

**UNIVERSITY OF CAPE TOWN**

**The experience of being pregnant and HIV positive and undergoing treatment  
against vertical transmission of HIV.**

**By**

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**A research report submitted in partial fulfilment of the requirements of the degree  
of Master of Science in Nursing**

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2003**

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## ABSTRACT

The aim of this study was to gain insight and understanding of the lived experience of HIV positive pregnant women who are undergoing antiretroviral treatment against vertical transmission of HIV.

The study was a qualitative phenomenological design using in-depth, free attitude interviews by the researcher as the method of data collection. A small purposive sample of three participants who met the criteria to participate in the study was recruited from the antenatal clinic at a Midwifery Obstetric Unit in the Southern Peninsula, Cape Town.

Data analysis was thematic and consistent with phenomenological method. Data was extensively read and listened to until there was a clear understanding. Themes that were related to the phenomena under study were extracted and grouped together. Meanings were formulated from these and put together as clusters of themes that were compared with the original data for validation.

The findings revealed that these women went through a series of emotions, when they first discovered their sero-positive status, which ranged from those that were destructive and reduced their quality of life (fear, emotional turmoil, loss, negative impact on their self-worth) to those that were positive and enabled them to cope with their situation (hope and regaining of self-worth).

The issues arising from the themes are discussed with reference to Maslow's theory of human motivation and Roy's adaptation model. Recommendations for the nursing practice and further research are discussed.

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# CHAPTER 1

## INTRODUCTION TO THE STUDY

### 1.1 Introduction

HIV/AIDS is one of the worst pandemics to impact the modern world. The rate at which this pandemic grows has climbed steadily since its first identification, with women bearing the greatest burden of the pandemic. In 1997 the estimated number of women infected with HIV/AIDS, of the adults living with HIV stood at 41% globally, and by the year 2000 this number had grown to 47%. By the year 2000 an estimated 21.8 million people worldwide had died of AIDS, of which 9 million (41%) were women, 8.5 million (39%) men and 4.3 million (20%) were children (UNAIDS 2001 in UNIFERM 2001).

In 2002, the number of people living with HIV/AIDS worldwide had risen to 42 million, of which 38.6 million were adults. 19.2 million of adults living with HIV/AIDS are women and 3.2 million are children under the age of 15. The number of new HIV infections for 2002 was 5 million. 4.2 million of these new infections were adults, of which 2 million were women ([www.who.int/hiv/en/1/12/2002](http://www.who.int/hiv/en/1/12/2002)).

In Africa and particularly in sub-Saharan Africa, the worst affected by the HIV/AIDS pandemic, the number of HIV/AIDS orphans and child headed households is a cause for concern. According to Whiteside and Sunter (2000), the number of AIDS orphans in South Africa is rising steadily, with Kwazulu-Natal estimated to shoulder the burden of 65 000 AIDS orphans in 2000. The projection

further showed an estimated 500 000 AIDS orphans in South Africa by 2010. According to the Medical Research Council (MRC) annual report of September 2001, the HIV/AIDS epidemic will have a significant impact on the infant mortality rate (IMR) and the under five-mortality rate. The mortality rates for infants under one year will increase slightly, rather than decline, while the under five mortality rate will increase to double the current levels: 79 deaths per 1,000 live births (The World Bank Group, 2000). Based on the cumulative index, the number of HIV/AIDS deaths is expected to exceed 6 million by 2010, while the number of people with full blown AIDS in South Africa alone will be over 1 million (MRC 2001).

AIDS orphans, who are children themselves, are now faced with many reversed roles. They are now heading the households, parenting the other siblings, going hungry much of the time as they do not have the necessary skills or resources to look after the families they now head (Whitehead & Sunter 2000).

The report by UNIFERM (2001) supports the above findings, stating that sub-Saharan Africa bears the greatest burden of HIV/AIDS pandemic. Women bear the greatest burden as they represent an estimated 54% of adults infected with HIV/AIDS (UNAIDS 2001 in UNIFERM 2001).

In South Africa the pattern is similar. 17.1% of women between the ages of 14 to 49 are living with HIV/AIDS. In South Africa, the urban informal settlements have the highest prevalence rate of HIV at 20.2% followed by urban formal settlements with a prevalence rate of 9.3%. The rural areas, which include the tribal communities and farms, have the lowest prevalence rate of 7% and 8.6% respectively (Human Sciences Research Council 2002).

Van der Vliet (2001) cited in Skordis and Natrass (2002, p.405) states that 'South Africa has the fastest-growing AIDS epidemic in the world, and more HIV positive people than any other country.' It is stated that the increase of HIV prevalence has been five-fold between 1990 and 1999. It is further stated that the number of deaths due to HIV/AIDS in South Africa can only be comparable to those produced by war. It is argued that 'the government's response has been slow, stumbling and at times counter-productive' especially with matters regarding mother-to-child transmission of HIV (Van der Vliet 2001 cited in Skordis & Natrass 2002, p 405).

According to UNAIDS/WHO, 'antenatal HIV prevalence in South Africa increased rapidly from 0.7% in 1990 to 10.5% in 1995 and then 22.8% in 1998. HIV prevalence among ANC attendees was 22.4% and 24.5% in 1999 and 2000 respectively' ([www.unaids.org/hivaidsinfo/statistics](http://www.unaids.org/hivaidsinfo/statistics), 2002).

HIV infection is the most common complication of pregnancy. Pregnancy and childbirth is the major route of HIV transmission to infants accounting for over 90% of such HIV transmissions. Transmission can occur when the foetus is still in utero, during birth (labour and delivery) or after birth through ingestion of breast milk (Young, Ntobongwana & Coetzee 2000; Dabis & Ekpini 2002). Projections show that in South Africa, vertical transmission of HIV is at least 30% (Young et al. 2000).

Whiteside and Sunter (2000) state that, secondary to sexual transmission, mother-to-child transmission (MTCT) is the commonest mode of transmission of HIV. They further state that mother-to-child transmission is influenced by the following factors:

- **Viral load**

The higher the viral load of HIV, the higher the risk of mother-to-child transmission and the lower the viral load of HIV, the lower the risk of mother-to-child transmission.

- **Antiretroviral therapy**

This may decrease the viral load and may also inhibit the transmission of HIV to the infant (Whiteside & Sunter 2000).

## **1.2 Prevention of mother-to-child transmission of HIV (PMTCT)**

Pilot programmes to prevent mother-to-child transmission of HIV have been initiated in Africa over the past few years with the support of UNICEF, the Elizabeth Glazer Paediatric AIDS Foundation and bilateral donors and technical agencies. This has resulted in pilot programmes in 90 locations in 13 African countries (Dabis & Ekpini 2002).

The PETRA study was conducted in five sites in South Africa, Tanzania and Uganda to investigate the effectiveness of three regimens of a combination of Zidovudine and Lamivudine in the prevention of mother-to-child transmission of HIV. This study further established that antiretroviral treatment (a combination of Zidovudine and Lamivudine in this case) whether a long or short course, given as prophylaxis, reduces the risk of vertical transmission of HIV (McIntyre & Gray, 2002).

The PMTCT programme was first implemented in the Western Cape in January 1999, as a pilot programme in the Khayelitsha district. The programme was based on the Thailand regimen (Young et al. 2000), where Zidovudine (AZT) was given

to pregnant HIV positive women from 36 weeks of gestation, during labour and delivery and shortly after birth. Coupled with formula feeds, this programme reduced mother-to-child transmission of HIV by 50% (Baggaley & Praag, 2000).

Another study which was conducted in Uganda used Nevirapine to reduce vertical transmission of HIV. It was found that if a single oral dose of Nevirapine is given to an HIV positive pregnant woman during her prenatal care, and the woman is instructed to take it when labour starts, and another single oral dose is given to the neonate within 72 hours of birth, vertical transmission is reduced by about 47% when compared to the use of AZT (Stringer, Rouse, Vermund, Goldenberg, Sinkalala & Stinett 2000). The administration of Nevirapine is the method of choice in South Africa today, and is the practice in all the Midwife Obstetric Units (MOU's) in the Western Cape including the MOU at which this study was conducted.

Today the Western Cape is hailed as the leader in South Africa and the rest of the continent in the prevention of mother-to-child transmission of HIV through the use of short-term regimen using Nevirapine. It is estimated that in greater Cape Town, there is a 100% access to Nevirapine for pregnant HIV positive women (Health Systems Trust 2002).

Women, because of their anatomical and physiological structures relating to reproduction, together with social structures, are much more vulnerable to the Human Immune Deficiency Virus (HIV) which causes Acquired Immune Deficiency Syndrome (AIDS). Their anatomic structure allows for much larger doses of semen to be taken in at one time and the vaginal area is also vulnerable to lacerations. A report issued by the Canadian AIDS Society (November 2001), outlined reasons for women's vulnerability to HIV infection:

- **Biological factors**

HIV concentration in seminal fluid is much higher than in the vaginal fluid. Sexually transmitted infections (STI's) increase the risk of contracting HIV as they cause weakening and perforation of the mucous membranes of the genitals. Given that women often do not recognize or experience the symptoms of STI's, their presence may go unnoticed, thus making them much more vulnerable to HIV infection.

- **Social factors**

There has always been an imbalance in economic, social and physical power between men and women. This contributes significantly to the lack of negotiation about safer sex, for fear of abandonment, violence or even stigma, thus diminishing the chances of safer sex in intimate relationships. This report also states that women in abusive relationships are much more vulnerable than those in non-abusive relationships. This is compounded by the fact that women in abusive relationships usually suffer from low self-esteem and fear of provoking violence, which further restricts their ability to negotiate safe sex. Furthermore, in many long-term relationships, sex without the use of condoms is seen as a sign of loyalty between the sexual partners, thus increasing the chances of contracting HIV. In other cases the fear of pregnancy rather than the fear of contracting HIV/AIDS or the other STI's is the main motivation for the use of a condom. This makes condom use insignificant to those involved once the alternative methods of preventing pregnancy are in use (Canadian AIDS Society 2001).

Other factors that contribute to unsafe sex are:

- Embarrassment in negotiating safe sex.

- Embarrassment in collecting, buying and keeping condoms.
- Inadequate knowledge about STI's and HIV/AIDS.
- The belief that condoms somehow decrease sexual pleasure (Canadian AIDS Society 2001).

Tapper (1998) reported that women in the lower income countries of Africa, Asia and the Latin America almost always find themselves on the losing end when it comes to the issues that pertain to their health and their right to self-determination. In these countries, women depend more on their spouses or willing partners for economic support, as they are economically insufficient and dependent. Thus an ability to woo and to please the spouse or the willing partner becomes the sole means of attaining economic support.

My interest in this field as an undergraduate student led to a study which I and four colleagues at the University of Botswana conducted in 1998 to investigate the knowledge and attitudes of children (6 to 12 years) about HIV/AIDS. This study was conducted in two cities, Gaborone in Botswana and Maseru in Lesotho. The children in this study believed that the major cause of HIV/AIDS was witchcraft and the will of God. The factual knowledge of how HIV/AIDS is acquired and transmitted was very low. I realized that these children, with the little knowledge that they have, have little or no power to change the course of HIV/AIDS in their lives.

According to Friedland and McIntyre (1992), despite the counselling and advice that is given to HIV positive women to protect themselves against further pregnancies, HIV positive women still return to the health care facilities with planned subsequent pregnancies. It is for this reason that I decided to conduct a

study to find out how the mothers view the situation as the number of AIDS orphans keeps on rising steadily as more potential orphans are born. Furthermore, despite numerous studies conducted in South Africa about vertical transmission of HIV and its prevention, a literature search has revealed no reported study about the responses of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV with the administration of anti-retroviral drugs.

While I was still considering doing the study, I spoke to an HIV positive mother (who chose to remain anonymous) who confided in me that, immediately after being diagnosed with HIV in 1994, she decided to have another baby, and fell pregnant. The reason was that she wanted to retain the control over her fertility and choice to have a child.

I have become aware of how much pressure the well-intended safety precautions issued by the health professionals to HIV positive women can cause. The “Do’s and Don’ts” that are present in Health Education materials may have a negative effect and may even provoke a response which challenges the information, resulting in further problems.

### **1.3 Problem Statement**

While Nevirapine therapy against vertical transmission of HIV is now accessible, little is known about pregnant women's responses to this treatment.

