of the women were married, and four women were widowed. Of the six women, three had one child, one had two children, and two had three children after learning of their positive HIV-status. What was significant about the group of widows was their shared sense of rejection by their families. They reported their struggle prior to joining the support groups. They shared that their health was not good enough for them to seek employment. Before becoming members of the support group they could only turn to their neighbours for support. Even neighbours became tired of assisting them because their needs were so great: assistance with food, nursing when sick, and taking care of their children. The support group had been of great emotional and practical support. They no longer went to bed without food as a result of the food parcels they received. They had friends who understood their condition and were constantly available.

Based on the results presented it seems that couples in the Mthatha region do not test for HIV & AIDS before getting married. Twenty-five percent of married women discovered their HIV-positive status during their pregnancy; and seventeen percent were “omakoti” who learned of their fate shortly after marriage. It was apparent that a group of people had entered into marriage knowing their HIV-positive status without informing their partners. The main reason given for withholding this information was their fear of having to deal with rejection, stigma and discrimination. The marriages that started with secrets did not last. The results of this study suggest that the Xhosa culture emphasises the need
to have children, not just one child. As we have seen twenty (fifty-six percent) women out of the total sample had more than one child after being diagnosed with HIV & AIDS.

The discussion of the findings pertaining to the questions asked in the focus groups and individual interviews will follow in the next section.

6.2.5 Data capturing and editing

This section presents the final list of themes used when analysing data. The list is condensed into a table that displays an explanation of the meanings of each theme, how these themes relate to the study and finally quotations taken from the focus group discussions to offer illustrations of the meanings participants associated with the themes listed.
<table>
<thead>
<tr>
<th>Theme that Emerged from the Pilot Focus Groups</th>
<th>Application to the Study</th>
<th>Excerpts from Pilot Focus Group Discussions Confirming the Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Antiretrovirals:</strong> Nevirapine, AZT, &amp; Efavirenz</td>
<td>Protect the baby from vertical transmission of HIV by the mother.</td>
<td>“What gives comfort to the decision to procreate is the availability of antiretroviral therapy which offers protection to the baby,” clarified Mandlovu.</td>
</tr>
<tr>
<td><strong>2. Post Test Counselling</strong>&lt;br&gt;Counselling offered after HIV &amp; AIDS test.</td>
<td>Provide information to people who have tested positive to HIV, so that they know its implications and how to manage HIV-infection and prolong life.</td>
<td>The respondents unanimously informed the researcher about their post test counselling experience, and Madlamini specifically reported, “when I was counselled when I tested HIV-positive, the counsellor helped me explore how I was feeling; she encouraged me to carry on with life by assuring me that most HIV-positive people survived for longer than ten years; she gave me advice on how to slow the virus’ activity in the body, that was by practicing safe sex, avoiding stress, attending to ailments early, not procreating, and eating a balanced diet. The main purpose of post-test counselling I was told was to soften the shock.”</td>
</tr>
<tr>
<td><strong>3. Xhosa Culture</strong>&lt;br&gt;The ideals, values, norms, and</td>
<td>The developmental tasks of</td>
<td>Bhele, who stated the reason for procreation to be performing a wifely duty</td>
</tr>
</tbody>
</table>
assumptions about life for Xhosa people which guide specific behaviours.

| 3.1 FAMILY VALUES AND BELIEFS | adulthood within the Xhosa culture, conceptualized by the anthropologist as the stage of ubudoda (manhood), and ubufazi (womanhood), involve establishing a family and assuming a parental role. | reported, “When I got married I was told that I was not getting married to my husband but to the family. As a wife in that family I was expected to take care of my in laws, particularly my mother and father in law; my husband and most importantly bear children into the family.” |
| 3.2 COUPLE VALUES AND BELIEFS | Within the family system parents are the key people who preserve and protect the cultural values and norms etc | The researcher requested her to be clear as to the pressure she was referring to and Bhele explained that this was the pressure from their parents ensuring that they perform all their developmental duties. |

The individual child has now grown into adulthood and has met a partner, in an attempt to fulfill the developmental task of establishing a family. Both

The couple strives to fulfill the developmental tasks prescribed to them by the Xhosa culture.

“I and my husband had to make decisions, such as whether we should disclose our situation to our parents, and whether to have children or not. We loved each other very much and we did not want anything or anyone coming between us and so we decided not to tell anyone about our HIV-status. We also decided to have at least two children whilst our CD4 count was still high
members of the couple are Xhosa and therefore have a shared meaning of life.

<table>
<thead>
<tr>
<th>4. CHRISTIAN BELIEFS</th>
<th>Christian belief is pro-life. This means being sure that life begins at conception.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Christian belief is anti-abortion, meaning, abortion is murder, and therefore prescribes to its members not to abort.</td>
</tr>
<tr>
<td></td>
<td>so as to fulfill our duty as a married couple thus keeping our parents happy”, stated Bhele.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. FEAR</th>
<th>This is the fear of knowledge about one’s HIV-status.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This causes people to refrain from testing for HIV-infection.</td>
</tr>
<tr>
<td></td>
<td>“When I was requested to test by a nurse I refused because I was afraid of the knowledge that I could be HIV-positive”, Matshutsha explained.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. STIGMA AND DISCRIMINATION</th>
<th>This means being treated as an outcast by the community and/or family.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>People sometimes resort to hiding their HIV-positive status in fear of being ostracized.</td>
</tr>
</tbody>
</table>
|                            | “I once asked a patient the reason she never attended to my referral and she said, and her exact words were, ‘it is enough for me to know that I have this disease but I do not want the whole world to know. Everybody in Ngangelizwe knows that people who go into that hall have ‘AIDS’. Some
<table>
<thead>
<tr>
<th>6.1 DENYING THEIR HIV STATUS BECAUSE OF THE stigma and discrimination associated with HIV &amp; AIDS.</th>
<th>People in denial refuse to face the reality that they are HIV-positive and may continue with life without paying attention to the infection.</th>
<th>“It was very difficult for me to believe that I was HIV-positive. I thought the nurses were mistaken. I learned about my status three day before my wedding which was why it was so difficult for me to believe. I was just giving moral support to a friend who was sick at the time only to discover that I was also sick but wasn’t aware. I could not risk loosing my husband therefore I blocked the HIV-positive status from my mind and continued with my life. I was forced to face reality after four years when I became very sick.” Xabsi reported.</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. CURRENT STATE OF HEALTH HIV-positive individuals who are in the asymptomatic stage of the HIV-infection. This stage lasts for ten years</td>
<td>Some people take an advantage of this stage to procreate.</td>
<td>“We also decided to have at least two children whilst our CD4 count was still high so as to fulfil our duty as a married couple thus keeping our parents happy”, stated Bhele.</td>
</tr>
</tbody>
</table>
6.3 DISCUSSION OF FINDINGS

6.3.1 DISCUSSION OF THE FOCUS GROUP DATA

6.3.1.1 Reasons for Taking the HIV Test

The group members offered three explanations for being tested. These included: protection of unborn babies from the vertical transmission of HIV, experience of reoccurring illnesses, and as a result of discovering their partners’ HIV-status.

(a) Protection of unborn babies from the vertical transmission of HIV & AIDS

All the women in the focus groups were advised by the nurses in the antenatal clinics to test for HIV & AIDS. The nurses urged them to do so because this would provide them with an opportunity to protect their babies from vertical transmission of HIV when HIV-positive. Some of the women reported that they suspected that they were HIV-positive even before falling pregnant. They had experienced recurrent STI’s, such as herpes zoster, vaginal candidiasis, genital warts, and severe illnesses, such as TB, pneumonia, or prolonged diarrhoea. They procrastinated testing because they were too scared to discover the truth about their status. Some of the participants shared that they only tested once they knew they were pregnant. They did so out of moral obligation to their unborn. They did not think they would be able to live with themselves if their babies became infected. Others reported not having had any suspicion of being HIV-positive. In fact, when they tested positive they were shocked. Being in what they considered committed relationships they assumed that their partners were faithful.

(b) Experiences of reoccurring illnesses

Some women tested because they developed severe and prolonged illnesses, such as, TB, pneumonia, recurrent STI’s, diarrhoea. The WHO (2004) states that these are the signs and symptoms of the onset of AIDS. Once diagnosed with AIDS the participants were
started on ARVs and their health improved. WHO (2004) stipulates that people who are in stage four (AIDS stage) of HIV-infection remain on that stage even when their CD4 count improves and they do not suffer from any opportunistic infections. What was surprising was that these women intentionally fell pregnant while on ARVs. Apparently the participants had no knowledge of the fact that once you have AIDS there is no chance of going back to the less advanced stages of HIV-infection. They placed their faith on ARVs to sustain and prolong their lives for a number of years to allow them to raise their children into puberty.

(c) Discovering a partner’s HIV-positive status

Some of the women tested when they learned that their partners had tested HIV-positive. They unanimously shared that their partners had tested only after experiencing severe illness. On learning of their partners’ statuses the women followed suit and discovered that they too were HIV-positive. One woman, Mangxabane, expressed her feelings saying, “I felt betrayed by my husband. I was very disappointed at him for bringing this awful, merciless disease into our marriage, and into our family. I did not leave him though. I couldn’t because I loved him so much.” Another woman, Mamaya, sorrowfully reflected upon her disappointment at herself, “I knew that he had another woman on the side, but I never did anything about it. I was so angry and disappointed at the same time for allowing him to ruin my life. I left him. I couldn’t stand him. I hated him for what he had done to me.”

6.3.1.2 Thoughts and reactions prior and subsequent to the HIV test

(a) Denial

Within the group of women who had learned of their HIV-status during pregnancy their reactions tended to be that of denial. In some instances it was a complete surprise to
them. In others, there was suspicion about a possible HIV-positive status.

- **Feeling total surprise:** Some of the women who discovered their HIV-positive status while pregnant reported not having suspected that they were HIV-positive at all. They were totally surprised by the HIV-positive result because they were in committed relationships and believed that their partners were faithful to them.

- **Avoidance of testing although there was suspicion about possible HIV-positive status:** Ten of the women in this group suspected that they were HIV-positive prior to the pregnancy. They stated that they had shown some symptoms of HIV-infection but had procrastinated over testing as they were too afraid of having to deal with the reality of being HIV-positive. One of the group members, Mamngxongo stated, “I had an experience of recurrent herpes zoster and vaginal yeast infection two years back. When asked to test for HIV-infection I was told that this was one of the symptoms of HIV-infection. The nurse wanted to know the cause of the recurrence of the yeast infection and herpes. She sensibly told me the importance of knowing the root cause of sickness and stressed that she was not saying I was HIV-positive but wanted to rule out HIV-infection as the cause. I refused because deep down I knew that I could be HIV-positive.”

- **Fear of testing:** Fear of dealing with the harsh reality of being HIV-positive was by far the biggest factor that perpetuated their denial. However, when pregnant they realised that they had no choice but to test out of a deep sense of responsibility to their unborn babies. At this point the women realised that because of the strong cultural and religious convictions they held their only recourse for the protection of their babies and themselves was testing so that if fear associated with discovering a positive HIV-status was the fear of having to
accept God’s wrath. The researcher identified that some members viewed HIV as a consequence of sin. They believed that infection was a sign of God’s anger as Leviticus (26: 15 & 16) states: “If you refuse to obey my laws and commands and break the covenant I have made with you, I will punish you. I will bring disaster on you, incurable diseases and fever that will make you blind and cause your life to waste away” (Good News Bible, 2000). They stated that God was punishing the sexually immoral, and that this was the reason why no one wanted to be associated with HIV-positive people. This belief resulted in tremendous reluctance to test because on finding that they were positive it became too scary to contemplate how they would appease God. People only tested when it was a matter of life and death or, in their case of falling pregnant, out of obligation to protect their children from vertical transmission. A member confessed, “I seldom practiced safe sex and in the past year I had gone in out of love affairs. A year ago I fell pregnant and it was then that I felt compelled to test for the sake of my baby because I did not think I would be able to live with myself if my baby got infected. I tested positive with a CD4 count of 320.”

6.3.1.3 Women’s account of the HIV testing process

The HIV-test involved pre-and-post-test counselling. The participants’ experiences were very similar.

(a) Pre-test counselling

Pre-test counselling involved a counsellor assessing their reasons for testing; providing basic information on what it means to be HIV-positive; an exploration of the person’s feelings prior to being tested.
(b) Rapid test

After pre test counselling the nurse administered the Rapid test, which took fifteen minutes. The rapid test involved the prick of the index finger with a needle so that a small amount of blood oozed out. This blood was taken into the control test. Once the blood was taken the patient was requested to wait on a chair to be called. After fifteen minutes the patient was called into the counselling room to be told her results. That waiting period was very stressful. For this group of women those fifteen minutes seemed much longer.

“The fifteen minutes seemed like an hour, the way I was frightened.” a member named Mamaya commented.

(c) Post-test counselling

After the waiting period the nurse shared their results with them in private. The counselling that followed was based on the HIV-positive status results. The counsellor began by trying to assist them to explore their feelings. Once given the opportunity to ventilate the counsellor made a point of trying to help them recognise that they could continue with their daily lives with little change provided they took good care of themselves. They were told that most HIV-positive people survived longer than ten years. The counsellor proceeded to offer advice on how to slow the virus’ activity in the body. The important facts they were told were to practice safe sex, avoid stress, attend to ailments early, refrain from falling pregnant and eat a balanced diet. The group members interpreted the main purpose of post-test counselling as “helping to soften the shock”.

Clearly, counselling at this stage failed to fulfil an educative or supportive function. Xesibe described her state of mind in that counselling session as follows, “When I was told I was HIV-positive, to me it meant I was dying. I became numb. I could not hear a thing the counsellor said. When she required a response from me that is when she saw that my mind was not there. So she suggested that I leave and return the next day. She also advised that I take the ELISA (antibody Enzyme-Linked Immuno Sorbent Assay) test to determine my CD4 count. I agreed and left but I only revisited the counsellor after a week.” Xesibe displayed total shock to the news that she was HIV-positive. Mandlovu,
on the other hand, could not believe her result. She stated, “I was shocked. I could not believe what I was told. I thought my husband and I were faithful to each other but seemingly I was wrong. But I trusted my husband. The only explanation that I could come up with, I thought, the test must be wrong. And so I demanded for another, more accurate test. My blood was taken to the lab for the ELISA test. The results returned positive. This meant one thing.... that there was something my husband never told me. I demanded the truth from my husband but he never gave it to me. He went for the test himself and tested positive. The explanation he gave me was that HIV hides itself and the possibility was that when we met two years ago he was already HIV-positive”. For Mandlovu this was a terrible shock because she discovered her status in the second trimester of her pregnancy. No other member attested to having taken an ELISA test but all of them had taken a CD4 count test. The ELISA tests were reported not to be accompanied by counselling.

(d) The logistics of post-test counselling

The participants reported having one post-test counselling session which took an hour. Xesibe and Mandlovu, of course were the exception because they could not participate in that session and were therefore requested to come back for a follow up session. Otherwise the other participants were numb and could not say much. The amount of information shared with them was too much to absorb in one hour. Mandlangisa described her experience of post-test counselling as follows, “That talk the counsellor gave me did not help me. Not because what she said was not relevant but I could not absorb most of what she said in my mind. I heard her talk about living for a very long time with the virus but all I could think about was that I had a terminal illness. It was like the end of the world to me. All I thought about were my children. What would become of them when I die? Reality only dawned on me as I attended the support groups. Otherwise the counselling I had with the counsellor after the test is a blur to me.” For those members who joined the support groups the information covered during post-test counselling was shared in later sessions amongst the support group members within an
educative and supportive context. Their feelings were not dealt with in any other therapeutic context.

(e) Topics covered during the post-test counselling session

As already mentioned, the topics covered during PTC included: promoting responsible sexual and preventive behaviours; encouraging disclosure and seeking support from others; encouraging early management of opportunistic infections; facilitating access to mother-to-child intervention/ treatment through referral; referral to support groups; contraceptive advice. According to Pronyk, Kim, Makhubele, Hargreaves, Mohlala, & Hausler (2002) the South African Department of Health guideline on post-test counselling contains more topics that need to be covered, such as, facilitating acceptance of the HIV-status, enabling women to identify their coping mechanisms, changing negative attitudes and stigma about HIV & AIDS in order to minimise the mother’s self blame and promoting planning for the future. The Department of Health however does not stipulate the amount of time it may take to cover all these topics. Apparently, the format of PTC that women were exposed to did not completely adhere to specified guidelines prescribed by Department of Health, and the lack of clearly stipulated post-test counselling process caused irregularities in the way it was conducted and the effectiveness of this protocol was compromised.

The participants described their emotional disposition during the counselling session as being in shock, feeling numb, and experiencing denial and fear. This state of mind caused most of the participants to have difficulty assimilating the information shared by the counsellor. Most of them reported not remembering completely what was discussed. Listening to the participants, the researcher recognised the turmoil HIV & AIDS caused in peoples’ lives, and imagined how difficult it must have been to weigh up the pros and cons of having children at that time. The members described how as HIV-positive people they felt compelled to proceed with their lives in an uninterrupted fashion, as if HIV & AIDS was not at all present.
There was general consensus that there was a need for individualised, couple, and family counselling to help them address issues associated with being HIV-positive. Issues such as disclosing their status to loved ones, managing stigma and discrimination, the benefits of condomizing, reviewing the reproductive decision, all needed to be discussed within a couple context (where applicable) rather than just with women. In their patriarchal society arming these women with information did not empower them sufficiently to enable them to take decisions about sexual behaviour and reproduction. They found it difficult to influence their partner’s behaviours and attitudes within these areas. Their partners were not willing to listen to them.

Participants such as Madlamini refused to believe that they were HIV-positive and simply disregarded the information given. This is termed denial which is “an outright refusal to admit or recognize that something has occurred or is currently occurring” (DiMatteo, 1991:237). Another group of participants feared that they were about to die because when they tested they were very sick. This group of women found it difficult to believe at the time that they would be able to proceed with a normal life as told by their counsellors. For them it was a pleasant surprise to recover and regain their strength to such an extent that they were motivated to have another one or two children without contemplating the long term implications.

The following section discusses the results of the focus groups about their life experiences after discovering their HIV-positive status.

6.3.1.4 Life after discovering their HIV-status

This section outlines the experiences of the participants concerning the disclosure of their statuses to significant others, facing the reproductive decision, the impact of pregnancy on their CD4 counts after delivery, developing healthier lifestyles as a means of managing their HIV & AIDS, support systems used by the women, common fears
experienced by HIV-positive mothers, the wishes of the women, and their future plans.