### **1.4 The aim of the research**

The aim of this study was to gain insight, and understanding of the lived experience of HIV positive pregnant women who are undergoing antiretroviral treatment against vertical transmission of HIV.

### **1.5 Importance of the study**

According to Baggaley and Praag (2000), if the antiretroviral interventions are to be successful, interrelated services should be incorporated. It is anticipated that the findings of this study may prove useful to health professionals working in the services:

- to understand the experiences of these women as they undergo the PMTCT programme.
- to identify concerns that pertain to the interventions.

This study will also contribute to the body of knowledge in relation to PMTCT programmes and care of pregnant women with HIV/AIDS. The findings of this study may also be useful in curriculum development for nurses as it will provide information regarding the needs and care of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV.

## 1.6 Conclusion

The prevalence of HIV/AIDS globally is rising steadily, with the Sub-Saharan Africa bearing most of its impact. Women bear the greatest burden, as statistics indicate that women represent the majority of adults living and dying with HIV, and also transmit HIV to their unborn babies. This may be attributed in part to social and economic factors especially in situations where women rely on men for their livelihood. Anatomic factors in women also contribute to the high prevalence of HIV in women, as they are more vulnerable to being infected with HIV. These vulnerabilities, which have led to high HIV/AIDS prevalence in women, adversely impact on the prevalence of HIV/AIDS in infants. With the introduction of the PMTCT programme, which gives pregnant HIV positive women a chance of reducing the risk of transmitting HIV to their offspring, it is important that the health care workers gain an understanding of the impact of this programme on pregnant HIV positive women. While research in the field of HIV/AIDS is extensive, little is known about HIV positive pregnant women's lived experience of taking Nevirapine in order to prevent vertical transmission of HIV. This study will use a qualitative design to investigate this phenomenon. This study will therefore contribute to the body of knowledge relating to women's perceptions and experience of this treatment approach.

## CHAPTER 2

### RESEARCH METHODOLOGY

#### 2.1 Introduction

The research was conducted within the qualitative paradigm using a phenomenological approach.

##### 2.1.1 Phenomenological approach

Phenomenology is a methodology within qualitative research paradigm in which the lived experiences of individuals with regards to a certain phenomena and their intentions within their "life world" are examined and understood using the very descriptions that are given by the subjects under study. It answers questions like, "what is it like to have a certain experience?" (Crabtree & Miller 1992, p.26).

The purpose of phenomenological research is to seek an understanding of the experience of the phenomena under study, and how people who experience these phenomena interpret them and then find meaning. It focuses on the experience itself and how it is interpreted by the subject, thus revealing his or her "life world" and what is happening in it. The following questions are answered: What seems to be important about the experience? What alterations can be made? (Crabtree & Miller 1992, p.26).

Phenomenological methodology was most appropriate for this study as it sought to understand the 'life world' of pregnant HIV positive women who are

undergoing treatment against vertical transmission of HIV. The 'life world' is taken from the perspective of these women and it is taken to be true.

## **2.2 The research process**

The aim of this study was to gain insight and understanding of the lived experience of HIV positive pregnant women who are undergoing treatment against vertical transmission of HIV.

### **2.2.1 Participants**

The participants were recruited from one Midwife Obstetric Unit (MOU) in the Southern Peninsula (Western Cape) that was providing treatment to pregnant HIV positive women against vertical transmission of HIV.

Criteria for inclusion in the study were as follows:

- A pregnant woman over 18 years and beyond 34 weeks of gestation.
- The woman must be HIV positive.
- The woman must be undergoing treatment against vertical transmission of HIV.
- The woman must be willing to participate in the study.
- The woman must be able to communicate in English, as the researcher does not speak either Afrikaans or Xhosa. However in cases, where during the interview the participant chose to use her mother language to express herself better, this was recorded on the audiotape and this section was later translated into English for analysis purposes.

### 2.2.2 Sampling

In qualitative research, sampling is purposive and it relies on good informants. It is purposive in that the researcher deliberately chooses participants and settings in such a way that a wide range of possible characteristics is covered and the phenomenon of interest is sufficiently represented (Katzenellenbogen, Joubert & Abdool Karim, 1997). Morse (1989) describes purposive sampling as involving the selection of informants who best satisfy the informational needs of the study. Good informants are those people who possess special knowledge, status or communication skills and are willing to share those skills and knowledge with the researcher. These informants are capable of providing access to information either by giving the information themselves or linking the researcher to the person who can provide information about the phenomena of interest (Crabtree & Miller 1992).

Participants were further identified through the coordinators and counsellors of the PMTCT programme of the chosen MOU. This programme offers women the opportunity to be tested for HIV when they make their antenatal booking at all antenatal clinics and Midwife Obstetric Units in the Western Cape. Women who test positive for HIV are offered the opportunity to participate in the PMTCT programme, to increase the possibility of preventing the transmission of HIV to the foetus. Counsellors selectively approached those women whom they felt were ready to consider being research participants and more receptive to the PMTCT programme. To minimize any sense of obligation or coercion, only after the women had agreed to be interviewed was the researcher introduced to them.

The following aspects were taken into consideration when selection of potential participants was made:

- The length of time the participant had known about her HIV status and accepted the PMTCT intervention. According to Young et al. (2000), most women do not know about their HIV status until the time they are tested at the antenatal clinics. This, as pointed by Baggaley and Praag (2000), may lead to the inability by the woman to accept her HIV status, which in turn requires significant counselling. For this reason pregnant women (of 34 or more weeks of gestation) who had only recently learned of their HIV status and accepted the PMTCT interventions were not included in the study. This applied to those women who had made their first antenatal booking and were first diagnosed with HIV within the late second trimester and the third trimester, or those women who made an early antenatal booking but made a decision to be tested for HIV in order to participate in the PMTCT programme within the late second trimester and the third trimester, hence their recent diagnosis with HIV. Only those women who had known about their HIV status for some time (for example, those who had been tested and diagnosed with HIV on the first trimester or early second trimester) and shown some signs of acceptance, for example, talking willingly about their HIV status or the PMTCT programme were included in the study.
- The willingness of the participant to talk willingly about her own HIV status. As pointed out by Baggaley and Praag (2000), one of the many concerns these women have is confidentiality, as there is stigma attached

to being HIV positive, which may lead to further worries of abandonment by their spouse or partners.

Three women were recruited from one MOU in the Southern Peninsula while they were attending their regular antenatal clinic. The participants ranged in age from 19 to 31 years and were all of African origin. They were all unmarried. One participant was living with her partner (the biological father of her unborn infant) while the remaining two participants lived with their parents although they met with their partners (biological fathers of their unborn infants) regularly. This was a first pregnancy for each participant and they were all beyond 34 weeks of gestation.

One participant had already given birth when the follow-up interview was conducted for clarification purposes, but was able to reflect back on her experience while pregnant.

Two of the women had partially disclosed their HIV status (telling one or two close persons, a relative or a partner but withholding the HIV status from others). The other woman had maintained complete secrecy about her HIV status, and her HIV status was known only to her immediate health care providers.

### **2.2.3 Access to the research setting**

For this study permission was sought and obtained in writing from the following stakeholders before the commencement of the study:

- The health authority under whose jurisdiction the Midwife Obstetric Unit (MOU) resorts.

- The written individual consents of the participants.

#### **2.2.4 Procedure**

The HIV/AIDS counsellors, together with the PMTCT coordinator, selected from their list of women on the PMTCT programme those HIV positive pregnant women whom they felt might be ready to talk about their lives. On coming for their regular antenatal care, these women were taken aside individually by the counsellors who explained the study to them and asked if they were willing to participate. If they agreed to participate, they were referred to the researcher who further explained the study verbally and gave each person an information sheet.

The first meetings, which were mostly ordinary conversations, to build rapport, and to encourage familiarity were conducted at the clinic. The subsequent interviews were arranged thereafter at a mutually suitable place and time.

#### **2.2.5 Rigour**

According to Morse, Barret, Mayan, Olson and Spiers (2002), rigour refers to measures of establishing reliability and validity in qualitative research. They argue that reliability and validity in qualitative research can be substituted with the concept of trustworthiness, which revolves around four dimensions, credibility, transferability, dependability and confirmability.

Guba and Lincoln (1981), cited in Morse et al. (2002, p.2), state that inherent to the four dimensions mentioned above are 'specific methodological strategies for demonstrating qualitative rigour, such as the audit trail, member checks when coding, categorising or confirming results with participants, peer debriefing,

negative case analyses, structural corroboration and referential material adequacy.’

Krefting (1991) describes rigour as different ways that aim to ensure the quality of findings in qualitative enquiry. This includes trustworthiness or merit that can be assigned to that inquiry. For this study, bracketing, intuiting and the measures of trustworthiness were applied so as to ensure rigour.

#### **2.2.5.1 Bracketing**

This involves the self-awareness and self-reflection by the investigator so that any preconceived ideas or opinions regarding the phenomena are not brought into the study as they can cloud and distort the findings so that the true picture is not seen (Brink 1996). For this reason, a further literature review was done after data analysis.

#### **2.2.5.2 Intuiting**

According to Munhall and Oiler Boyd (1993 p.42) intuitive knowledge refers to “knowledge within a person, in the form of insight that becomes present in consciousness: an idea or thought produced by long process of unconscious work. This process of discovery is nurtured through the experience with the world”. The transcripts were read and re-read until the investigator was familiar with them and had the feel of what they were all about. This gave the investigator an “intuitive sense of the whole data as well as the context in which the abstractions will be placed” (Morse 1989 p.49). Intuitive knowledge also helped the investigator to compare and contrast the data and to determine the themes and threads that were revealed by the data (Brink 1996).

### **2.2.5.3 Trustworthiness (reliability and validity)**

According to Brink (1996), this is a measure that looks for truthfulness and accuracy in scientific findings.

Data on the audiotapes was compared for common themes (Katzenellenbogen et al. 1997). In cases where clarification was needed, information taken from the transcripts was taken back to the participants for them to check on the accuracy.

This was also used to promote authentic presentation of the data (Munhall 1994).

## **2.3 Ethical concerns**

### **2.3.1 Informed consent**

A written informed process consent was obtained from the individual participants before the commencement of the study. This means that the study, its purpose and expectations, was explained to the participants before obtaining the written consent. Although the interviews were conducted in English, information sheets and consent forms were made available in the home language of the participant to facilitate understanding.

It was also made clear to the individual participant that she has the right to refuse to participate or to withdraw from participating should she feel like she does not want to continue with the interviews. Participants were further informed that the decision to refuse to participate or to withdraw from the study will in no way affect their obtaining treatment against vertical transmission of HIV.

The participants were assured that they were neither chosen because they were different from the other women who are in the same situation nor for the purposes of harassment or intimidation.

This was a process informed consent, in that whenever the researcher felt that the information being sought was too sensitive or private, the process of informed consent was carried all over again throughout the study. This is in line with Crabtree and Miller (1992) who state that, in its nature, qualitative research places the researcher in the sensitive position with the lives of the participants.

In situations where the participant became distressed during or as a result of the research, the researcher gave support and the interview was managed using good clinical judgement. The participant was offered options for further support and/or counselling through the services provided at the health centre or other service of her choice. Munhall (1994) states that the appropriate personnel or primary caretaker should be made aware of the need for continued support and/or counselling.

### **2.3.2 Confidentiality**

It was made clear to each individual participant that whatever information she gives will be held in strict confidence and that she will remain anonymous unless otherwise specified by her. However, her personal details will be kept in strict confidence so that if she so wishes, the results of the study can be sent directly to her.

Consent for audio-taping the interviews was also sought from each participant before the commencement of the interviews. It was also made clear to the participant that the tapes will be kept in a safe private place where they can only be accessed by the researcher and other authorised persons (for example, supervisor) for transcription and analysis purposes.

No tapes were labelled with the respondent's name. For purposes of identification, numerical codes were used for each participant. After the completion of the study, these tapes will be destroyed.

#### **2.4 Data collection**

A free attitude interview was used as an instrument of data collection. This means that the interviews were treated as a "full blown human interaction" in which the interviewer was open to and used a non-judgmental attitude to anything that emerged during the interview whether it be the meanings or the perceptions which the interviewee gives to the whole experience of undergoing treatment to prevent infecting her unborn baby with HIV (Meulenberg-Buskens 1996, pp. 2-3).