(a) The disclosure of HIV-status to significant others

After learning of their HIV-status the first hurdle the women reported facing was for each to decide whether or not to disclose her status. Clearly the stigma and discrimination experienced by a majority of the participants meant that they restricted disclosing their HIV-status to their partners only. They reported that their community lacked an adequate understanding and compassion for HIV-infected persons (Skinner & Mfecnane, 2004). A few of the women even felt compelled to withhold their HIV-status from their partners. Mamcira, whose husband divorced her on discovering that she was HIV-positive, related her sad experience. “I only disclosed my status to my husband two years after I had been diagnosed. This was a time when I fell very sick after delivering our last born. My husband overheard me informing the doctor about my status and when he confronted me I did not deny. He was very angry with me and told me to stay with my disease alone. He wanted no part of it. This was the reason I did not disclose my status to him in the first place. I knew he would have such a reaction. He never visited me at the hospital and when I was discharged I discovered that he had moved out. He took my children including the new born to his mother and has not brought any of them back to me until today. I am only allowed to visit them but I cannot take them to my house. I am still trying to fight him through court but it is not looking good because I am unemployed and he has a good job. We have been divorced for a year already. My baby is one year old and I did not see him grow.” She sobbed profusely whilst sharing her story and concluded by saying, “It is like he has buried me alive.”

Some of the unmarried participants reported that they disclosed their HIV-statuses to their families. Thirty percent of the group felt that they were accepted by their families after disclosure and seventy percent complained that their families had been discriminatory towards them thereafter. Madlomo explained her situation, “After I disclosed I was never treated the same in my family. I was given my own separate room
where I live on my own with my baby. I cook for myself and do everything else there. When I am sick neighbours help me. My family looks at me with disgust.”

During the focus group discussions it emerged that a number of cases needed social work intervention particularly in relation to their disrupted relationships with family members after disclosure. Such cases were referred to community based welfare organisations to enable them to deal with the realities of their statuses and better manage feelings of rejection and discrimination.

(b) Facing the reproductive decision

The participants offered six reasons for deciding to have babies despite their HIV-positive status. These were the need to fulfil their wifely duty; to strengthen the bond between themselves and their partners, to fulfil one of the most important developmental tasks of couples namely “to extend the couple to include children”; to satisfy the intrinsic desire to be a mother; Christian and Xhosa cultural beliefs; belief that ARVs would protect their babies. Each of these reasons will now be discussed.

- **Need to fulfil a wifely duty:** Like many of the participants, Bhele, reasoned that her primary motivation for procreating whilst HIV-positive, was a result of the deeply rooted social sanction of having to perform her wifely duty (Mama, 1996). Bhele elaborated, “When I got married I was told that I was not getting married to my husband but to his family. As a wife in that family I was expected to take care of my in-laws, particularly my mother-and father-in-law, my husband and most importantly bear children into their family. Two months after my marriage my husband fell very sick and was advised to test for HIV. I had to test as well and I also tested positive. This was shocking and painful to me because I had just got married and now I had to deal with HIV & AIDS. My husband and I had to make decisions, such as whether we should disclose our situation to our parents, and whether we should have children or not. We loved each other very
much and we did not want anything or anyone to come between us and so we decided not to tell anyone. We also decided to have at least two children whilst our CD4 count was still high so as to fulfil our duty as a married couple. We knew this would keep our parents happy. We had the two planned children who are now three and five years old respectively. What is pleasing is that we don’t have to deal with pressure from anyone about our status. We are treated like other normal families.”

- **Strengthening /keeping the relationship together:** The participants who were cohabiting explained that having children in the relationship held the couple together and made it difficult for the partner to leave. Some married women even deliberately fell pregnant when they felt their relationship with their partner was strained because they believed that another child would bring them closer together, as indicated by Mama (1996).

- **Fulfilling the developmental task of young couples:** Childbearing was seen as a natural progression or developmental task of couples, as stated by Smith (2006) and some participants such as Mabharha felt that their HIV status should not prevent them from transcending that developmental stage. Mabharha shared her success story, vindicating her position, “When I met my partner I was already HIV-positive and so was he. Our motto was ‘we are not going to be scared of HIV & AIDS. We will treat it like diabetes. So we had three children together. This made our bond to be even stronger and after five years living together we decided to make our relationship official. We have been married for three years,”

- **Innate desire to be a parent:** The group of unmarried participants who had the desire to be mothers stated that they had a deep yearning within to have a baby of their own to love and care for. They did not care if the father of the baby was reluctant to take responsibility for and be involved in raising the child. They stated that they procreated despite being HIV-positive because they saw that they
would soon be beyond the reproductive age. They were between the ages of thirty-six and forty years old. The main reason they gave for delaying having children was that they had been hoping for marriage.

- **Christian and Xhosa cultural beliefs:** Some participants only discovered their status during their pregnancies. These women presented different reasons for seeing their pregnancies to full term. A fairly consistent explanation was that as Christians they had no other alternatives. Their Christian beliefs had instilled in them the notion that children are God’s gifts and that abortion was not an alternative because it was equal to murder. This concurs with Hammond’s (2007) notion. The issue that further strengthened their resolve was that the Xhosa culture is against abortion as well because of the important value it ascribes to child-bearing. This is consistent with Hutchison’s (2004) findings.

- **Access to ARVs:** When the women reflected upon the choices they had made about seeing their pregnancies to full term it became evident that ARVs had helped them to make this decision more easily. “What gives comfort to the decision to have babies is the availability of antiretroviral therapy which offers protection to our future unborn children”, clarified Mandlovu. “What is important is to take dual therapy of ZDV plus nevirapine at thirty-three weeks and then shortly after delivery you stop taking the drugs, and just keep healthy.” said a member who felt that ARVs offered them and their babies’ sufficient protection from disease progression. Some women were in such a state of denial before they fell pregnant or during their pregnancies that they failed to make use of ARVs thereby putting them and their babies at greater risk.

The researcher noted that people had different philosophies about HIV & AIDS which kept them strong and able to go on with their lives. The participant’s choices were influenced not only by culture or family values and beliefs but by their personal values as individuals and couples.
(c) The impact of pregnancy on the CD4 count of the participants after delivery.

A small number of the participants reported that after child birth their low CD4 counts were reversed. However it seems that a majority of these women did not feel that their health had fully recovered. Most of the participants, especially those who had three children after being diagnosed with HIV & AIDS, reported some disease progression. They stated that their CD4 count during pregnancy dropped from 350 to around 150 and 110. They started taking ARVs and were told they would take them for life. They mentioned that it took a while after their pregnancies for their health to improve. A majority of the women who were on ARVs highlighted one great difficulty in taking the medication, the unaffordability of good nutrition as their total monthly income was between R50 and R500. They expressed difficulty in securing a social grant to assist them get proper nutrition. Others narrated that they only got the disability grant for the first six months and when they went for review their applications were turned down because their CD4 count was above 200 and they appeared healthy. The participants complained that taking ARVs on an empty stomach caused severe nausea and stomach cramps. They explained that ARVs were very strong drugs that needed to be taken with food. Their major problem was that they did not have enough money to sustain the healthy lifestyle required, nor did they have the energy for the unskilled work most of them had to do to support themselves and their families.

Matshustha stated, “I am a single parent of three. I do not have a job nor do I get social assistance from the Government. I used to receive the disability grant in the past eight months but I was turned down on my second review because my CD4 count had improved from 123 to 290, and I was healthy and fit. It’s been two months since I last received the disability grant and I am telling you life is a struggle. I have to constantly think about where we are going to get our next meal and remember food is not the only necessity in life. The children have to attend school. They need money for transport to go to school, they need to carry lunch boxes to eat at school, they need uniform, and school fees. I don’t have many options in finding a job because I have a two year old baby
whom I have no one to leave her with whilst I search for employment. I do get small jobs like washing laundry, cleaning the garden, or spring cleaning houses around the community. These small jobs are taxing on my health because I no longer have the same energy that I had before I started using ARVs. I get moral support from my friends in the support group and the social worker brought the Department of Agriculture to help me fence my garden and gave me seeds to cultivate. In my garden I have spinach, carrot, cabbage, potatoes, and beetroot. When I get money I buy maize-meal, rice, samp, sugar etc. Life is a little bit bearable now. I no longer have the amount of stress I had when I did not have a garden”.

The participants also explained that ever since they took ARVs they were not totally healthy. They had complaints ranging from painful and sometimes swollen feet, nausea, sporadic confusion, etc. Even during the focus group discussions a majority (sixty-five percent) of the participants complained about one part of the body that was painful. Only thirty-five percent of the members had no complaints. There are many women like Matshutsha whose life is a daily struggle. The Government seems not to be doing enough to deal with unemployment and HIV. These findings are in keeping with the findings of Gwele (2006) which showed that HIV infection is exacerbated by poverty.

(d) Developing a healthy lifestyle as a means of managing their HIV & AIDS

In order to manage HIV & AIDS one has to develop a healthy lifestyle as Manxasane remarks, “One has to keep healthy by eating a balanced diet and exercising, avoiding stress, and practicing safe sex. This was the key to boosting a low CD4 count during pregnancy. I have done it three times but still I have not yet been included amongst those who qualify for ART.” Whilst this opinion was strongly supported by the members it proved more difficult for some to execute in their daily lives. Some members had little or no money to buy all the recommended and necessary healthy foods.
A further hurdle in managing their HIV & AIDS that was identified by the women was that their partners and in some cases even themselves were reluctant to use condoms as a means of engaging in safe sex practices. Madleiks stated, “This is the major challenge we have, me and my partner. It is very difficult for him to use a condom. He states that condoms do not get him aroused. We are really struggling with this ‘condomising’ business, and of course we have a recurrent herpes problem.” An issue such as this makes one aware of just how difficult it is for this vulnerable group of women to safeguard themselves against the progression of the HI-Virus.