The purpose of the interview was explained to the individual participant so that she understood the reason for the interview. This was also done so as to enable the participants to make choices with regards to the informed consent.

Data collection was built around the following central question:

**Please tell me about your experience of being HIV positive and pregnant and choosing to undergo treatment to prevent your unborn baby from being infected with HIV.**

The rest of the interview flowed from this central question (Katzenellenbogen et al. 1997).

Open-ended questions were used to guide the interviews throughout the study.

The following types of questions/statements were occasionally used as prompts throughout the study:

**How do you feel about...?**

**What is your opinion about that?**

**Go on I am listening.**

These questions, probes and prompts were used as a means of clarification or reflection of what the interviewee said.

Other indirect observations were made to take into account those unspoken things that impacted on the phenomena under study. Field notes were “formatted to enable the researcher to record the observations and to facilitate her reflections on the research process and the simultaneous data analysis process” (Munhall & Oiler Boyd 1993, p.443).

The selected participants were interviewed individually at the agreed upon place. This was at the MOU where a quiet private room, which afforded privacy, was provided for the purposes of the interviews (Katzenellenbogen et al. 1997).

The duration of each interview was approximately one hour. This included any support that was necessary. Data was collected over the period June to August 2002.

#### **2.4.1 Follow-up Interviews**

Follow-up interviews are a means of gathering further information to clarify, verify or provide detail on the data that was collected previously. This gives the interviewer another opportunity to probe or explore responses (School of Information, University of Michigan 2003).

Follow-up interviews were possible for two participants (the third was no longer contactable) in order to check the accuracy of the transcription and for clarification of the transcribed data. One of the participants had already given birth since the main interview. It was however, decided that her information was still important to the study and the transcription was therefore retained in the study.

The purpose of the follow-up interview was explained to the individual participant before it was carried out. The follow-up interviews took approximately 45 minutes to one hour.

## **2.4.2 Data management and analysis**

### **2.4.2.1 Preparation of data for analysis**

Analysis of data commenced as soon as data collection began and proceeded simultaneously throughout data collection (Crabtree & Miller 1992).

### **2.4.2.2 Transcription**

The researcher transcribed data immediately after data collection. Full interviews were transcribed, and notes made regarding non-verbal communication, e.g. long silences and body language, e.g. fiddling or supporting the pregnant abdomen with hands. Sections of the data where the participants used their mother tongue to express themselves better were taken for translation before analysis.

Data analysis was consistent with the phenomenological method. Collaizi's method (in Valle & King 1978, p.59), was used as the basis for analysis, and includes the following steps:

- Reading all the descriptions made by the participant in order to acquire a feel for them and to make a sense of them.
- Extracting significant themes from the data. This means that all the sentences and phrases that are directly related to the phenomena under study were extracted from the data. This was also used to eliminate repetitions.
- Formulating meanings. This involves trying to make out meanings out of the extracted significant statements; “leaping from what the subjects say to what they mean” (Collaizi, in Valle & King 1978, p.59).
- Organising the formulated meanings into clusters of themes. These clusters of themes were then compared with the original data to validate them.

Munhall and Oiler Boyd (1993, pp.443-444) further suggest the following guidelines, which were adhered to in the data analysis:

- “Ponder the meaning of data in parts and as a whole and on repeated occasions.
- Search for repeated instances that support each interpretation.
- Reach for complex interpretations to account for variations in the data: contradictions in the data sometimes call attention to real contradictions in people’s lives.”

## 2.5 Conclusion

This study was conducted within the qualitative paradigm using the phenomenological approach. The aim of this study was to gain insight and understanding of the lived experience of HIV positive pregnant women who are undergoing treatment against vertical transmission of HIV. Participants who met the set criteria were identified through the MOU and the HIV/AIDS counsellors in the MOU. Permission was granted by the MOU for the study to be conducted. Sampling was purposive and relied on good informants.

Data was collected using free attitude interviews. Ethical considerations complied with the principles of informed consent, confidentiality and protection of participants from harm.

Data analysis was consistent with the phenomenological method, which involves reading, or listening to the data extensively until there is an understanding of what it is about. Themes that were related to the phenomena under study were extracted and grouped together. Meanings were formulated from these and put together as clusters of themes that were compared with the original data for validation. These are presented in full in the next chapter.

## CHAPTER 3

### RESEARCH FINDINGS

#### 3.1 Introduction

For the participants in this study, the experience of being HIV positive and pregnant and undergoing treatment to prevent vertical transmission of HIV has been described in five major themes, which are intertwined. These themes are *fear, loss, emotional torment, loss and regaining of self-worth and hope*.

The participants shared these experiences in that they all experienced shock when they first heard that they were HIV positive. This shock resulted in fear of losing control, fear of abandonment on disclosure of HIV status, fear of impending sickness and death and fear of physical and emotional abuse, especially by their partners.

They also shared the experience of loss as recognition of inability to meet previously set goals. Loss, in the form of helplessness or inability to do anything about the situation; loss, as they anticipated an early death, therefore failure to be there for their children as they grow up; loss of their dignity as human beings, and loss through being tricked into the situation by their partners.

Their HIV status also had a significant impact on their self-worth. They all experienced a feeling of loss of self worth, which made them feel as if they were not people anymore and that they did not deserve to live. This situation was reversed when they discovered there is something that could be done and that they

can be involved in the prevention of transmission of HIV to their as yet unborn infants. They also regained their self-worth through participation in the support groups and counselling.

They shared the feelings of emotional torment, shock, disbelief, uncertainty, sadness, confusion and suicidal tendencies, which were triggered by different situations including depression, loneliness, and feelings of betrayal. These feelings seem to be linked to the support they got, especially from the loved ones and the care-givers in that when the support was increased, these feelings of distress were reduced.

They also experienced hope. This was linked to good support structures, for example, the support groups and counselling at the clinics and their participation in the PMTCT program, and the realization that the situation was not hopeless after all. The following dimensions of hope were revealed: hope for living longer until the treatment or cure for HIV/AIDS is available, hope for protecting their as yet unborn infants from contracting HIV/AIDS, hope for achievement of dreams and hope for learning to live with the situation.

## **3.2 Emerging themes**

### **3.2.1 Fear**

Despite the hope that emanated from the realisation that something can be done to prevent the transmission of HIV in utero through the use of Nevirapine, there is still for the woman a persistent nagging fear brought by the realization that there is no turning back on her situation.

The fear was expressed in different dimensions:

- **Fear of losing control**

Despite the courage and strength shown by these women in dealing with their situation they live in constant doubt of their ability to cope when the crucial time arrives (when their babies are born and the time thereafter as they wait for their babies to be tested for HIV). They seemed uncertain of whether they will be able to handle the situation positively and cope regardless of the outcome (whether the baby is born HIV positive or negative).

One woman described this emotional struggle:

*"...having a baby is a very huge, huge responsibility and if I am weak or I start neglecting my baby, not taking care of her because I tell myself that anyway I am gonna die, why should I care, and when I look at the baby I am gonna see maybe an infected baby, maybe the baby is gonna be more sick than the other babies, somehow I am gonna start neglecting my baby or thinking negatively about my baby." [P1 follow up]*

Another woman stated:

*"I told myself that if my baby lives and I die, people will take care of her knowing that she is not HIV positive because she has been treated, if she is not HIV positive, so after they test her I will know if she is HIV positive or not." [P2]*

- **Fear of abandonment on disclosure of HIV status**

Fear of disclosure seemed to be related to their uncertainty about the reactions the disclosure may provoke. They mostly feared abandonment, scorn and ridicule as well as the emotional and economic implications of their HIV positive status.

*“...I can’t tell my boyfriend because if I tell him he will run away and he will not support the baby...” “...I went home but I couldn’t tell my family.<sup>1</sup> But I am not worried, but when I am sleeping I am very worried because I don’t know what’s happening in my life.”*  
[P3]

*“In my family, only my mother knows but she is very supportive and she said that I must take one step a day, maybe to tell my sisters or my brothers, or if, whenever I felt comfortable tell them, maybe after I give birth...”* [P1]

There was also a feeling that disclosure may elicit mockery, ridicule and scorn.

- **Fear of impending sickness and death**

Despite their hope and acceptance of the reassurances that being HIV positive does not necessarily mean “the end of the world”, these women experienced a constant and nagging fear of the inevitable sickness and death that would be the consequence of their situation. This sometimes brought to their minds the issue of whether clinging to life and making the most of it was worthwhile in the face of the impending doom, or whether they should just let everything go.

*“My worries are about that time when I get sick. That part. I know I’m gonna lose weight. Getting all those coughs...”* [P1]

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<sup>1</sup> Family in this context refers to family of origin, that is, blood relatives and people who are married. This excludes cohabitation.

*“...If ever I am dying then I will see that day that I have to stop...” “...I don’t know what is going to happen to me then. I can’t decide for what I don’t know.” [P2]*

In some cases that fear stemmed from the uncertainty of whether there would be sufficient support at this stage. One participant said:

*“...If I am very ill my mother won’t be able to help me because she is too old...” [P3]*

Another participant said:

*“...So I must just tell them so that if I get sick, they should know how to take care of me”. [P1]*

Because of the uncertainty of what the future holds, especially the impending illness and inevitable death, these women expressed a desire for euthanasia (mercy killing) from their carers rather than go through the process of dying.

*“...I want to tell the doctor that if I am seriously ill with the HIV, I will tell the doctor to give me the injection, to give me an injection and to die then...” [P3]*

*“... I don’t need to stay a long time then because I know I must die...” [P3]*

- **Fear of physical or emotional abuse especially by the partners**

While close relatives (especially mothers) were supportive, even though they were disappointed when they were told of the situation (except for one woman who had not told anyone), the partners (the biological fathers of the two women who had disclosed their HIV status to their partners) showed denial, anger and disbelief when told about the situation. This may indicate that the fathers knew of their own

HIV status before fathering the babies. These women experienced fear of physical and emotional abuse from their partners. Any discussion with partners on the matter provoked angry responses, denial, and thus the women feared a violent response if they tried to pursue the discussion.

*“...I told him just to accept facts and take precautions for his life, that’s all, but I don’t want to press him too much because its like he gets very, he gets very angry. And just now I can cope much easier because he is not here. He works out of town. I can think more clearly and see things more clearly”. [P1]*

*“...he didn’t want to listen. He made everything hard for me about the baby and things like that...” [P1]*

*“He doesn’t even care about it because he says I am not HIV positive...” [P2]*

A participant described experiencing fear of discussing the issue of HIV/AIDS with her partner because their baby looked healthy and she was uncertain and scared of her partner’s response.

*“He doesn’t even care about it because he says I am not HIV positive. When he sees the medicine he says it’s for the baby. I tell him that it’s for treating her that she cannot be HIV positive, then he says I am lying, the baby wouldn’t be so healthy. The baby seems so much healthy and she is healthy. She can’t have that thing.” [P2]*

### **3.2.2 Loss**

The losses experienced by women in the study were portrayed in a number of ways:

- **Shattered dreams**

The participants experienced a sense of loss as for them being infected with HIV meant giving up whatever plans they may have had for the future as they might not be able to achieve those goals.

*“...I did have a life but I spoilt it or whatever...” [P1]*

*“...I had dreams but now those dreams seem like they won't ever happen because I know that I am going to die...” [P2]*

- **Helplessness**

These feelings of loss together with the feeling that nothing was worth pursuing anymore left them helpless and feeling that they were failures in life, that their productive life had passed them by. They experienced the feeling that there was nothing they could do anymore.

*“...I am already infected so I must just accept one day at the time just...” [P1]*

*“When I first heard that I am HIV positive I wanted to kill myself and I thought it was the end of the world...” [P2]*

- **Losing out twice on life**

For these women, there was a feeling that they had lost out twice on life. It was not only they who were facing the consequences of being infected with HIV, their as yet unborn infants may also be infected with HIV. If infected, they would be faced with the same challenges as their mothers, which made the situation even more unbearable for the participants.

*“...I would feel more comfortable if I was not pregnant so that I know that I am alone in that, but now my child, my family, eh, its very confusing.” [P1]*

*“...maybe if I was not pregnant, maybe things would be different...”*  
*[P1]*

There was the sense of loss of options, because of being HIV positive themselves, to see their babies grow up. They experienced this as a two-way loss. Loss, as they would miss the developmental milestones of their babies and the perceived loss that their as yet unborn infants would have when they (as mothers) were no longer there.

*“...Also for me it will give me time to see my baby. Maybe the first step of my baby when my baby is walking. And taking the baby to school and things like that. Maybe my baby would be, you see, I will get the chance to see my baby grow up.” [P1]*

Another woman said:

*“...so I told myself that I have to learn to live with it so my baby would have a mother...” “...I have to take care of my baby 'cause when I die, no one would take care of her...” [P2]*

- **Loss of dignity as human beings**

The participants also experienced loss of their natural status as human beings. For them, being pronounced HIV positive was the same as being denounced as being no longer human beings. They felt that once diagnosed as being HIV positive, they lost their status as human beings. They sensed that what people see when they look at them was the HIV, not the person.

*“...I went for counselling and support group at the hospital and I saw that there are people who have this and they didn’t kill themselves but they learned to live with it, so I told myself that I have to learn to live with it so my baby would have a mother, so I tried and afterwards I felt like a person, so there is no need to kill myself...” [P2]*

Another participant said:

*“By believing it, it means I must accept it. That’s the best thing, the main thing. I must accept it and I have accepted it. I must now be able to look after myself, to take all those necessary precautions. Everything that will give me a day extra to my life. So that I get more worthy of living...” [P3]*

- **Loss by betrayal**

There is the betrayal by a partner who, although he knew he was HIV positive, he chose not to tell the woman.

*“...He already knew but he was so unfair not to tell me...” [P1]*

*“...So he is very stubborn. That’s when I told myself that he is the one who gave me AIDS because in the process of talking I heard that he knew he had AIDS but he didn’t want to accept it, like to him its like he doesn’t want to accept anything that comes to AIDS...” [P1]*

### 3.2.3 Loss of self-worth and regaining of self-worth

- **Loss of self-worth**

The first encounter with the antenatal clinics is for many women a good experience, but for these women it was a shock as they discovered they were HIV positive. They experienced a sudden loss of self-worth, almost as if they were not human beings anymore and did not deserve to live anymore.

*“When I first heard that I am HIV positive, I wanted to kill myself and I thought it was the end of the world because I knew that one day I am going to die...” [P2]*

*“Yah it is different because when, ah, before, I told myself that I want to be something. I had dreams but now those dreams seem like they won't ever happen because I know I am going to die...” [P2]*

*“I am like, the drug for me is a starting point of being positive about your life 'cause if there was no drug, maybe I was going to think more negatively than I feel now...” [P1]*

However for the women who were able to get beyond this, there was a sense of purpose.

*“...so I told myself that I have to learn to live with it so my baby would have a mother, so I tried and afterwards I felt like a person, so there is no need to kill myself...” [P2]*

*“...But at least when the sister explained to me that the drug is not actually clearing the disease but its giving me more time, then I should take that time and use it oh, positively...” [P1]*

- **Regaining of self-worth**

Those moments of deep depression (especially those early days after being told of their HIV status) heralded feelings of worthlessness which were gradually replaced by regaining of self worth on discovery that they could do something positive about the situation (taking treatment to prevent their unborn babies from being infected with HIV). They regained a sense of purpose in life.

*“...I went for counselling and support group at the hospital and I saw that there are people who have this and they didn’t kill themselves but they learned to live with it, so I told myself that I have to learn to live with it so my baby would have a mother, so I tried and afterwards I felt like a person...” [P2]*

*“...To me to be able to do something about it. I feel great. Because even if I was negative, having a baby is something special, you see, so having to do something good like that, that could cure my baby from HIV, and at least it will have a good life and its nice for me.”*

*[P1]*

Self worth was also regained by the realization that HIV/AIDS does not necessarily deprive one of the natural status of being a woman, thus being able to reproduce and to take charge of the process. The realization that they could still perform duties as mothers despite being HIV positive gave them a considerable sense of self-worth.

One participant expressed her feelings:

*“To me having a baby is special. Having a baby growing inside me, it’s a miracle, its nice. Like having a picture of yourself, even though*

*you gonna get sick, or you gonna maybe die. At least there will be something that you left in this world.” [P1]*

She recognises the importance of time:

*“...Also for me, it will give me time to see my baby. Maybe the first step of my baby when my baby is walking. And taking the baby to school and things like that. Maybe my baby would be, you see, I will get the chance to see my baby grow up.” [P1]*

Another woman stated:

*“...We are all going to die whether you are positive or not but you must let your baby be taken care of because if you do the testing and find out that you are positive, you must go for the treatment and there are chances that she can be treated well and she cannot be positive...” [P2]*

### **3.2.4 Emotional torment**

Each participant experienced conflicting and painful emotions as they struggled to make the best of their situation. These emotions had the effect of making life an unbearable daily ordeal, which they must endure, making them feel worthless

They experienced emotions of shock, disbelief, uncertainty, sadness confusion and suicidal tendencies.

- **Shock**

All the participants stated that their first reaction on receiving the news that they were HIV positive was shock. They had never suspected that they could be HIV positive. They knew of the existence of HIV/AIDS, knew of others with

HIV/AIDS, but this did not in any way prepare them for their own diagnosis of being HIV positive.

*“...I was shocked (in a loud seemingly crushing tone) and then I was crying because I didn’t know in my life that I was HIV positive...” [P3]*

*“...It was difficult because I was shocked. I was shocked and I couldn’t believe it...” [P1]*

*“...I thought it was the end of the world...” [P2]*

The participants felt like they were in a roller-coaster, as a series of destructive emotions impacted their lives.

*“...I don’t know what’s happening in my life”. [P3]*

For this woman, the shock led to confusion, sadness and loss of control over her situation.

- **Disbelief**

Disbelief or the denial of the existence of the problem became one of the coping mechanisms for these women. These seemed to prevent total disintegration of composure.

*“ ...I must just accept it because the sooner I accept it, the more easier it is for me because if I go on denying it and not taking advises or medical treatment, it will spoil me and the baby...” [P1]*

- **Uncertainty**

The participants also experienced uncertainty that seemed to dominate almost all areas of their lives. They did not know what would happen next. This made whatever plans they may have had for the future seem somewhat blurred or

uncertain. Each day they waited for the tragic moment to occur (sickness and the inevitable death).

*“...I must accept one day at a time just...” [P1]*

Or for this participant:

*“...If ever I am dying, then I will see that day that I have to stop, but I will continue with my studies. If I pass then I will do my...I don't know what is going to happen to me then. I can't decide for what I don't know”. [P2]*

- **Suicidal tendencies**

The participants also experienced suicidal tendencies, which seemed to be more pronounced at the initial stages of knowing about their HIV status. With counselling and support groups offered at the health centres these suicidal tendencies reached a plateau and then gradually declined but never really disappeared completely, re-occurring when things got tough (when they don't get enough support). One woman described this experience:

*“When I first heard that I am HIV positive, I wanted to kill myself and I thought it was the end of the world because I knew that one day I am going to die. I don't know when but I know that I am going to die...” [P2]*

She was able to get through this phase:

*“...and I saw that there are people who have this and they didn't kill themselves but they learned to live with it, so I told myself that I have to learn to live with it so my baby would have a mother...” [P2]*

The emotional torment was aggravated by the fact that they had to face difficult circumstances on a daily basis. They faced scorn or ridicule of persons who are HIV positive, by others who were unaware of their HIV status. All around them were reminders of their HIV status.

*“...You can’t avoid it even though you sometimes try to. Like it’s everywhere in the news, everywhere you go. Some people make fun because they don’t know you have it. So you must just be strong everyday and everyday, because everywhere you go people don’t finish talking without talking about HIV...” [P1]*

### **3.2.5 Hope**

Although there was hope, that hope fluctuated with feelings of hopelessness/powerlessness.

The following dimensions of hope emerged:

- **Hope for living longer until the cure for HIV/AIDS is found**

For these women the Nevirapine drug, used to prevent vertical transmission of HIV to their unborn children, was seen as a positive indication that the cure for HIV/AIDS was possible. They clung to this belief as a lifeline to staying alive and seeing their babies grow up:

*“...Maybe there will be a cure after all.” [P1]*

She went on to say:

*Maybe they will find a cure like they found Nevirapine to reduce the spreading of it to the baby. Maybe the lab or... (long silence) ...they will eventually find the cure...” [P1]*

*“I am like, the drug for me is a starting point for being positive about your life ’ cause if there was no drug, maybe I was going to think more negatively than I feel now...” [P1]*

She hoped that this will help her to stay focused and healthy:

*“...Everything that will give me a day extra to my life...” [P1]*

- **Hope for protecting the unborn baby from HIV/AIDS and its possible consequences**

Nevirapine was regarded as a lifeline for their unborn babies, as it offered them hope of protecting their unborn babies from HIV/AIDS. It was a chance of life and a chance to give their children a bright future without HIV/AIDS.

*“...Hmmm, like it will give the baby more time to grow, yes. Maybe it will not die at a very young age. Maybe the baby will get the experience of going to school...” [P1]*

The hope helped the women to keep going:

*“...don’t give up because there are possibilities that your baby can be cured...” [P2]*

The treatment created the possibility that the infants would be HIV negative. There was hope that they would be spared the suffering of stigma and rejection which the participants themselves have experienced.

*“I told myself that if my baby lives and I die, people will take care of her knowing that she is not HIV positive because she has been treated, if she is not HIV positive...” [P2]*

Hope was also about protecting their babies from economic difficulties after their own death, that they would have an acceptable standard of living and not be a burden to their guardians.

*“...Then I will start banking the money now to support my baby when I am gone.” [P3]*

*“...I must create a plan, how I am going to leave my child. I must start having a job soon, and keeping money so that if maybe anything happens to me or the child, my family is not going through the hell of...(did not finish sentence).” [P1]*

- **Hope for achievement of dreams**

Their dreams, at first shattered by their diagnosis with HIV and its implications, were reawakened when the participants discovered that there was something that could be done to minimise the risk of transmission of HIV to their babies. They also discovered a new meaning to their life, which enabled them to begin dreaming and hoping again. Finding a reason to live became a strong motivating force in their lives.

*“...I believe that everyone has a reason or a purpose of living...”*  
*[P1]*

*“ ...The first thing is for you to find a reason to live. It can be your family, it may be your child, it can be something, maybe that you were planning to do before you knew you were positive. Maybe you were planning for a degree. You just have to think of that degree and*

*see yourself that you achieve it, so that everyday that you live, so that everyday that you live, you live for something.” [P1]*

*“...I want the mothers to be to know that if you go for testing and you find that you are HIV positive, don't give up because there are possibilities that your baby can be cured, so take the risk for her and not for yourself...” [P2]*

- **Hope for learning to live with the situation**

Hope was also learning to make the best out of a difficult situation. It helped to meet with others who are coping.

*“...I went for counselling and support group at the hospital and I saw that there are people who have this and they didn't kill themselves but they learned to live with it...” [P2]*

Another woman stated:

*“By believing it, it means I must accept it. That's the best thing, the main thing. I must accept it and I have accepted it...” [P1]*

### **3.3 Conclusion**

The participants' experience of being pregnant and HIV positive and undergoing treatment against vertical transmission of HIV emerged under the following themes, which were interrelated: fear, loss, emotional turmoil, loss and regaining of self-worth and hope. These themes brought to light a series of emotional adaptations that the participants had to make as they learned to live with the knowledge of their HIV positive status and its implications for themselves and their (then) unborn infants. Their world was different, they hoped to move from a

place of fear and loss to a place in which they could re-establish their sense of self, find meaning and purpose. This was obvious as they found hope in the treatment which offered the chance of life for their as yet unborn babies, even if they might not be there to see them through adulthood.

In the next chapter, I will discuss these findings in relation to relevant literature.

University of Cape Town

## CHAPTER 4

### DISCUSSION

#### 4.1 Introduction

In many cultures, especially the traditional cultures, pregnancy is considered a rite of passage for a woman. This gives the woman's social status a higher level, that of being a mother. Although pregnancy comes with certain responsibilities and obligations, these are mostly viewed in a positive light as enhancing the woman's social standing. Pregnancy and childbearing gives her certain privileges, which she cannot otherwise get as a childless woman. Pregnancy to many is viewed as a joyous occasion, which signifies or celebrates womanhood (Bedimo, Bessinger & Kissinger 1998).