(e) Support systems used by women

The participants mentioned their support system as their belief in God, support from friends, partners, family members, and support group. These are discussed in more detail below:

- **Belief in God:** All the women considered God the Almighty as their greatest source of strength. This is interesting because they also feared Him and some mentioned that they believed He had sent the HI-Virus to punish them. God was regarded as mysterious. He was described as loving, forgiving, and protective on one hand and aggressive and cruel on the other. Even though the persona of God appeared to be so confusing to them, they believed that He was the answer to the unexplainable circumstance and would support them and/or humankind through the trials experienced.

- **Support from partners:** The women who were in committed relationships characterized by high levels of openness found their greatest sources of support to be their partners. They could share feelings pertaining to the difficult times of illness and celebrate the good triumphant times of achieving a higher CD4 count with them.

- **Support from friends:** Single women and those who were divorced and widowed stated that their sources of strength were friends. Friends were reported to be their anchor because when times were hard they were always there to offer support and
assistance. Friends nursed them when sick and took care of their children. Some friends were described to help with material support by providing food when there was none, or money to see a doctor. When a friend died some friends fostered the children. In instances where the participants had been rejected by their families, friends had come to their assistance. The participants were realistic though and mentioned that friends could not always fully understand their situation and that was why their involvement in support groups had provided the additional support they needed.

• **Support from family members:** Only thirty percent of the participants reported having support from their families. In these cases HIV & AIDS was treated like any sickness rather than a source of shame. One of the participants commended the support she received from her family, “My parents and my siblings were very sad to learn that I had contracted a terminal illness in so much that when I am not well they take care of me and pray for my deliverance as they would if I had any other sickness.” This response should be considered against a previous comment made that stated that seventy percent of the total sample population did not have the support of family members because of the community’s ongoing rejection of HIV-positive people.

• **Support group:** The support groups were described as the participants’ “second family” and for those who were not accepted by their families the support group was viewed as the only “real family” they had. The participants stated that in the support groups they received acceptance, understanding, support, and love. The support group was identified as a home away from home where they “formed meaningful, close relationships, developed sisterhood, and were mothered”. Clearly, one questions how women who do not participate in these groups cope without the high levels of support offered by fellow group members.
(f) Common fears experienced by HIV-positive mothers

The fears expressed by participants were plentiful. They were very anxious about falling sick, needing nursing, dying and leaving their children orphaned. These women were afraid of losing their health and becoming dependent on others. Almost all the women did not want to find themselves unable to control their bowels and having to wear nappies. They unanimously felt that would be a very traumatic experience. Participants who were rejected by their families were mostly concerned about who would nurse them and take care of the children. These women shared the same sentiment that they did not want to burden their children with the enormous responsibility associated with caring for a sick parent. All participants hoped to leave some legacy for their children. Those who did not have their own homesteads were trying to secure plots from the chiefs in their villages. Others were soliciting for Reconstruction and Development Program houses. The biggest fear expressed by these women was the likelihood that they might not live long enough to see their children grow into adulthood. They felt protective over their children and were concerned about their futures. They worried about them becoming “orphans”. All of the women recognised that the fundamental human needs of their children would be severely compromised by their premature deaths. Many of these concerns were openly expressed during support group meetings. Within these support group meetings they reviewed and rediscovered their coping skills for “living positively”.

(g) What the women wished for

All participants agreed that nobody considered themselves ready to die before reaching old age. They hoped to live until the age of sixty because that would be the normal progression of the lifecycle. As mothers they had a deep yearning to watch their children grow. They wanted to be around to watch over them and fight for their better futures. The women placed enormous hope on ARVs. They wished that the medications would keep them alive until their children were all grown up and financially self-sufficient. They believed that children need their mothers until they reach the age of about twenty. As far
as they were concerned this was possible if they maintained healthy life styles and took their ARVs religiously. They wanted to identify themselves with HIV-positive people appearing in the press confessing to have lived with HIV-infection for more than twenty years. For the participants, the barrier to realizing this wish was the challenge of trying to maintain a healthy life style given their economic circumstances. Another hope was that there would be a discovery of a cure for HIV & AIDS.

(h) Future plans of HIV-positive women

It was encouraging to note that the women were not passively accepting their fate. They felt sufficiently motivated to participate in food relief projects that had been started within the support groups. Each support group member had developed a vegetable garden at home for her and her family's own consumption with the assistance of the Department of Agriculture. The Department helped them with cultivating and fencing the garden areas and provided the vegetable seeds. These clinics had developed sewing and baking projects and the women who acquired these skills were encouraged to sell the clothing and biscuits they produced. The income generated was shared amongst the participants to enable them to buy other necessary foodstuffs that they could not produce.

The support group members felt compelled to be vigorously involved in fighting the stigma and discrimination associated with HIV & AIDS. They wanted to be actively involved in the awareness campaigns organised by the clinics. A few of the members stated that at the time of the study they were preparing drama and musical items. Generally several members expressed an interest in becoming involved in clinics as care-givers.
6.3.2 DISCUSSION OF THE DEBRIEFING SEMI-STRUCTURED INTERVIEWS

After the focus group discussions the researcher conducted debriefing semi-structured interviews with each participant. The points of interest that emerged will now be presented. On the whole the data gathered during these interviews were consistent with data gathered during focus group discussions.

6.3.2.1 The need for special counselling and preventive services for HIV-positive pregnant women and their families in antenatal clinics

The individual participants shared the same sentiment that had been shared in the focus group discussions. The sentiment was that specialized counselling and preventive programmes should be developed and offered by antenatal clinics. The participants felt the need for the involvement of their families particularly their partners during management of their pregnancies. They advocated that a similar system of using "treatment supporters" for those people who are prescribed ARV treatment should be developed to ensure the support and compliance required for HIV-positive pregnant women. When a person begins taking ARVs, the requirement is for the person to bring someone he or she lives with as a treatment companion, to inform the companion about the treatment regime. It is felt that this knowledge helps the companion to encourage and support the HIV & AIDS patient to comply with the treatment prescribed. Participants shared that treatment supporters helped them to stay focussed on their treatment when they were disheartened by some of the adverse side effects caused by the ARVs. They said that the same practice should apply to pregnant and HIV-positive persons. Such services would strengthen the much needed support system for HIV-positive pregnant women. The treatment supporters could help to keep the HIV-positive pregnant women focussed on living a healthy lifestyle and this would help to slow down disease progression.
6.3.2.2 Feelings about the focus group experience

The participants reported that they had greatly benefited from the professional services of a qualified social worker during the discussions. The social worker facilitated discussions rather than imparted information. This meant that group members felt engaged, respected and were more open to learning from one another. Interaction with others allowed members time to reflect on their own positions and values. This assisted them to make informed, better contemplated, self-sustaining decisions. The social worker was quick to identify people who needed one-on-one counselling and made necessary referrals. The social worker was well informed about resources available in the community. The social worker was better equipped to cover the psycho-social aspects of HIV & AIDS and pregnancy. The groups in Civic and City Centre clinics felt that they had benefited to such an extent that they would motivate for the co-ordinator of the HIV & AIDS programme in the clinic to network with locally based NGO’s in order to utilize their social work services to cover certain topics in their support groups.

6.3.2.3 The impact of the focus group experience on the participant’s life

The participants stated that the process of the focus group discussions had offered them an opportunity to clarify and explore both their personal and collective realities. The process had motivated members to address some aspects of their lives which they had not dealt with. Aspects like engaging in safer sex practices, attempting to lead healthier lifestyles, reflecting on future planning for their children, and reviewing their position as women in that community. The focus groups had empowered them to lobby for better services for pregnant HIV-positive women. They would lobby for specialised counselling services at clinics, prevention programmes that were tailor made for pregnant women, programmes that were directed at young families deciding to reproduce. It was not enough to inform women about the risks of falling pregnant when HIV-positive. Their partners needed to be targeted as well. Families within the community needed to be made aware of why their supportive role was critical for pregnant women infected with the
virus and how they could assist in practical terms. The women had been made aware of just how valuable regular antenatal check ups were. Every participant had welcomed the opportunity to meaningfully engage with other group members, get to know them better, and strengthen their bonds with the group.

6.3.2.4 Sensitive topics which touched the participant during the discussion (topics they could not discuss in the group)

The participants appreciated the fact that they could talk about their sex lives because talking about sex in their community was, “indaba yakwamkhozi”, (something spoken about in secrecy behind closed doors). The openness helped them to challenge misconceptions they held, accept their feelings and experiences, and secure vital information about healthy sexual practices. The participants also appreciated being given an opportunity to talk about the hurt that they caused their husbands and families especially as a result of their withholding their HIV-positive status. The discussions around this topic helped them to understand the reasons why they had been secretive and this minimised their feelings of guilt. Within the discussions they had been enabled to reflect on their feelings pertaining to being HIV-positive and this was a critical start to the facilitation of a healing process.

The next section presents the summary of the findings.
6.4 SUMMARY OF FINDINGS

This section provides a summary of the findings according to the research questions of the study.

6.4.1 Research question one: What are the reasons for HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?

There were two popular explanations given by fourteen of the participants. Firstly, fourteen of these women had deliberately chosen to procreate in an attempt to avoid being ridiculed for failing to fulfil the cultural duty of a Xhosa wife. Closely related to this motivation was the fact that fourteen women feared that if they failed to produce a child for their partners they would be rejected, their partners would divorce them, or their partners would take an ‘idikazi’ (concubine) or an additional wife. Legal abortion was considered an immoral solution to managing HIV & AIDS disease progression by this group of HIV-positive women. Twelve women expressed extremely negative sentiments about abortion stating that according to their Christian belief it was equal to murder. On discovering their HIV-positive status whilst pregnant they were morally left with no other solution but to carry the baby to term. Clearly, Xhosa culture promoted an anti-abortion stance. Twelve women said that Xhosa stance was closely related to the emphasis that the culture placed on bearing children. Access to ARVs clearly had made a large portion of the women feel more secure about seeing their pregnancies to full term. In fact some even indicated that they hoped they would live long enough to see their children live to twenty years or older. Twelve women gave ARVs as one of the main reasons why they were not too concerned about the risks involved in disease progression and vertical transmission of the virus from mother-to-child. However, there were several issues about ARVs that did not give these women complete peace of mind. The negative side effects and their limited
economic resources prevented most of these women from being able to afford a healthy lifestyle indicated as essential for recipients of this treatment regime.