While Saunders and Robbins (1989) describe pregnancy as a moment of crisis, they also acknowledge that over time identities change and new roles are acquired and explored. Bedimo et al. (1998) share this view, stating that childbearing is viewed as 'an element of social identity and self-esteem'. They also state that 'apart from being the source of pride, self expression, or womanhood, child bearing and mothering may be the only way a woman can rise to the ranks of adult status and accomplishment in the society' (Bedimo et al. 1998, p.176).

## 4.2

### **Discussion of the emerging themes**

The findings of this study, as described in full in the previous chapter, have emerged as five themes, *fear, loss, emotional turmoil, loss and regaining of self-worth and hope*, which will be discussed in relation to other literature in this field.

The findings in this study highlight some of the emotional dilemmas and challenges faced by HIV positive pregnant women who are undergoing treatment against vertical transmission of HIV.

In this study the participants did not know that they could be HIV positive until their first booking at the antenatal clinic. They were faced with the challenge of deciding whether or not to have an HIV test to find out their HIV status, and if the test was positive, face the challenge of accepting treatment in the hope of preventing vertical transmission of HIV to the foetus, or to choose not to be tested and avoid the knowledge and perhaps the stigmatisation and scorn from partner, family and community.

Young et al. (2000) in their pilot study carried out at Khayelitsha to prevent vertical transmission of HIV using antiretroviral drugs, found that most women who come for antenatal care for the first time were not aware of their HIV status. The women chose to know their HIV status for the sake of their babies. This suggests that, to them, saving their babies lives was much more crucial than trying to preserve their own psychological well being by remaining ignorant of their HIV status. This also suggests that while the need to know one's HIV status and that of the partner is crucial before engaging in unprotected sex and ultimately falling pregnant, for some people this may still be a difficult challenge.

The participants in this study described having experienced turbulent emotions, which ranged from those that were self-destructive to those that were positive and enabled them to cope with their situation. They experienced self-destructive emotions on first hearing that they were HIV positive. These were replaced by positive emotions such as hope as they learn to live with their situation.

Miller (1987) found that when first being told of their HIV positive status, people experience turbulent emotions, which range from shock to disorientation.

A statement made by one of the participants interviewed by Miller reflects this:

*“When I first discovered that I was antibody positive I felt shock and disorientation. I woke up in the mornings shaking, had problems sleeping, and lost my appetite. I wrote a will, drank heavily and seriously considered suicide. I thought, like others, I was bound to develop AIDS” (Miller 1987, p.21)*

Self destructive emotions such suicidal ideation, fear, denial, loss of self-worth and loss of control may be linked to how people in general view persons who are infected with HIV. The participants may have related the above experience of stigma and non-acceptance or rejection to themselves, which in turn may have the potential to affect their economic and social standing in the community.

Issiaka, Cartoux, KY-Zerbo, Tiendrebeogo, Meda, Dabis and Van de Perre (2001) suggest that dependence on partners for economic sustenance greatly influences HIV positive women’s decision not to disclose their HIV status for fear of rejection and abandonment. According to Bedimo et al. (1998), most people who are infected with HIV come from minority groups, are mostly women and are often economically disadvantaged. This would suggest that women in this group

may be more dependant on their partners and the findings from my study support this.

The self destructive emotions may also be linked to the realization that they have an incurable condition that may also be passed onto their unborn babies whom they feel do not deserve this burden, and who in turn will experience rejection.

Bedimo et al. (1998) identified two dilemmas of HIV positive women who are undergoing antiretroviral treatment to prevent vertical transmission of HIV:

- On taking the antiretroviral treatment, which offers a chance of reducing vertical transmission of HIV, the woman may give birth to a healthy child, but there is also the possibility that she may die when the baby is still young and needing her care.
- There is the possibility that her unborn baby may be infected with HIV with the consequent of imminent illness and ultimately death (Bedimo et al. 1998).

#### **4.2.1 Pregnancy as a double challenge.**

For the participants in this study, this was their first pregnancy. Under normal circumstances these women would mainly be concerned about the course of their pregnancy. These might include issues such as wondering whether their unborn babies will be normal or not, whether the babies will be boys or girls, whether the morning sickness will get any better or worse and how painful the labour pains will be.

*"...I'm also scared of having her because it's the first time so I can't have everything balanced on my head at the same time." [P1]*

Pregnant HIV positive women, in addition to these concerns, have to deal with the possibility that they may infect their unborn babies with HIV. Their pregnancy is filled with dread of what might happen to their unborn babies. They constantly worry about their babies getting sick and dying from AIDS.

*"...I tell myself that anyway I am gonna die, why should I care and when I look at the baby I'm gonna see maybe an infected baby, maybe the baby is gonna be more sick than the other babies, somehow I'm gonna start neglecting my baby or thinking negatively about my baby." [P1]*

While feelings of uncertainty and fear may be common in pregnant women, especially in first time pregnancies, these are even more pronounced in women who are HIV positive, as they do not just face problems of pregnancy and parenthood, but are now faced with a life threatening situation for themselves and their as yet unborn babies. They live with a persistent feeling of impending doom, which makes pregnancy for them even more of a challenge.

Despite their taking the drug (Nevirapine) as a measure to protect their unborn babies from being infected with HIV, this protection is not certain as they still have to wait a long time until their babies are nine months old, before they can know whether or not they have passed the virus to their babies. The participants in this study agreed that pregnancy by itself is hard, but coupled with the problems that they have, it becomes almost unbearable.

Corbin, in Stern (1989) found that when women are faced with a chronic illness in pregnancy, their task becomes even more difficult and complicated, as they now have to contend with “normal” risks to themselves as well as to their babies that may be brought on by both the pregnancy as well as the illness. There is also the possibility of illness and death related to the illness.

This has implications for understanding the HIV positive woman’s situation. Pregnancy does not pity them because they have HIV. They still have to go through the physiological changes and discomforts together with the anxieties that go with a normal pregnancy. To them, these physiological changes and discomforts that go with pregnancy become almost insignificant when compared with the emotional torment they have to go through about the possibility of passing HIV to their unborn babies.

This has implications for nursing practice in that, in their efforts to reduce the risk of HIV transmission to their unborn infants and the stresses accompanying this, HIV positive women may overlook the other “normal” complications of pregnancy with the resultant further danger to the developing foetus. The health care workers caring for these women therefore need to be more alert when giving care so they can detect these complications even if they are not reported.

As is true for most pregnant women, these women want to give birth to healthy babies. They feel that to achieve this, they should do anything that promises to offer their babies an opportunity for good health and are therefore willing to take Nevirapine therapy. They are willing to do almost anything as long as it reduces the risk of transmitting HIV to their babies. These suggests that their ability to make choices regarding the treatment becomes compromised as they strive to do whatever they can to protect their unborn infants from being infected with HIV.

This requires empathy and understanding from health professionals as they give care to these women.

There is a recognition for the women that they are unlikely to be able to care for their children until they are self-sufficient and they want to arrange for guardians for their unborn babies. However, they seem to doubt whether there is anyone who can take proper care of their babies as they would do.

They also see their pregnancies as a potential burden for the loved ones who will be left behind to take care of their babies. For this reason they feel it is imperative to make early financial arrangements for their unborn babies even if it means giving up their own dreams. There is a sense of urgency to provide as much as possible while they are still well enough to do so, and that there is no time to waste.

These women also see their pregnancies as a proof of betrayal by their partners. They see the pregnancy as a proof of their own naiveté by believing in their partners and having unprotected sex without considering the possibility of contracting HIV.

#### **4.2.2 Perceived insensitivity from other people and the media**

The findings also suggest that these women perceive other people to be insensitive about their situation. They are more vulnerable to others' insensitivity when people talk about HIV in their presence, especially in casual discussion. Because they fear people's negative responses if they discover that they are HIV positive, they further withdraw into themselves and shy away from sharing their predicament with others. They are suspicious of others and hypersensitive to any

discussion that is related to HIV/AIDS. My findings concur with those of Miller, who stated that people who have only recently learned of their infection with HIV, are usually “acutely self-conscious about their condition” (Miller 1987, p.30).

The perceived insensitivity may also be linked to the blame and scorn that is often directed towards HIV positive people. Women may feel more vulnerable to this blame as they are often seen as vectors of HIV transmission and men as passive victims of HIV transmission. Sacks (1996) cited Schur (1984) and Ickovics and Rolin (1992) to demonstrate how power relations between men and women become reversed in the face of HIV/AIDS. In their view, female sexuality becomes one that is composed of a threat to the health of the man and female sexuality is seen as both unclean and dangerous and prostitution as the driving factor. Male sexuality is seen as normal and men’s suffering becomes of primary concern.

It is often implied in the media and health education materials that HIV/AIDS can be overcome through certain behaviours, which among others include ‘self control’ and ‘good discipline’. This may imply that those who become infected with HIV lack ‘self control’ and ‘good discipline’. ‘Promiscuous or indiscriminate sex as well as drug addiction or inappropriate pregnancy become powerful indices for loss of self-control’ (Alcon 1988, cited in Sacks 1996, p.69).

Nurses, when giving care to HIV positive women should be aware of how delicate their emotions are and be always on the alert for any signs that they could be interpreted as being insensitive. This necessitates empathic responses from nurses when giving care to HIV positive women.

### **4.2.3 Therapeutic support groups**

The findings suggest that while these women get minimum support from the community, they derive maximum support from the support groups that are run at the health centres. The support groups seem to 'give them their lives back'.

The participants in this study reported feelings of giving up on life and suicidal tendencies on first discovering that they were HIV positive. Once they had made a decision to attend the support groups, so as to meet and get encouragement from other people in similar situations, the feelings of giving up on life and suicidal tendencies were replaced by feelings of self-worth and the desire to make the best out of their situation. This has implications for planning of care for HIV positive pregnant women as nurses can play a vital role in facilitating support groups.

Issiaka et al. (2001) found that women living with HIV derived great benefit from support groups as they are able to meet other HIV infected women and are able to share ideas. There is for them the realization that they are not alone in their predicament and that others do accept them.

### **4.2.4 Hope against all odds**

Positive emotions expressed by participants in this study are those of hope and regaining of self-worth. These women cope by learning to live with their situation. As they accept their situation, they are able to let down their defences and to stop blaming themselves. This may be linked mainly to the support they get from the support groups at the health centres.

The findings suggest that hope is the motivating factor for these women to make the best out of their situation. The treatment that they get through the PMTCT

program offers some hope, as it is a lifeline for their unborn infants as it holds the promise of life without HIV. They cannot think of anything better to offer their unborn babies than a healthy life.

Even though these women sometimes regret falling pregnant, as part of the conflicting emotions they experience, they also see the treatment as facilitating their desire to fulfil their need to leave their legacy behind (in the form of a baby) after their own death. This will bring some sense of achievement even though they perceive an early death as inevitable. This confirms their need to be recognised as women, that they still retain the choice to have a baby. For them, this brings some sense of normality as women of child-bearing age who are able to give birth to babies, even though they are HIV positive. Bedimo et al. (1998) pointed out that, when faced with the complications of HIV/AIDS and eventual death, some women may desire to leave their legacy behind so that their partners, their family and the world would remember them.

The participants in this study also believed that by taking Nevirapine to reduce the risk of passing HIV to their unborn babies, they would benefit and live longer even though the health professionals have informed them that this is not true. They also perceived that Nevirapine therapy was part of the search for a cure for HIV/AIDS. This gave them something to hold on to and reduced their sense of helplessness. A study done by Bunting and Seaton (1999) suggests that HIV positive women derive hope from the belief that a cure for HIV/AIDS will be found. They see their task as keeping themselves healthy until the cure is found.

#### **4.2.5 Issues and concerns for the women**

According to the findings, these women had concerns and worries that they lived with everyday. Most importantly they worried about the future of their babies.

They constantly worried about whether or not they will be infected with HIV.

They worried about the future of their children without them after their own death.

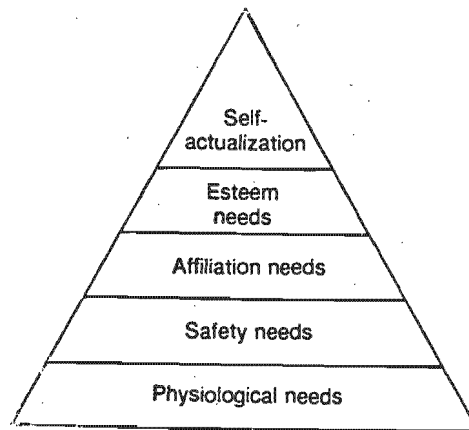
Although they mentioned that they were already making plans regarding finances and guardianship for their babies, this did very little to alleviate the anxieties regarding the future of their babies after their own death.

They also worried about the uncertainty of sickness and death. Although they had heard stories of courage and hope about people who were dying with HIV/AIDS, nothing could prepare them for their own sickness and death. They worry about their families (as they seemed to be the ones who would be faced with most of the practicalities of their sickness and death), whether they would be strong enough to handle the situation when the moment came. As other authors have pointed out, uncertainty about the future was one of the major stressors for people living with HIV/AIDS (Miller, 1987).

### **4.3 Theoretical understanding of the findings**

#### **4.3.1 Introduction**

Further insight can be gained through examining the experience of the pregnant HIV positive woman using the models of theorists such as Abraham Maslow (Maslow's theory of human motivation) and Callista Roy (Roy's adaptation model).



**Figure 1** Maslow's hierarchy of needs (Louw & Edward, 1993).

Abraham Maslow's theory of human motivation consists of five levels of needs (physiological, safety, love and belonging, esteem and self-actualization). These needs are arranged in hierarchical order. The lower level of needs must be satisfied in order for the needs on the next level to be evident and be satisfied. This theory is based on the notion that all human behaviour is motivated by unmet needs. Another notion is that human beings are basically rational and trustworthy and tend to be inclined to love and growth. All these needs are 'prepotent' in that they greatly determine a person's behaviour. A 'prepotent' need for one person may not necessarily be a 'prepotent' need for another person. When one level of need is met, other needs from the higher level arise (Gwynne, 1997).

The physiological level is made up of basic needs, which a person requires for survival on a day to day basis. These are air, water, food, sleep. Failure to satisfy these needs may lead to irritation, sickness or pain and need to be satisfied as soon as possible in order to maintain homeostasis. Their fulfilment becomes crucial for the fulfilment of needs on other levels. The safety level needs are those that motivate one to achieve stability and consistency in the otherwise chaotic world and are psychological in nature. These needs include feeling secure in a home or

family. Love and belonging needs are those needs that motivate one to belong to groups (family, clubs, religious groups, work-groups, gangs). These needs motivate the desire to be loved and accepted by others. Esteem needs motivate the desire for mastery of a task or competence. This results in recognition from others as being competent and able to master a task and is driven by a desire to feel powerful. Self-actualization needs motivate the desire to find the true self so as one's potential can be maximised (Gwynne, 1997).

According to Gwynne (1997), needs vary according to individuals in that what might appear to be a pressing need for one person may not necessarily be a pressing need for another person on the same level. These needs may not be gratified all at the same time.

Maslow's theory can be applied to the experience of HIV positive pregnant women in this study as follows:

As these women discovered their HIV status, they were faced with the challenges of coping at all levels of the Maslow's hierarchy of needs.

- **The physiological level**

The discovery of their HIV status threatened their most basic level of needs, that of the physiological needs level. As indicated in the previous discussion, most women who are HIV positive are economically disadvantaged and depend on their partners (men) for their livelihood. The findings in this study also suggest that these women's partners were not supportive when they learned their HIV status (this applies to the two women who chose to disclose their HIV status to their partners). The disclosure carried with it the threat of abandonment and the subsequent lack of economic support for both themselves and their babies. This in

turn threatened the woman's ability to meet the physiological needs for both herself and her baby.

*"...the sister said to me, ' you must tell because you don't even know your boyfriend' and then I said: no sister, I cannot tell my boyfriend because if I tell him, he will run away and he will not support the baby..." [P3]*

Bedimo et al. (1998) state that women who live in situations where survival needs become much more pressing, put more emphasis on the fulfilment of the immediate, day to day short-term survival needs rather than long term needs. This suggests that measures to prevent being infected with HIV may be sacrificed in order to meet the day-to-day survival needs (for example, having unsafe sex, therefore getting economic support from their partners).

Issiaka et al. (2001) found in their study that the most common reason for HIV positive women not to disclose their HIV status to their partners is fear of rejection and abandonment with the resultant loss of economic support. This decision not to disclose to partners is also motivated by the fear of being seen as unfaithful.

- **Safety needs**

After the discovery of their HIV status, these women's sense of consistency and stability within the home and the relationship with their partners was shattered. Their relationships with their partners and family became dysfunctional as they could no longer relate to their partners, especially regarding matters relating to their HIV status. The women experienced threats and emotional abuse from their partners. The women continually lived "on the edge" not knowing what would

eventually push their partners to the point of physical abuse. Their “lifeworld” became chaotic.

*“...but I don't want to press him too much because its like he gets very, he gets very angry...” [P1]*

*“Like when he was here, he didn't want to listen. He made everything hard for me about the baby and things like that...” [P1]*

According to UNAIDS, (www.unaids.org 11/12/2001) some men, when urged to consider the existence of HIV/AIDS and therefore to take the necessary precautions, may react with anger, violence or abandon their partners.

- **Belonging and love**

This level is motivated by the desire to be loved and accepted and to belong to groups. Threats of abandonment and abuse by loved ones as they shut them out of their lives, adversely affected their sense of being loved and accepted, as they felt like they did not belong anywhere anymore. This was compounded by their sense that, being HIV positive, they are not people anymore. They lost trust in persons who are not HIV positive and felt intimidated by them. They live in constant fear of rejection by loved ones and the whole society, and they feel like outcasts.

- **Self-esteem needs**

As stated earlier, this level is motivated by the desire for competence and mastery of tasks. The participants' HIV status incapacitated this as they felt like failures in life. To them, being diagnosed HIV positive meant that they have failed to achieve their dreams and in their potential as mothers. They experienced an overwhelming sense of worthlessness. Their sense of identity was severely compromised, and they experienced a sense of loss as their HIV status became the

predominant factor in determining who they were as people. For them, there is a real fear that once they disclose their HIV status, they will be known only with respect to their HIV status, and not be acknowledged as human beings in their own right. This created the feeling that they don't deserve to live anymore therefore they contemplated suicide as a way of dealing with their problem.

Quinn (1980, p.20) describes self-esteem needs as identified by Maslow, as comprising of "strength, achievement, mastery, competence, reputation, prestige and dignity", all of which were severely compromised once the women discovered they are HIV positive.

Their reputation was threatened as being infected with HIV is sometimes associated with low moral standards and promiscuity and other non-accepted sexual practices.

Helman (1994, pp.118-119) points out the following as the images or metaphors of AIDS:

- "AIDS as a plague: this may sometimes be referred to as a gay plague and is seen as an "invisible destructive force" which brings with it chaos and negative alterations to relationships and the society as a whole.
- AIDS as a contagion: this view regards AIDS as an invisible highly contagious condition which involves almost any contact with the infected person, be it body wastes, body surfaces, sharing breathing air with an infected person. Infection can occur anywhere, be it the home, the church, work or any social gathering. The infected

person is perceived as being surrounded by “a cloud of poisonous or bad air” which can infect anyone at any time.

- AIDS as a moral punishment: in this metaphor, AIDS sufferers are divided into the innocent and the guilty. The guilty ones are blamed with a "deviant lifestyle". This includes prostitutes, homosexuals, bisexuals and drug users.
- AIDS as war: in this metaphor AIDS is viewed as war against deviant and immoral lifestyles, promiscuity, acquiring foreign lifestyles and stigmatized minority groups like prostitutes, gays, drug users and immigrants (Helman 1994, pp 118-119).

For the participants in this study, their competence to make sound decisions was hampered by confusion, anger and emotional turmoil. Their competence as mothers-to-be who are capable of giving birth to healthy babies was threatened by the possibility of unintentionally inflicting harm on their unborn babies by transmitting HIV to them.

- **Self-actualization**

For the participants in this study, the discovery that they are HIV positive initiated a struggle to find out who they were as they no longer felt like human beings. There is the possibility that due to illness and ultimately death they may not realize their full potential as women and in particular, as mothers.

Quinn (1980, p.20) identifies the following characteristics as defining people who have successfully satisfied the needs on the self-actualization level: "More efficient perception of reality, acceptance of self and others, spontaneity, simplicity and naturalness, problem centering, quality of detachment and a need

for privacy, autonomy, independence of culture and environment, continued freshness of appreciation, peak experiences, deeper, more profound interpersonal relations, democratic character, philosophical, non-holistic sense of humor, creativeness and transcendence of any culture."

The following characteristics which indicate unsatisfied needs at the self-actualisation level will be discussed in relation to the participants in this study: inefficient perception of reality, non-acceptance of self and others, lack of spontaneity, simplicity and naturalness, excessive detachment and need for privacy, lack of deeper and more profound relationships and non-democratic character.

- **Inefficient perception of reality**

The participants' perception of reality became distorted as it was clouded by confusion and disbelief. They felt overwhelmed by the reality of being HIV positive and the implications of the diagnosis for themselves and their unborn babies. In the initial stages, they experienced disbelief and denial as a way of coping, thus escaping reality.

- **Non-acceptance of self and others**

After their diagnosis, it became difficult for the participants to accept themselves as human beings. Instead, they saw themselves as having lost their human identity, and they saw themselves as being no longer fit as individual persons. They saw themselves only as the bearers of HIV and therefore not worthy of living. Their HIV status became a guarded secret, which must not be discovered by others, especially those who are not HIV positive. They also became suspicious of other people, as they lost trust in themselves and others.

- **Spontaneity, simplicity and naturalness**

The women were unable to 'be themselves' and respond in a spontaneous manner as they had to guard their words and actions so as not to alert other people of their HIV status.

- **Excessive detachment and a need for privacy**

The quality of detachment and a need for privacy was carried to the extreme, as they withdrew from others. Depression may be experienced, linked to factors such as:

- The possible transmission of HIV to their unborn babies.
- Certainty of sickness and death.
- The possible distortion of relationships as a result of disclosure of their HIV status.
- Uncertainty about the future for both themselves and their babies.
- Lack of deeper, more profound personal relationships

The major source of support for the participants in this study came from the support groups at the antenatal clinics and close relatives (usually mothers). For them it became difficult to have deep relationships with their partners once their HIV status had been disclosed to them. Their partners seemingly "shut them out" by refusing to discuss the HIV problem and by resisting any mention of it.

- **Democratic character**

This is viewed as forming the defining characteristic for those who have successfully satisfied the self-actualization level needs. For the participants in this

study, the democratic character was adversely affected as they felt compelled to accept almost anything as long as it offered some protection for their unborn babies against HIV. They were overwhelmed by the sense of doing what is right for their unborn babies. Although the decision to participate in the PMTCT programme was not forced, their sense of self-determination became hampered by their sense of duty towards their unborn babies.

It is evident that, when applying Maslow's theory to the experience of pregnant HIV positive woman in this study, the participants found themselves at the lowest levels of the hierarchy and the higher levels, especially that of self-actualization, were perceived as not attainable.

#### **4.3.3 The Roy adaptation model**

The Roy adaptation model is primarily a systems model but it has interactionist elements in its levels of analysis (Roy in Riel & Roy, 1980). In this model, "the person or the patient is viewed as having parts or elements linked together in such a way that force on the linkages can be increased or decreased. Increased force, or tension, comes from the strains within the system or from the environment that impinges on the system" (Roy in Riel & Roy, 1980, p.179).

The person's system in Roy's adaptation model comprises the following four subsystems, the manipulation of which becomes crucial if adaptation is to be achieved: physiologic mode, the self-concept mode, the role function mode and the interdependence relations mode.

Roy's model of adaptation is based on the following assumptions:

- "The person is a bio-psycho social being.