Pregnancy marked the start of life according to eight women and as they believed that life was created by God, they had to graciously accept this gift that He had bestowed upon them. Sadly, all the publicity about practicing safer sex and condomising did not feature as a popular practice to minimise disease progression and cross infections. A group of five women expressed how difficult this strategy was. This resistance had been responsible for these women falling pregnant. Both partners and some participants in the study perceived condoms to compromise sexual pleasure. This was consistent with the finding of the study published by Bryceson & Fonseca (2004).

A smaller group of women, three participants, had deliberately fallen pregnant to achieve recognition as ‘women’ within the Xhosa community. Having failed to marry, they chose motherhood as a way to increase their social standing in the Mthatha region. The same group of women shared that they had a deep intrinsic need to experience motherhood.

This summary has been displayed on the table below:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Participant’s explanations</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian beliefs</td>
<td>This decision to carry the baby to term was strongly influenced by the belief that ‘life begins at conception’ and ‘abortion is murder’. The moral dilemma of committing murder left them no alternative but to have their babies despite the risks involved.</td>
<td>12</td>
</tr>
<tr>
<td>Xhosa cultural influence</td>
<td>The belief that children are a gift from God and therefore it is not their place to take away life that has been freely given by God.</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>They described Xhosa culture as being anti-abortion because of the enormous value attached to child-bearing.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Married women reported to have procreated in order to avoid being condemned, ridiculed, and sometimes excluded from membership to the family they married into. It is almost as though couples cannot choose to not have children if they value acceptance by Xhosa people.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To compensate for being unmarried, single women were having children out of wedlock so as to achieve some recognition as “women” by the society.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Another reason was performing a wifely duty. If a woman did not bear children the husband could find a concubine, ‘idikazi’ or even worse ask for a divorce and take another wife who will bear children for him. In such cases a woman usually does not receive any support from the family.</td>
<td></td>
</tr>
</tbody>
</table>
| ARVs                     | This group believed that ARVs would offer  


| Failure to practice safe sex | The women reported the difficulty experienced in practicing safe sex with their partners. Their partners strongly discouraged the use of contraception, especially condoms. Infrequent adherence to the recommendation of condom use led to unplanned pregnancies. |
| Innate desire to have a baby | The three single women stated their reason for procreating as a response to a deep desire to have children of their own. |

The participants offered several individualized reasons for deciding to procreate in spite of their HIV-positive status. These included:

- Avoidance of being labelled as “infertile”, in view of the fact that in the Xhosa culture infertility is blamed on the woman even when it is the male who is infertile. This was consistent with the findings of research undertaken by Makoba (2005).
- Avoidance of being singled out as different and not wishing to deal with interrogation of reasons for not bearing children. Pregnancy was chosen to avoid stigma and discrimination associated with HIV & AIDS.
- Good health: Some of the women found it hard to believe that their health would deteriorate and pregnancy would hasten disease progression to AIDS. This was attributed to the nature of the HI-Virus and the fact that HIV-positive people often remain asymptomatic for ten years.
- An attempt to strengthen their relationship with their partners: Some women who failed to enjoy the protection of marital rights opted for the second option, to select a partner to father a child. Smith (2006) stated that this option is used to
play upon the partner’s feelings and coerce him to remain in the relationship for the sake of the children.

1.4.1 Research question Two: To what extent and in what nature are HIV-positive women informed about such risks?

The HIV-positive women acknowledged that they had been warned of the risks of pregnancy and given specific advice about how they could minimise these. The advice included slowing virus’ activity in the body down by practicing safer sex, avoiding stress, attending to ailments early, preventing pregnancies, and eating a balanced diet. This advice was compromised by the information being given at the wrong time, during post-test counselling, straight after learning of their status. The participants clearly felt that they had been exposed to too much information at a time that the counsellor should have been helping them to come to terms with the emotional upheaval. The women were too upset having received the dreadful news about their HIV-positive status. The participants did not believe that people would be receptive to important information at that point. They felt that they needed to be helped to work through some of those emotions before they could be open to information shared that would make a difference to their lives. The participants described the state they were in during that counselling session as being in shock, feeling numb, and experiencing denial and fear. This emotional state of mind caused most of the participants to have difficulty assimilating the information that was shared by the counsellor. As a result most of them reported not to remember much of what was discussed.

It appeared that the information given was rather ambiguous and unclear because they received what appeared to be conflicting messages during the post-test counselling session. They chose to “hear” the messages they most wanted to. The message that they “heard” was that a HIV-positive status was not the end of the world and that HIV-positive people could live for a very long time, more than ten years. The sentiment shared by counsellors that most of them responded positively to was that HIV & AIDS should be
normalised. These statements were absorbed easily but further fuelled their denial of the severity of their situations. In some ways the efforts of the counsellors to reassure them and make them feel more accepted tended to normalise the women’s decision to procreate. Procreation enabled them to negotiate a culturally acceptable life and hide their HIV-positive status, protecting them from stigma and discrimination. On the other hand they were told that they had to be careful and prevent disease progression and vertical mother-to-child transmission. The information was critical but the women were not in much of an emotional position to take heed of the advice. Only two of the women were invited to return for further counselling when they had calmed down. The participants depended entirely on the information they received from their clinics, because they were mostly unemployed and could not access other health care. At the clinics HIV & AIDS and pregnancy were spoken about during the post-test counselling session, part of the VCT counselling process, and in the support groups.

6.4.3. Research question three: From the perspective of HIV-positive women, should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families?

The only formal post-test counselling the women in the study received was at the time of VCT testing. Although the participants had basic education they were not given any written information about HIV & AIDS and pregnancy. They were not made aware of community resources that would offer supportive services to them during and after their pregnancy. The women expressed many social problems related to their HIV-status but unless they had been in the support group or informed about these organisations from family and friends they would not have known how to source assistance. Post-test counselling was identified as insufficient for raising adequate awareness on the risks involved in falling pregnant while HIV-positive. They proposed that follow-up counselling sessions should be introduced as protocol to help patients work through the news of being HIV-positive, and to deal with the longer term implications of HIV & AIDS. Implications like, “How to disclose one’s status to the partner or family?” and
“How to adjust to the new life-style of living with HIV-infection?” were pertinent. They desperately wanted these follow up sessions to include partners and family so that as women they were not expected to carry the burden of HIV & AIDS on their own. They felt that the time had come for partners to be involved in antenatal, postnatal and family planning services.

6.5 CONCLUDING SUMMARY

This chapter aimed to identify the reasons why HIV-positive women procreate despite the risk of prenatal transmission, the risk of disease progression, and the infection or re-infection of their partner. The key informants and the sample drawn from the PLWHIV and PMTCT support groups provided these reasons.

This chapter identified the fundamental reason for procreation to be the universal inborn natural desire influenced by cultural prescripts. Childbearing in the Xhosa culture is viewed as a significant custom and is thus highly esteemed because of its power to ensure societal survival from generation to generation. Childbearing is bestowed as the responsibility of young adults in the Xhosa culture. Childbearing is culturally accepted to occur in and out of wedlock. Out of wedlock it occurs in cohabitation relationships and to single persons. Young adults who fail to bear children suffer social pressure such as, stigmatization, being treated differently from those who comply with the norms and having to forfeit the social privilege associated with adulthood. HIV-positive young adults who do not bear children because of their status suffer a double dose of stigma and discrimination. They become stigmatized and discriminated for being HIV-positive, and for not bearing children. Additional to the innate desire to bear children and cultural prescripts, other reasons for women to procreate while HIV-positive included: the strengthening of the bond in their relationships; resistance of their partners to use contraception; the anti-abortion view of the Christian and Xhosa cultural beliefs. It is
important to note that the decision to procreate was also influenced by the women’s good state of health, most often facilitated by ARVs.

These women did not experience one situation in isolation, but a combination of these motivations mentioned above. A combination of these factors therefore influenced HIV-positive women to procreate despite the risks of vertical transmission, disease progression, and infection or re-infection of the partner.
CHAPTER SEVEN:  
CONCLUSIONS, SUMMARY AND RECOMMENDATIONS

7.1 INTRODUCTION

This study was concerned with mother-to-child transmission as an immediate determinant of the spread of HIV & AIDS. The researcher was interested in exploring the reasons why HIV-infected women reproduce even with the possibility of vertical transmission from mother-to-child, disease progression within themselves, and the cross-infection of partners. The study was also interested in trying to establish if there was a link between culture and the decision of HIV-positive women in the Mthatha region to procreate. The researcher hoped that this study would act as a preliminary study for more in depth studies that would help inform strategic planning aimed at mitigating HIV & AIDS. The results of the study have shown thus far, that all the strategies that are in place appear not to take this dynamic of HIV & AIDS into consideration.

This chapter concerns itself with the discussion of the main findings that were obtained in the study by drawing together the results from the previous chapters, thus making conclusions and recommendations.