- The person is in constant interaction with the changing environment.
- To cope with a changing world, the person uses both the innate and acquired mechanisms, which are biologic, psychological and social in origin.
- Health and illness are one inevitable dimension of a person's life.
- To respond positively to environmental changes, the person must adapt.
- The person's adaptation is a function of the stimulus he is exposed to and his adaptation level.
- The person's adaptation level is such that it comprises a zone indicating the range of stimulation that will lead to a positive response.
- The person is conceptualized as having four modes of adaptation: physiologic needs, self-concept, and role function, interdependence relations (Roy, in Riel & Roy, 1980, pp.180-182)

The focus of nursing assessment for this model involves two levels. The first level focuses on where the patient is or the state of the four modes of adaptation (physiologic mode, self-concept mode, role function mode and interdependence mode) through the use of objective and subjective data. The position of the patient on the health continuum also forms the first level of assessment. The second level of assessment involves the assessment of the stimuli (focal, contextual and residual stimuli), which influences the behaviour of the person. These two levels of assessment form a basis for a nursing diagnosis, which will therefore form a basis for nursing interventions. Nursing interventions comprise the manipulation of the parts of the person's system or the environment so as to help the patient to adapt (Roy, in Riel and Roy, 1980).

Roy's adaptation model views health as a continuum on which health is at one end and death on the other. Illness is viewed as inevitable, thus the model stresses the importance of adapting positively when faced with the inevitable in order to return to good health (Kershaw & Salvage 1986).

For the participants in this study the health continuum changes as the diagnosis of HIV impacts on their sense of well-being. Their health continuum becomes one of

hope on one end, which represents the best state of health these women can ever achieve, and despair and eventual death on the other end.

- **Adaptive and maladaptive responses**

According to Roy, in Roy and Riel (1980), adaptive and maladaptive responses are described in terms of the “source of difficulty” which is described as “the originating point of deviations from the desired state or condition” (Roy in Riel & Roy, 1980, p.184). A need becomes a requirement for any individual to stimulate a response that is aimed at maintaining integrity. The interaction between the internal and external environments affects the level of satiety, which may result in excess or deficit. These may manifest into either adaptive or maladaptive responses (Roy, in Riel & Roy, 1980).

It is stated by Roy (in Roy & Riel 1980) that the movement along the health continuum is the result of either adaptive or maladaptive responses. In this study, maladaptive responses plunged the participants down towards the despair point on the continuum while adaptive responses moved them up to the point of hope, which becomes the highest level of health for them.

One of the basic assumptions of Roy’s adaptation model is that “the person’s adaptation is a function of the stimulus he is exposed to and his adaptation level” (Roy, in Riel & Roy 1980, p.181). This is a three dimensional model: the focal stimuli which are the stimuli immediately confronting a person, the contextual stimuli which represent all the other stimuli surrounding the person and the residual stimuli which are composed of all the beliefs, traits, attitudes which has an influence on the prevailing situation (Roy, in Riel and Roy, 1980).

Another basic assumption is that "the person's adaptation level is such that it comprises a zone indicating the range of stimulation that will lead to a positive response" (Roy, in Riel & Roy 1980, p.181). This means that, should the stimuli fall within the adaptation zone of the person, the person will be able to adapt positively. On the other hand, should the stimuli fall outside the adaptation zone of the person, that person's ability to adapt positively will be compromised, resulting in maladaptive behaviours.

In applying Roy's adaptation model to the participants in this study, on being diagnosed as HIV positive, it can be seen that they were confronted with the concentration of all the three stimuli (the focal stimuli, the contextual stimuli and the residual stimuli), all of which proved to be outside their adaptation zones as they were not able to adapt positively.

- **The focal stimuli**

For the participants in this study the immediate stimuli which confronted them appeared to be the following:

- They have been diagnosed as HIV positive, which is incurable and [without treatment] progresses to an inevitable end result of sickness and death.
- The possibility that they could pass the same incurable and potentially fatal condition to their unborn babies.

- **The contextual stimuli**

The contextual stimuli in this study seem to be the following:

- Failure to take precautions against HIV/AIDS and taking for granted that their partners are not infected with HIV. These behaviour was influenced by the fact that there was nothing pointing to the fact that they and their partners could be HIV positive since there were no visible symptoms.
- Their age also served as a contextual stimulus. Not only are the participants young, but they did not expect to die so young without being able to achieve their dreams. An example of these dreams could be motherhood, raising their children and completing their studies.
- The uncertainty about the future for both themselves and their babies.
- **Residual stimuli**

In this study the residual stimuli seem to be the following:

- The fact that HIV/AIDS is a condition that bears social stigma, which often results in ridicule and abandonment. This is aggravated by the belief that people are infected with HIV/AIDS as a result of leading immoral lifestyles. An example of this could be prostitution and "abnormal" sexual preferences.
- The fact that people who are infected with HIV/AIDS are more likely to be marginalised by the society. This is further influenced by their own experience regarding sufferings of people who are infected with HIV.

As the concentration of stimuli described above challenged the women beyond their adaptive zones, the most affected modes of adaptation were the self-concept mode, the role function mode and the interdependence mode.

- **The self-concept mode**

Roy in Riel and Roy, (1980) describes this mode as having three dimensions: the physical self, the personal self and the interpersonal self.

- **The physical self**

The anticipation of dying of HIV/AIDS negatively impacted the participants' physical selves as they anticipated the nature of their own death. They associated this with their own experience of helplessness and suffering associated with people who are dying of AIDS. They realized that this is not the kind of sickness and death that normally elicits kindness from people and willingness to help the sick and the terminally ill.

- **The personal self**

The personal self was negatively impacted as these women experienced loss of self-worth, which left them feeling as if they are no longer human beings. They also experienced loss in terms of living longer and loss in failure to realize their dreams. They also suffered emotional turmoil, and developed suicidal tendencies. They experienced frustration at the helplessness of their situation.

- **The interpersonal self**

The interpersonal self was negatively affected as these women withdrew from other people because of the fear of disclosing their HIV status. They become suspicious of other people and were always on their guard so as not to let anything slip that would alert other people that they are HIV positive. They became angry with both themselves and their partners, angry with themselves for failing to take precautions against HIV/AIDS and angry at their partners for not telling them they are infected with HIV.

- **The role function mode**

Roy, in Riel and Roy (1980), describes the role function mode as consisting of two dimensions, role failure and role conflict. Role failure refers to an inability to perform expected behaviours as the role commands. Role conflict refers to a situation whereby the performance of roles does not match the expected role.

- **Role failure**

Being infected with HIV made the participants in this study feel as if they were bad mothers-to-be. These feelings were linked to the guilt of having exposed themselves to HIV and the thought of passing the virus to their innocent unborn babies. A further factor which impacted on perceived role failure was the realisation that they may die and not be able to see their babies grow up and be there for them. They also felt that they have failed their families by not taking precautions and becoming HIV positive and they see both themselves and their unborn babies as potential burdens to their families. The fact that they may not achieve their dreams because of HIV/AIDS aggravated their sense of loss in life. Being lied to by their partners who did not inform them of their own HIV status made them feel like they were not worthwhile as partners.

- **Role conflict**

For the participants in this study, pregnancy and motherhood ceased to appeal as one of life's ultimate attainments, that is, being able to reproduce and take care of one's offspring. As being HIV positive takes precedence, other issues surrounding a "normal pregnancy" (like anticipation of the baby's sex, what the baby would look like, common irritations surrounding pregnancy), became almost insignificant.

They felt rejected and alienated by their partners as they felt lonely and left out to such an extent that they contemplated giving up entirely on life.

- **Adaptive responses**

Certain stimuli seem to have elicited adaptive responses for the participants in this study. This means that the stimuli were moved from outside their adaptive zones to inside their adaptive zones resulting in their ability to cope positively:

- The possibility that their unborn babies may be protected from contracting HIV through the use of Nevirapine to prevent vertical transmission of HIV. This also raised their hopes that the cure for HIV/AIDS may be found.
- The realization that other people have the same problem and they have learned to live with it with desirable results. This motivated them to do the same with their lives.
- The support they get from people close to them (in this case mothers) who give them back their sense of self-worth and the desire to hang on and to make the most of the situation.

Both of these models (Maslow's and Roy's) have relevance in understanding the lived experience of pregnant women who are HIV positive. As both of these models are familiar to nurses in practice, they can be helpful in enabling the nurse to plan care based on sound theoretical understanding of her client or patient's responses and life situations.

#### **4.4 Implications for nursing practice and recommendations for further research**

As reflected by the findings, the participants' problems were mostly psychosocial in nature. This suggests that in order to meet the needs of these women, there was a need for their knowledge empowerment through ongoing counselling and follow-up. While economic empowerment still remains one of the challenges facing women today, the need for economic empowerment becomes even more pronounced for pregnant HIV positive women as they are faced with making economic provisions for their children as their life expectancy is shortened, especially given the current situation of non-availability of anti-retroviral therapy to persons accessing public health services.

The findings in this study may be used to:

- Understand the experiences of HIV positive pregnant women as they reveal their concerns about antiretroviral interventions as well as their medical and social care needs.
- Further build on the Nursing body of knowledge regarding HIV/AIDS and the care of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV.
- Acknowledge the importance of health professionals in supporting pregnant HIV positive women through the PMTCT programme.

#### 4.5 Limitations to the study

Because of the sensitive nature of the study and the stigmatisation of persons infected with HIV/AIDS, it was difficult to find participants who readily talked about their HIV status and how it affected them. Although the PMTCT programmes are highly accessible in the Western Cape, personal concerns resulted in persons declining to take part or initially agreeing to participate but changing their minds at the last minute hence the small sample size. Two major concerns were noted:

- **Confidentiality:** As mentioned earlier in the report, HIV positive women worry about confidentiality because of the stigma surrounding HIV/AIDS. For this reason, the potential participants were reluctant to participate in the study.
- **Distress:** Although the potential participants were carefully selected by the HIV/AIDS coordinators and counsellors by selecting those women who appeared ready to talk about their experience, some of the potential participants decided not to participate in the study because they found talking to another person in addition to those people who already knew their HIV status too much to bear.

Because of the small sample size in qualitative research (and in particular this study, as the focus was on the experience of three women), the findings of this study cannot be considered as generalizable to the general population. They may only be transferable to a similar group. Another limitation is that the study was conducted in English, which is not the first language for both the researcher and the participants. For this reason (although provisions were made such that, if a

participant during the interview wished to use her mother language, this was recorded on the audio-tape and the translation of that section analysed), some information may have been lost in the process. A further limitation is that all the participants in this study were from the low socio-economic group hence the findings of this study may not be transferable to women in other socio-economic groups (high socio-economic group and middle socio-economic group). It would be important to study the experience of HIV positive pregnant women in other socio-economic groups.

#### **4.6 Conclusion**

The aim of the study was to explore the lived experience of pregnant HIV positive women who were undergoing treatment against vertical transmission of HIV. Of particular interest was the understanding of how these women interpret the experience of being pregnant and HIV positive and having to make a decision to take Nevirapine treatment to reduce the risk of transmitting HIV to their babies.

The findings of this study reflect the experience of these women as occurring in five interrelated themes: fear, loss, emotional turmoil, loss and regaining of self-worth and hope. Their experience is influenced by the nature of HIV/AIDS, which is surrounded by stigma with a threat of possible rejection and abandonment. The disease also bears connotations of 'bad' behaviour. The social circumstances of the participants in this study, which puts them at the mercy of their partners for economic support makes them even more vulnerable to HIV/AIDS and its consequences.

HIV/AIDS threatens the life of the woman and her unborn baby who will also suffer the same consequences as the mother, if not successfully treated. This threat diminishes all other alternatives for the woman except taking Nevirapine to help reduce the risk of passing HIV/AIDS to her unborn baby.

For the woman, taking Nevirapine therapy gives hope that the baby will not be infected with HIV/AIDS and indirectly creates hope of a possible cure for HIV/AIDS and the possibility of living longer. The support groups help them to re-focus and make the best out of their situation.

The findings of this study raise questions of whether current health education material achieves that which it aims to achieve in the prevention of HIV/AIDS as some people still do not give priority to preventive measures and the stigma surrounding HIV/AIDS remains one of the greatest worries for those infected with HIV/AIDS.