7.2 THE RATIONALE FOR AND CONTEXT OF THE STUDY

The motivation behind the research was to try to understand the reasons why HIV-positive women in the Mthatha region continue to procreate despite their positive status. It was thought that such understanding was essential for developing culturally specific interventions to reduce the incidence of vertical transmission from mother to baby, disease progression within HIV-positive mothers and cross infection of partners. These three factors have been clinically associated with the risks of procreating with a HIV-positive status. The research findings of this study have shown that not enough is done to assist these women in making informed decisions
about procreation. This sentiment is borne from the view that the post-test counselling offered is ineffective, and that the supportive nature of the groups these women are exposed to lack professional facilitation. The research findings therefore managed to provide an insight into the reasons why HIV-positive women in the region of Mthatha procreate despite their positive status. It is hoped that culturally specific interventions can thus be developed.

The context of the study was the health clinics in the Mthatha region where there was a high rate of pregnant HIV-positive women attending the antenatal clinics. The study was based in the Mthatha General Hospital and KSD clinics where the sample attended support groups linked to the antenatal clinics. These women were strongly influenced by Xhosa cultural practices that regulated their social behaviour. According to Friedman et al., patriarchal practices compromise the autonomy of women and impact on their decision making relating to health issues and family life, amongst other issues (2006: 88). The locally specific participatory nature of the research was meant to project the voices of the women who participated in the study so that new ways of addressing their challenges would be sought. Challenges like the services rendered to HIV-positive women that are not holistic and comprehensive were identified. Richter (1999) attributed this situation to the lack of the implementation of the NACOSA National AIDS Plan, which acts as a guide for HIV & AIDS counselling to Government and Non-Government Organizations. The major reason for the lack of implementation of the NACOSA plan is that counselling services remain under-resourced due to inconsistencies in funding. This result in counselling services that is undeveloped at community level (Richter, 1999: 19).

7.3 THEORETICAL FRAMEWORK

The theoretical framework for the study was the Culture Life Span Approach authored by Trommsdorff (2002). According to the framework the Xhosa culture life cycle development stages are defined by the gender-specific biological age and marked by gender specific rituals. As one expects most procreation in families to occur between the ages of twenty to forty years, this study was particularly interested in the adulthood stage. The adulthood stage in the Xhosa culture is marked by the initiation ritual called ‘intonjane’ for girls and ‘ukwaluka’ (circumcision) for boys.
Trommsdorff (2002) believed that each stage of development has developmental tasks that a person has to fulfil. In the Xhosa culture the expectation is for young adults to establish families and assume parental roles. This is accomplished by either getting married and bearing children, or by bearing children without getting married (though this option is allowed it is also discouraged). As Brisil’s theory assumes, social pressure is exerted on those who deviate from the norm (1993). In this study Xhosa women who because of their HIV-positive status, fail to fulfil the young adulthood developmental tasks are doubly ostracised and discriminated against. Firstly for being HIV-positive and secondly for not bearing children. In the Xhosa culture individual choices become secondary to community and cultural identity. The findings of this study revealed that the Xhosa culture influences health related and family life decisions. There is an established link between culture and the decision made by HIV-positive Xhosa women in the study to procreate.

7.4 OBJECTIVES OF THE RESEARCH

The study had three objectives to achieve. The first objective of the study aimed to provide a locally specific perspective to the reasons why HIV-positive women procreated in spite of the risks. This study yielded that the Xhosa culture, Christian beliefs, ARVs, failure to practice safe sex, and the innate desire to have a baby influenced the decision to procreate in spite of a HIV-positive status. These factors were found to compensate and overshadow the risks associated with vertical transmission from the mother to the baby, disease progression within the mother, and cross-infection of the partners. The second objective of the study aimed to propose culturally specific interventions to reduce the incidence of vertical transmission from mother- to-baby, disease progression within HIV-positive mothers, and cross infection of partners. These are expanded upon within the recommendations for the practitioners dealing with HIV-positive pregnant women in the Mthatha region. The third objective aimed for the study to present a preliminary study that would generate hypotheses for more in depth studies to help inform strategic planning aimed at mitigating HIV & AIDS. A proposed example is a study that focuses on moral regeneration for the Xhosa culture. The study also had three key questions. The first question explored the reasons behind HIV-positive women choosing to procreate despite the risk of vertical transmission, the risk of disease progression, and the
infection or re-infection of the partner. The second question explored the extent to which HIV-positive women are informed about such risks. The last question explored whether family planning antenatal clinics should offer specific counselling to HIV-positive pregnant women and their families?

From the findings of the study hypotheses to the above key questions were developed and included:

- The main reason why HIV-positive women procreated despite the associated risks was the social pressure exerted on young adults, particularly females who failed to procreate during that stage. This social pressure is usually in the form of discrimination, condemnation and ostracism.
- Secondly, the non-involvement and non-inclusion of men in antenatal services who are viewed by Friedman et al., (2006) to hold decision making power over sexual relations matters, such as when or whether to have a child and health seeking behaviour, significantly influenced HIV-positive women’s decision to procreate.
- Thirdly, this decision to procreate was regarded as a less informed one, because of the ineffectiveness of the PTC offered, and the lack of professional facilitation of support groups.
- Lastly, follow-up post-test counseling sessions that included partners and /or family members were proposed in order to help women cope with their status, and to be in a position to make a collective informed decision with their partners about procreation.

The findings yielded by these research questions provided a better understanding of the constraints and challenges experienced by HIV-positive women in the Mthatha region. The findings can be used by researchers to generate and test new hypotheses on a larger population with more diverse samples representing other ethnic and racial groups within South Africa. Further research is indicated to help the government to develop more informed strategies on:

- How to target young families who are ‘getting settled and starting a family’ to co-operate in the fight against HIV&AIDS?
• What relevant programmes at Mthatha antenatal clinics need to be developed to address the specific needs of HIV-positive pregnant women?
• What Provincial and National Government Departments policies, legislation and programmes need to be in place to appropriately respond to the impact of HIV & AIDS on families within different socio-cultural contexts?

7.5 CONCLUSION OF THE STUDY BASED ON THE RESEARCH METHODOLOGY

The study was qualitative and exploratory in nature and relied on ethnographic methods. The researcher studied Xhosa HIV-positive women residing in the Mthatha region who planned pregnancies using exploratory, descriptive, contextual and ethnographic strategies of enquiry. The research process was divided into four stages. The first stage focused on exploring the topic through covert and overt participatory observations. In covert participatory observations the researcher engaged in informal conversations with clients, students, and colleagues. These informal conversations assisted the researcher to formulate the research problem, objectives of the study, and the interview guide for the key informant interviews. Semi-structured interviews were conducted with a traditional chief, anthropologist, two nurses, and a social worker, all of whom were Xhosa and resided and practiced in this region. These were locally specific key informants interested in this topic who had access to specialised knowledge. The interviews with the key informants helped develop the research questions, yielded themes to structure the interview guides for the focus group discussions and semi-structured interviews. The themes were: Xhosa culture and Christianity, including family values, beliefs and denial; ARVs, VCT; importance of child-bearing, stigma and discrimination; current status of health; ignorance and lack of knowledge. These criteria were later used as themes for the analysis of findings in the research process.
The second stage involved developing the research methodology. This stage established focus group discussions and semi-structured interviews as data collecting methods, and identified a sample through a purposive sampling method. Forty-eight HIV-positive women who attended antenatal clinics in this region were selected as the sample for the study. The women were divided into eight geographically determined groups, with six women in each group. The third stage was the pilot study for the focus group discussions and semi-structured interviews with group members. As the study had set up eight focus groups for data collection, the last two groups, group seven and eight, were used to pilot the study. During this stage the data collecting process was established and additional themes were identified, marked and coded the EDM process. The fourth stage was the data collection stage through which focus group discussions and semi-structured interviews were conducted. The recording and editing of field notes used the themes that emerged during the pilot study and focus group discussions. These themes included: ART; PCT; Xhosa culture including family and couple values and beliefs; Christian beliefs; fear, stigma and discrimination; denying HIV-positive status; current state of health. The themes facilitated the data analysis process. This stage also yielded the main findings for the study by providing answers to the three key questions. These will be expounded upon in the next section.

7.6 CONCLUSIONS OF THE STUDY BASED ON THE RESEARCH FINDINGS

The conclusions are presented in accordance with the three key questions of the study, as follows:

7.6.1 What are the reasons behind HIV-positive women to consciously plan parenthood despite the risk of vertical transmission, the infection or re-infection of a partner, and the risk of hastening disease progression?

The study yielded two sets of findings for this research question. The first set was obtained from HIV-positive women who learned of their status when pregnant but opted to carry their babies to term instead of the alternative to terminate the
pregnancy. From the findings the research concludes that these women attributed their reasons for keeping their babies to Christian beliefs, Xhosa cultural influences, and ARVs. The Christian belief is based on the assumption that life begins at conception, children are a gift from God, and abortion is murder (Hammond, 2007). The Xhosa cultural influences are anti-abortion because of the enormous value attached to child-bearing. The ARVs were believed to offer adequate protection to the baby against vertical transmission of HIV, and inhibit disease progression in themselves.

The second set was obtained from HIV-positive women who fell pregnant after discovering their status. Based on the research findings, the researcher arrived at the conclusion that married HIV-positive women (who knew their status and took part in this study) procreated to avoid being discriminated against, condemned and sometimes excluded from membership to the family they married into. Another reason was so that they would fulfil a wisely duty, because failure of a woman to procreate often results in the husband finding a concubine, ‘idikazi’ or even worse divorce. Little or no support is provided to such women by the family as was pointed out by Dyer, Abrahams, Mokoena, Lombard, & Van De Spuy (2005:1938). The choice not to procreate seemed not to be an option for married couples who valued being accepted by Xhosa people. Non-married single HIV-positive women with a known HIV-positive status procreated out of wedlock so as to achieve recognition as ‘abafazi’ (women) by their society. Another group of non-married single HIV-positive women procreated in response to a deep desire to have children of their own. This sample of HIV-positive women experienced difficulty in practicing safe sex with their partners because their partners strongly discouraged the use of contraception, especially condoms and hence ended up with unplanned pregnancies, which they could not terminate because of Xhosa cultural influences. Other HIV-positive women with known HIV-status procreated in order to avoid being labelled as “infertile”, being singled out as different and not wishing to deal with interrogation of why they were not bearing children. Some of the women found it hard to believe that their health would deteriorate and pregnancy would hasten the progression of AIDS. This was attributed to the nature of the HI-Virus and the fact that HIV-positive people often remained asymptomatic for ten years. Some women who failed to enjoy the protection of marital rights opted for the second option, to have a chosen partner father a child. This option was used to play on the partner’s feelings and coerce him to
remain in the relationship for the sake of the children. This group of women also placed their hope on the intervention of ARV therapy.

It can be concluded that both groups of HIV-positive women appeared to be commonly influenced by culture, religion, individual natural desires, and the avoidance of stigma and discrimination. These women surrendered to such influences because of their belief in ART. Although ARVs have been proven to offer reliable protection to the baby from HIV transmission (Harley, 1999), there are other factors to be dealt with such as baby feeding options which have been proved by the study not to be affordable to a majority of the participants, and the uncertainty of how long the person will live with the virus before the body succumbs to opportunistic infections and dies. Statistics have shown a vast number of children orphaned as a result of HIV & AIDS and a surge in the incidence of child-headed house-holds (Skweyiya, 2007). Orphaned and vulnerable children are the real effects of the HIV-pandemic that millions of families in South Africa have to grapple with.

7.6.2 To what extent and in what nature are HIV-positive women informed about such risks?

The researcher concludes that the advice given to HIV-positive women during post-test counselling was compromised because it was shared straight after learning of their statuses. The messages communicated to them appeared to be misinterpreted. Some of the confusing messages given were: making the participants understand that a HIV-positive status was not the end of the world; assuring them that HIV-positive people lived for a very long time, more than ten years, thus normalising HIV & AIDS. These statements were absorbed easily and further fuelled their denial of the severity of their situations. These projected views made it easy for the women to procreate as it allowed them to live a culturally acceptable life, whilst at the same time keeping their HIV-status concealed. In other words they could rationalize their reasons for having babies and at the same time protect themselves from stigma and discrimination. The advice given appeared to be centred around the likelihood of the mother transmitting the virus to the child and disregarded other implications of HIV & AIDS such as the mother not responding to ARV treatment and dying sooner than expected, or the body giving in to opportunistic infections despite ARV treatment
resulting in leaving children young and orphaned with no adult to take care of them (Harley, 1999).

7.6.3 From the perspective of HIV-positive women should family planning antenatal clinics offer specific counselling to HIV-positive pregnant women and their families? What should these programmes cover?

From the utterances made by the participants, the researcher concludes that the participants strongly felt that follow-up sessions to PTC were essential to help patients come to terms with the news of being HIV-positive and such follow up sessions could be designed to assist them to deal with the implications of being HIV-positive, such as disclosing to their partners and/or families, and adjusting to the new life-style of living with HIV-infection. Since the decision to procreate is often influenced by men the participants felt that steps to involve men in these follow up PTC sessions should be undertaken, consistent with counselling principles, so that both men and women are advised on the implications of the reproductive decision. In cases where the couple makes an informed decision to procreate the participants should be referred to vertical transmission preventive programmes offered to couples and families. These programmes should cover information on how to keep the HI-Virus at low levels in the blood so as to sustain immune system’s strength for a prolonged period of time.

The information shared by the participants corresponds to a large extent with the key informants (i.e. the anthropologist, traditional chief, nurses, and social worker). The findings of the key informant interviews showed that the main reason for HIV-positive women choosing to procreate despite the risks was to fulfil all the cultural prescripts for the young adulthood stage, and thus avoid being treated differently from those who comply with the norm, and forfeiting the social privileges’ associated with adulthood. Secondly, the results showed that HIV-positive women were not adequately informed to make the decision to procreate in that counselling services offered in antenatal clinics were described as inadequately developed due to shortage of professionally trained personnel. Finally, these interviews revealed that the decision to procreate is in actual fact mostly made by men. This finding therefore justifies the request of the participants for a counselling programme that involves their partners and families.
7.7 SUMMARY OF IDENTIFIED THEMES

There were two identified themes. These themes explained the reasons why women delayed testing until HIV-infection was in an advanced stage and the reason why they did not seek help early. The themes were fear of knowledge about one’s HIV & AIDS status, which caused people to refrain from testing for HIV-infection and denial of a HIV-positive status due to the stigma attached to it. Such women who delay testing only discover their statuses either while pregnant or when severely sick. Denial is a normal reaction to learning about a HIV-positive status because being HIV-positive may lead to rejection and loss by significant others (Hall, 2009). This may be rejection by a partner or spouse, by family members, friends, and community. An HIV-positive status brings a lot of uncertainties which overwhelm people to such an extent that they slip into denial or depression (Harley, 1999). Women in denial do not seek help early and thus compromise their health. Intensive counselling is essential.

7.8 RECOMMENDATIONS

This section outlines the recommendations for practice, practitioners dealing with HIV positive pregnant women, policy recommendations, and the research recommendations. These are based on the findings of the study.

7.8.1 Recommendations for practice: Counselling services should be prioritised and form an integral part of the HIV & AIDS treatment regime

Recommendations are for counselling services to be prioritised and to form an integral part of HIV & AIDS treatment. Counselling needs to be understood as a method of treatment in psychosocial care. It therefore requires to be rendered by professionally trained practitioners (Solomon, Rooyen, Griesel, Gray, Stein, & Nott, 2004), such as psychologists and social workers. These practitioners are an essential part of the multi-disciplinary team responsible for rehabilitating and maintaining people’s wellness. Counselling services should also be made available in the termination of pregnancy services. The indigenization of counselling needs to be
advocated. The indigenization of counselling is the process of transforming counselling to fit cultural practices or beliefs, including the re-affirmation of indigenous values and resurgence of religious faith (Wikipedia, 2009).

More steps must be taken to involve men in health related issues. These initiatives must filter through to the poorest of the poor because they are the ones who are most affected by HIV & AIDS. Antenatal services should encourage supporter involvement such as a partner, friend of family member. This will help women who experience complications such as denial or depression.

Careful review of certain cultural practices that are not beneficial for society is recommended. Practices such as the empowerment of both girl and boy children, emphasising gender equality, advocating that boys receive the same covert expression of love and protection as bestowed upon girls, advocating that girls have the same rights as boy children. Community leaders, politicians, church leaders, social welfare professionals and parents should come together to advocate for cultural change so that we move closer to a generation of Xhosa men who are more responsible and respectful of the rights of women; and women who are free to make decisions about what they consider best for their lives. Other recommendations involve, building sustainable and flexible livelihoods within communities relevant to the industrial, urban, and digital era; and finding new ways to enhance the moral fibre of our people.

7.8.2 Recommendations for the practitioners dealing with HIV-positive pregnant women in the Mthata region specifically

Practitioners in this region should develop inter-sectoral debates with stake-holders involved in the fight against HIV & AIDS, such as NGOs, the church, community leaders (ward counsellors and traditional chiefs), and Government Departments. Culture, family life and values clarification in relation to HIV & AIDS need to be interrogated so that a necessary paradigm shift can take place. Resolutions from these inter-sectoral debates need to translated into policy and implemented within life skills programmes in local schools (focusing on sex education), antenatal services, church sermons, services rendered by NGO’s, and Government Departments. Community
leaders should raise these issues within their community ‘imbizo’s’ (meetings) in order to find culturally specific ways to protect the rights of women.

Antenatal services should specifically offer HIV-specific information related to pregnancy. Although the focus is usually on giving hope to HIV-positive women the reality of the implications must be spelled out. These must include information about vertical transmission about HIV & AIDS to the baby, ARV side effects, the possibility of cross infection of the partner which may hasten disease progression, and the reality that some day the woman may die and leave the young child with no one to take care of him or her. In the same light, the implications of HIV-infection on a woman’s life should be highlighted without taking away her human right to choose whether or not have a baby. Similarly, a woman should be afforded the right to decide on terminating a pregnancy after discovering her HIV-positive status. Women need to have adequate information so that they can make informed decisions.

7.8.3 Policy recommendations

The Department of Health’s policy should focus on strengthening psychosocial services within its health centres. Such policy must advocate for psychosocial care to become an integral part of treatment for HIV & AIDS related cases. Psychologists and social workers should form part of a psychosocial team within the Department of Health’s multi-disciplinary team. Counselling should be an integral part of the psychosocial services. Counselling offered by nurses and lay counsellors must be a temporary measure while the country is working to produce more qualified social workers and psychologists.

The Department of Health should declare psychology as a scarce skill and lobby Universities to train more psychologists by issuing bursaries and offering employment opportunities to those who qualify. HIV & AIDS needs specialized intervention by well trained practitioners. The lesser trained personnel must be a temporary measure. The Department of Health also needs to partner with the Department of Social Development and lobby for more social workers within its ranks. The Department of
Social Development should make employment for social workers more attractive in deep rural areas because these areas are most affected by the HIV & AIDS pandemic.