Despite the limitations of the study, the findings reflect HIV positive pregnant women's experience and concerns relating to accepting treatment to prevent vertical transmission of HIV to their unborn infants. A deeper understanding of the lived experience of pregnant HIV positive women, and the impact of accepting PMTCT interventions, with no certainty of treatment for themselves is required. There is a need for a deeper understanding of the experience of the pregnant HIV positive woman through further research, if quality care that addresses her needs is to be achieved.

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University of Cape Town

**CONSENT FORM**

**RESEARCH PROJECT: THE EXPERIENCE OF BEING HIV POSITIVE AND PREGNANT AND UNDERGOING TREATMENT AGAINST VERTICAL TRANSMISSION OF HIV.**

**INFORMATION**

My name is Esther Nako. I am a student at the University of Cape Town doing Master of Science in Nursing.

The purpose of this study is to understand the lived experiences of pregnant HIV positive women who will be undergoing treatment against to prevent their unborn babies from being infected with HIV.

Participation in this study is voluntary. If you decide not to take part or you decide to withdraw during the course of the study, this will bear no repercussions or affect your having the treatment. Should there be any distress during the study, appropriate support will be given. Your name will not appear anywhere in the study.

**CONSENT FORM**

Esther Nako has explained this study to me. I understand that the information that I will give will remain confidential. I give permission for this interview to be recorded. I understand that should I withdraw from the study, this will not affect my getting the treatment.

Participants signature.....Date.....

Researcher's signature.....Date.....

Witness.....Date.....

## INTERVIEW TRANSCRIPT

**Researcher: Can you tell me in your own words, your experience of undergoing treatment to prevent your unborn baby from being infected with HIV?**

Participant: I'm really willing to go along with these as the sister told me that it reduces the chances of the baby being infected with my HIV. Like the problem has actually happened more with my baby than me, so I'm already infected so I must just accept one day at the time just...I'm also scared of having her because It's the first time so I cant have everything balanced on my head at the same time..

**Researcher: Like you mentioned earlier on, the drug is aimed at preventing your unborn baby from getting HIV, not to cure you.**

**How do you feel about that?**

Participant: It is sad but (silence) at the same time there is a positive way if thinking because, yah..... I did have a life but I spoilt it or whatever but its more like, ah, ah, I am more strong everyday because of my baby. At least it will reduce him or her from getting the HIV. They say that like after 6months it can be totally cured. Then I must just go through with the procedure. So I'm just counting on that, praying of course.

**Researcher: So in your own words how do you see the program, What does it mean to you, knowing very well that its not going to cure you but**

**that It's aimed only at preventing your unborn baby from getting the HIV? How do you feel about that?**

Participant: As I said I feel terrible, I don't know how to explain it. It is terrible, but at the same time I must just accept it because the sooner I accept it, the more easier it is to for me, because if I go on denying it and not taking advises or medical treatment, it will spoil me and the baby, but I would feel more comfortable if I was not pregnant so that I know that I am alone in that, but now my child, my family, eh, It's very confusing.

**Researcher: OK. You are saying that it's very confusing. Can you just explain that?**

Participant: Like I have told my mother and she doesn't seem proud of me, but she has accepted because HIV is something like cough these days. Like its there everyday in the news. You can't avoid it even though you sometimes try to. Like its everywhere in the news, everywhere you go. Some people make fun because they don't know you have it. So you must just be strong everyday and everyday, because everywhere you go people don't finish talking without talking about HIV. Even in the news everyday it's about HIV. And at least it's a start now that it can cure the baby. At least it's a start of something great. Maybe there will be a cure after all.

**Researcher: You are talking of a start of something great. Can you explain that?**

Participant: Maybe they'll find a cure like they found Nevirapine to reduce the spreading of it to the baby. May be the lab or.... (Long silence) they'll eventually find the cure but I am not counting on that.

**Researcher: You are not counting on that?**

Participant: Yah.

**Researcher: What do you mean?**

Participant: Like it has been here for about 5, 6 years now? Like TB. TB was incurable in those days but today you can cure it though treatment. Maybe if it goes through the same path...(hanging sentence) but, so I am just having hope everyday. Everything I do is just to have hope and trust.

**Researcher: OK so you are aware that by taking the drug you are putting your unborn child's life before yours. How do you feel about that?**

Participant: Haaah...(sighs). To me to be able to do something about it. I feel great. Because even if I was negative, having a baby is something special, you see, so having to do something good like that, that could cure my baby from HIV, and at least it will have a good life and its nice for me.

**Researcher: What do you mean by saying that having a baby is something special? What does it mean to you?**

Participant: To me having a baby is special. Having a baby growing inside me, It's a miracle it's nice. Like having a picture of yourself, even though you

gonna be sick, or you gonna, maybe, die. At least there will be something that you left in this world.

Yah.

**Researcher: OK, I am sure after being told about your HIV status; it changed the way you looked at the world. Yah. And that time when you had to decide whether to go for the drug or not. What came to your mind?**

Participant: It was terrible. I was here at the clinic and the first thing that came to my mind was that maybe if I was not pregnant, maybe things would be different. I don't know. But for the sake of my baby I had to be sure because if...(hanging sentence). I took one step at the time and I told my mother. She was disappointed but there was nothing she could have done, surely.

**Researcher: That moment of indecision, you had to decide whether to take the drug or not. What went on through your mind at that time?**

Participant: Ah, I was just confused. I did hear about the drug but I didn't take any notice, but when they told me facially, like, its gonna at least reduce the risk for the baby...(hanging sentence) like now I...(hanging sentence) because if I wasn't pregnant or anything...(hanging sentence). So I thought of my baby first, so I said, ok if maybe it will reduce the risk for the baby, at least it will give the baby time to grow and may be...(hanging sentence). It was difficult to have the drug, but they explained to me how the drug works and it's not a very difficult procedure. It's simple and basic.

**Researcher: You are saying it was difficult. Can you explain that?**

Participant: It was difficult, how can I say. It was difficult because I was shocked, I was shocked and I couldn't believe it but in that situation I told myself that if I don't believe it, it will lead me to wrong perspectives in life. If I do believe it, ok, the first thing I must believe it, then I must accept it then I will take precautions after that. So I first believed it, that I have it and then after that I told myself I must just believe at all costs and take everyday as it comes, not just that now I am HIV positive and I am going to die, or I will be restricted in bed. So I must just live my life at least.

**Researcher: Ok can you just wrap up in your own words? Your experiences.**

Participant: My worries are about that time when I get sick. That part. I know I'm gonna lose weight. Getting all those coughs. My cousin is HIV positive and she was like, she was very bad but she did recover. Not that she was healed, but she did get her strength back again and I spend lots of time with her and she is positive about things in life. I didn't tell her that I am positive but we are very much close so that she talks and she told me that being HIV positive is not something to hide and maybe it's the same thing as all the other people who don't have HIV and it's fortunate for you to know that you have HIV so that you can take precautions, not that you don't. So I get support somewhere, somehow. But the only support that I will need is from myself. If I don't support myself, then the support of other people won't help. So I must just be strong for

myself.....(hesitation) and I have seen people face to face who have HIV, maybe for 5 or 10 years. They are just telling that its basically your diet, how you eat, how you take care of yourself. So if other people can do it, I can also do it...(interruption)... Because if I did hear about it and I said no, they made a mistake, or no, they took another persons blood or maybe I blamed the nurses or I blame everyone, it was not going to be good for me.

**Researcher: How is the world around you? How are people closest to you like?**

Participant: In my family, only my mother knows but she is very supportive and she said that I must take one step a day, maybe to tell my sisters or my brothers, or if, whenever I felt comfortable tell them, maybe after I give birth. So I must just tell them so that if I get sick, they should know how to take care of me.

**Researcher: Does your baby's father know about your HIV status?**

Participant: The thing is ...(shouting) he is the one who didn't tell me. He already knew but he was so unfair not to tell me. So now I told him that I did go to the clinic for HIV testing. He is very, how can I say, he is very, how can I say. He takes everything as a joke I may say, yes, because he was shot, I think it was about a year ago or 8 months ago. So at the hospital they took blood. That's when he heard about it, you see, but he didn't tell me, but after that I told him that I did come to the clinic to book and they took my blood and things like that. So he asked me. What did they say? I told him they took blood for HIV and things like that, so I asked why, and he said that they did

take his blood in the hospital when he was shot, so the doctor started talking about AIDS and things like that. So he is very stubborn. That's when I told myself that he is the one who gave me AIDS because in the process of talking I heard that he knew he had AIDS but he didn't want to accept it, like to him its like he doesn't want to accept anything that comes to AIDS. I told him just to accept facts and take precautions for his life, that's all but I don't want to press him too much because its like he gets very, he gets very angry. And just now I can cope much easier because he is not here. He works out of town. I can think more clearly and see things more clearly.

**Researcher: What do you mean you can think more clearly?**

Participant: Like when he was here he didn't want to listen. He made everything hard for me about the baby and things like that...(long silence). But the only thing that helps me if I feel distracted or maybe sad that day, if I don't talk to a person, I just pray.

**Researcher: Ok, but at least your mother is there.**

Participant: Yah.

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Participants signature.....Date.....

Researcher's signature.....Date.....

Witness.....Date.....

ATT: SHOAEFANG LEISIE

NNUS

REC NO = 107/29

**UNIVERSITY OF CAPE TOWN**



Research Ethics Committee  
Faculty of Health Science  
E46- 26 Old Main Building, Grootte Schuur Hospital,  
Observatory, 7925  
Queries : Xolile Fula  
Tel : (021) 406-6492 Fax: 406-6411  
E-mail : Xfula@curie.uct.ac.za

11 March 2002

**REC REF: 012/2002**

Mrs E Nako  
Nursing Midwifery

Dear Mrs Nako

**THE EXPERIENCE OF BEING HIV POSITIVE AND PREGNANT AND UNDERGOING TREATMENT AGAINST VERTICAL TRANSMISSION OF HIV**

Thank you for submitting your study to the Research Ethics Committee for review.

*It is a pleasure to inform you that the Committee has **formally approved** your study.*

Yours sincerely

**A/PROFESSOR. CR SWANEPOEL**  
**CHAIRPERSON**

University of Cape Town

Forest Hill Mill Court 9

Mowbray 7700

1<sup>st</sup> May 2002.

The Medical Superintendent

Mowbray Maternity Hospital

Mowbray

Sir/Madam

**Re: Application to conduct a study on the lived experiences of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV.**

Sir-Madam,

I hereby request to do a study on the lived experiences of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV at one of your Midwife Obstetric units running this programme.

This study has the potential of building up new knowledge on the experiences of women who are undergoing this programme and promoting quality of care of pregnant HIV positive women who are undergoing treatment against vertical transmission of HIV. Enclosed, receive a copy of approval by the ethics committee of the University of Cape Town

My name is Esther Nako. I am a student at the University of Cape Town doing Master of Science in Nursing.

I hope my application meets with your favourable consideration.

Yours faithfully,

Esther Nako.

ENQUIRIES  
NAVRAE Ms VC Neutt  
IMBUZO

TELEPHONE  
TELEFOON (021) 659 5550  
IFOWUNI

REFERENCE  
VERWYSING  
ISALATHISO

DATE  
DATUM 30 May 2002  
UMHLA

PROVINCIAL ADMINISTRATION: WESTERN CAPE  
**Health and Social Services**  
**MOWBRAY MATERNITY HOSPITAL**

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PROVINSIALE ADMINISTRASIE: WES-KAAP  
**Gesondheid en Maatskaplike Dienste**  
**MOWBRAY KRAAMHOSPITAAL**

---

ULAWULO LWEPHONDO: INTSHONA KOLONI  
**Lezempilo Neenkonzo Zentlalo**  
**MOWBRAY ISIBEDLELE SOBELEKISO**

Dear Mrs E Nako

**RESEARCH PROJECT:**

**Re: THE EXPERIENCE OF BEING HIV POSITIVE AND PREGNANT AND  
UNDERGOING TREATMENT AGAINST VERTICAL TRANSMISSION OF HIV**

Permission is hereby granted for you to commence the above named research / study at  
Retreat MOU.

Please report to Headnurse Sister Smith on Thursday morning 30 May 2002

Thank you for your interest

Yours sincerely

**MISS VC NEUTT**  
**ASSISSTANT DIRECTOR: NURSING**

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**MOWBRAY**  
MATERNITY HOSPITAL / KRAAMHOSPITAAL

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