7.8.4 Recommendations for future research

Now that the reasons why HIV-positive women procreate have been established a more in-depth study on moral regeneration that is culture specific and gender sensitive can begin to be developed. Such a study would investigate how the Xhosa culture can be regenerated to strengthen its vulnerability to the HIV pandemic, and focus on prevention and deal with the impact of HIV & AIDS.

It is also recommended that this research project be replicated amongst women from different cultural groups and similar research projects be undertaken amongst Xhosa men and women from the middle and upper classes.

7.9 LIMITATIONS OF THE STUDY

As this study was of a qualitative explorative nature with the aim to examine the motivations and expectations of HIV-positive women who plan pregnancy despite their own status, the research methodology employed yielded the following limitations:

7.9.1 Generalisability of the study: The study relied on opinions and experiences of the participants; the sampling method used relied on the researcher’s judgement; the small sample size suggest that the results of the study may not be applicable to all HIV-positive women who plan pregnancy. The researcher used triangulation of data sources by including patients from different clinics and conducting focus group discussions with different age groups in an attempt to make the findings as representative as possible given the nature and scope of the study.

7.9.2 Loss of meaning: Since the study focused on meanings of information shared during the focus group discussions some inaccuracies in transcribing may have occurred. It is however hoped that the Xhosa speaking research team kept this to a minimum. The triangulation of data collection methods, namely focus group
discussions, semi-structured interviews with key informants and research participants using a research team were all attempts to obtain truth value, neutrality and consistency of data.

7.10 SUMMARY AND FINAL NOTE

This study bore testimony to the fact that the prevention of vertical transmission through ARVs provides hope for HIV-positive people to lead relatively culturally accepted lives. ARVs, in a sense, create a life line for HIV-positive people. But this is only part of the solution because cross-infection and disease progression remain a risk to the couple who does not condomize. The literature reviewed portrayed that cross-infection among ARV-users results in a drug resistant strain of HIV which reduces the chance of prolonging their lives enabling them to raise their children into adulthood. One may therefore question whether it is ethical or moral for HIV-positive people to procreate, given that until there is a cure for HIV & AIDS, they will compromise the quality of life for their offspring. Children born to HIV-positive parents face a multifaceted burden of having to take care of their ailing parents, become orphans and more vulnerable to abuse. They experience a compromised future with little or no education, family support, and may end up living on the streets. Orphaned children often find themselves living completely without family support, ending up living on the streets or in institutions. Others live at least for a period, in child-headed households. Children living in child-headed house-holds may have the biggest challenge. Persistent hunger, followed by a range of other poverty-related concerns, which include: the struggle to pay school-fees; lack of school uniforms and other clothing; lack of money for transport and health care; inadequate housing; insufficient warmth, are typical realities for this group. The Government has made strides to absorb the blow of HIV & AIDS in our communities through policy formulation, but questions for thought by the reader are:

- Is the responsibility for protecting children’s rights only that of policy makers, governmental, and national children’s rights movement?
• Or should parents not be challenged to consider whether they have the resources required to fulfil their responsibilities to their children until they are old enough to fend for themselves?"

• With this pandemic, should planned - parenthood not be given the spotlight it deserves?

These questions of concern are for each and every citizen of South Africa to ponder and take initiatives in trying to resolve.
LIST OF REFERENCES


Centres For Disease Control and Prevention (CDC). 1999. Family planning methods and practices: Africa (Special Section on AIDS). USA: CDC.


Cuba, N. Social Auxiliary Worker. Hospice Association of Transkei. Meeting, 06/05/2007.


Hude, N. I. 2006. \textit{An investigation into the knowledge that HIV-positive women have of the prevention of mother-to-child transmission of HIV}. Dissertation towards MPhil degree: Stellenbosch University.


Lamla, D.S., Dr. Lecture at University of Transkei. Meeting held 23/08/2007.


Zwane, P. 2008. HIV in pregnant women drops. Available on line at: 
ANNEXURES

Annexure 1: Semi-structured interviews for exploring the topic

A. Anthropologist and Traditional Chief

1. What is your understanding of the importance of Childbearing in the Xhosa Culture?

2. What role do Xhosa men play in the decision to procreate?

3. What is your perception of the HIV & AIDS pandemic as a Xhosa person?

7. Briefly tell us about the impact of HIV & AIDS on the Xhosa society, families, individuals etc.

8. General comments

B. Social Worker and nurses

1. Planning pregnancy, what does it entail?

2. What impact does pregnancy have on HIV-positive mothers and what are the risks?

3. What form of aid is made available for these women?

4. What impact does HIV & AIDS have on families, especially children?
5. Children born to HIV-positive women, what are your projections of their future in light of the risks involved?

6. What do you think may be motivating HIV-positive women to plan pregnancy despite their status?

7. Would counselling services be available to families affected and infected with HIV?

8. General comments
Annexure 2: Interview guide for the focus group discussions

1. Brief introduction: The purpose and the process of the interview will be explained.

2. The participants should discuss the experiences they had when they were diagnosed with HIV & AIDS. Their discussion should be guided by:

2.1 Their reasons for testing

2.2 The whole process of pre and post test counselling.

3. The participants should explain their life after diagnosis. In their discussion they must make mention of their disclosure to family members, friends and relatives, that is, their significant others. How the significant other’s reaction, opinions, and treatment of the participants has been ever since the disclosure.

4. The participants should examine their decision to have a child, making mention of:
   4.1 The fundamental reasons for their decision,
   4.2 Who is supporting them,
   4.3 How pregnancy has affected their health,
   4.4 Their fears,
   4.5 Where they draw strength to go through such an ordeal, and
   4.6 Their future plans.

5. The participants should discuss the effects of the infection on their families. Focus must be on how the virus has infected and affected their families.
Annexure 3: semi-structured debriefing interviews

1. How do you feel about focus group experience?
2. Has it impacted your life in any way?
3. Were there any sensitive topics which touched you during the discussion, topics you could not discuss with the group?
4. How are you coping with the disease at home?
5. How are the family relations?
6. Do you need any professional help?
2 STOKWE ROAD
SOUTHRIIGDE PARK
MTHATHA
5100
13/10/2005

MTHATHA GENERAL HOSPITAL
ELEXENDER ROAD
MTHATHA
5100

Dear Madam/Sir

REQUEST FOR PERMISSION TO COLLECT DATA FROM
THE ANTENATAL CLINIC WITHIN THE HOSPITAL

My name is Bulelwa Plaatjie and I am a registered student at Unisa for a Master’s Degree in Social Work. I am conducting research on the impact of HIV & AIDS on planned parenthood in the area of Mthatha. The main interest of this research is to explore the rationale behind the decision made by HIV-positive women to procreate in spite of the risk of vertical transmission, infection or re-infection of the partner, and disease progression in themselves. I therefore request to gather data from HIV-positive pregnant women and those that have had babies knowing their HIV-positive status.

The findings of this study will help us understand the impact HIV & AIDS has on women of the reproductive age, and thus afford the helping institutions to make intervention services that are relevant to such women.
I am aware of the sensitive nature of this topic and can assure you that I know how to carry myself in such environments as I am a social worker by profession.

I would appreciate negotiating the logistics of this exercise on contact so as to mutually agree on how this would be best done.

Yours Sincerely

[Signature]

Bulelwa Plaatjie (Researcher)
Date: 20/10/2005

Enquiries: Dr N. Linda

Attention: Ms B. Plaatjie

Subject: GRANTING OF PERMISSION TO COLLECT DATA FROM THE ANTENATAL CLINIC WITHIN THE HOSPITAL

Your letter requesting permission to collect data from the antenatal OPD has reference.

I have spoken to the HOD of the antenatal OPD and after careful consideration of your request we identified the Infectious Disease Center (IDC) as the most suitable place for you to get the data you require. I have already briefed Mrs Mathandabuzo who is part of management at IDC and she is expecting you.

Wish you all the success.

Dr N. Linda
Hospital Manager
KING SABATHA DALINDYEBO MUNICIPALITY
MTHATHA DISTRICT
5100

Dear Madam/Sir

REQUEST FOR PERMISSION TO COLLECT DATA FROM
THE NGANGELIZWE, CITY & CIVIC CENTRE CLINICS

My name is Bulelwa Plaatjie and I am a registered student at Unisa for a Master’s Degree in Social Work. I am conducting research on the impact of HIV & AIDS on planned parenthood in the area of Mthatha. The main interest of this research is to explore the rationale behind the decision made by HIV-positive women to procreate in spite of the risk of vertical transmission, infection or re-infection of the partner, and disease progression in themselves. I therefore request to gather data from HIV-positive pregnant women and those that have had babies knowing their HIV-positive status.

The findings of this study will help us understand the impact HIV & AIDS has on women of the reproductive age, and thus afford the helping institutions to make intervention services that are relevant to such women.

I am aware of the sensitive nature of this topic and can assure you that I know how to carry myself in such environments as I am a social worker by profession.
I would appreciate negotiating the logistics of this exercise on contact so as to mutually agree on how this would be best done.

Yours Sincerely

Bulelwa Plaatjie (Researcher)
Enq : Mrs Z. Mafeke
Date : 27/10/2005

2 STOKWE ROAD
SOUTHRIDGE PARK
MTHATHA
5100

Dear Ms Plaatjie

REQUEST FOR PERMISSION TO COLLECT DATA FROM THE
NGANGELIZWE, CITY & CIVIC CENTRE CLINICS.

Your letter dated 13/10/2005 refers.

Permission to collect data from the above-named clinics is granted subject to conditions that will be stipulated by the clinic managers. I have approached the clinic managers and they are expecting you. Please make the necessary appointments with each of them, and good luck.

[Signature]

Mrs Z. Mafeke
Area Manager – Clinical Services: KSD