

**INFLUENCE OF THE HOME ENVIRONMENT ON PREVENTION OF MOTHER TO  
CHILD TRANSMISSION (PMTCT) OF HIV/AIDS**

by

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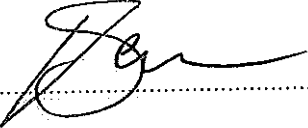
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## DECLARATION

I declare that **INFLUENCE OF THE HOME ENVIRONMENT ON PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) OF HIV/AIDS** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

A handwritten signature in black ink, appearing to read 'Asha', written over a horizontal dotted line.

**SIGNATURE**  
**(Mrs Asha Sewnunan)**

15 June 2013  
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# **INFLUENCE OF THE HOME ENVIRONMENT ON PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) OF HIV/AIDS**

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## **ABSTRACT**

This study aimed at exploring the influence of the home environment of women that were on the prevention of mother-to-child transmission (PMTCT) programme for HIV/AIDS. A qualitative descriptive study was conducted to explore the home environment for the psycho-social support that was available for women on the PMTCT programme and the influence this had on compliance to the programme. Data collection was done using a semi-structured interview guide, with a sample size of 14 participants (n=14). The data was then coded and grouped into categories and major themes.

The findings revealed that the common barriers that prevented full disclosure of an HIV positive status included stigma and discrimination, fear of social isolation and financial dependence. A major constraint that affected the women's full utilisation of the PMTCT preventative strategies and their adherence to treatment was the poor acceptance of people living with HIV in the family and community.

## **KEY WORDS**

HIV/AIDS, prevention of mother-to-child transmission (PMTCT) OF HIV, psycho-social support, barriers to disclosure, stigma and discrimination, home environment, community involvement.

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God bless you all

*This dissertation is dedicated*

*In Loving Memory of my Dearest*

*Dad*

*Mr Rosan Ganasee  
(07/11/1923 - 19/09/2000)*

*and*

*Mom-in-law*

*Mrs C Sewnunan  
16/12/1929 - 14/08/2013*

*Thank you for everything*

*I miss you*

Annexure A

Approval from Ethics Committee – UNISA

Annexure B

Letter Seeking Permission to Conduct the Study

Annexure C

Letter of Consent from Department of Health



Annexure D

Consent Form

Annexure E

Interview Schedule

**CHAPTER 1****ORIENTATION TO THE STUDY**

1.1	INTRODUCTION .....	1
1.2	BACKGROUND TO THE RESEARCH PROBLEM .....	2
1.3	STATEMENT OF THE RESEARCH PROBLEM.....	4
1.3.1	Research questions .....	5
1.4	AIM OF THE STUDY .....	5
1.4.1	Research purpose .....	5
1.4.2	Objectives of the study .....	5
1.5	SIGNIFICANCE OF THE STUDY .....	6
1.6	DEFINITIONS OF KEY CONCEPTS .....	6
1.7	FOUNDATIONS OF THE STUDY .....	7
1.8	RESEARCH DESIGN AND METHODOLOGY .....	8
1.8.1	Research population .....	9
1.8.2	Sample selection .....	9
1.8.3	Sample size .....	9
1.8.4	Data collection .....	10
1.8.5	Data analysis .....	10
1.9	TRUSTWORTHINESS .....	11
1.9.1	Credibility .....	11
1.9.2	Dependability .....	12
1.9.3	Confirmability .....	12
1.9.4	Transferability .....	12
1.10	ETHICAL CONSIDERATIONS .....	13
1.10.1	Protecting the rights of the participants.....	13
1.10.2	Ethics pertinent to the research topic.....	14
1.11	SCOPE AND LIMITATIONS OF THE STUDY .....	14
1.12	STRUCTURE OF THE DISSERTATION .....	15
1.13	CONCLUSION.....	15

**CHAPTER 2****LITERATURE REVIEW**

2.1	INTRODUCTION .....	16
2.2	AN OVERVIEW OF THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV/AIDS PROGRAMME .....	16
2.2.1	What is mother-to-child transmission?.....	17
2.3	THE POTENTIAL RISK FACTORS FOR MOTHER-TO-CHILD TRANSMISSION OF HIV INFECTION .....	18
2.4	PREVENTATIVE STRATEGIES FOR MOTHER-TO-CHILD TRANSMISSION OF HIV INFECTION .....	19
2.4.1	Antiretroviral therapy within the PMTCT context.....	19
2.4.2	Safer obstetrical practices .....	20
2.4.3	Infant feeding options .....	21
2.5	HIV COUNSELLING AND TESTING .....	23
2.6	CHALLENGES EXPERIENCED BY HIV POSITIVE WOMEN.....	24
2.6.1	Socio-economic status.....	24
2.6.2	Vulnerability .....	25
2.6.3	Stigma and discrimination.....	25
2.7	PSYCHOSOCIAL SUPPORT .....	26
2.7.1	Role of the family and the community.....	26
2.8	BARRIERS TO PSYCHOSOCIAL SUPPORT .....	28
2.8.1	Disclosure .....	28
2.8.1.1	Barriers to disclosure .....	28
2.8.1.2	Benefits of disclosure.....	28
2.8.2	Findings on factors influencing male involvement .....	29
2.9	CONCLUSIONS FROM THE LITERATURE REVIEWS .....	29

**CHAPTER 3****RESEARCH DESIGN AND METHODOLOGY**

3.1	INTRODUCTION .....	31
-----	--------------------	----

Table of contents		Page
3.2	PURPOSE AND OBJECTIVES OF THE RESEARCH .....	31
3.2.1	Research purpose .....	31
3.2.2	Research objectives .....	31
3.3	RESEARCH DESIGN .....	32
3.3.1	Qualitative design .....	32
3.3.2	Exploratory design .....	32
3.3.3	Descriptive design .....	33
3.3.4	Contextual design .....	33
3.4	RESEARCH METHOD .....	33
3.4.1	Population .....	33
3.4.2	Sampling and sampling technique .....	34
3.4.3	Data collection .....	35
3.4.3.1	Data collection approach and method .....	35
3.4.3.2	Other data collecting methods used .....	37
3.4.3.3	Characteristics of the data collection instrument .....	37
3.4.3.4	Data collection process .....	38
3.4.3.5	Ethical considerations related to data collection .....	39
3.4.4	Data analysis .....	40
3.5	TRUSTWORTHINESS .....	40
3.5.1	Credibility .....	40
3.5.2	Transferability .....	41
3.5.3	Dependability .....	41
3.5.4	Confirmability .....	42
3.6	CONCLUSION .....	42

## CHAPTER 4

### DATA ANALYSIS

4.1	INTRODUCTION .....	43
4.2	PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS .....	43
4.2.1	Sample characteristics .....	44
4.2.1.1	Age .....	45
4.2.1.2	Highest level of education .....	45
4.2.1.3	Marital status .....	46
4.2.1.4	Duration of current relationship .....	46
4.2.1.5	Religious affiliation .....	47
4.2.1.6	Occupation and economic status .....	47

<b>Table of contents</b>		<b>Page</b>
4.2.1.7	Number of pregnancies .....	48
4.2.1.8	Number of live children .....	48
4.2.1.9	Gestational age of current pregnancy.....	48
4.3	DATA THEMES AND CATEGORIES .....	48
4.3.1	Emotions.....	49
4.3.1.1	Theme 1: Emotional and psychological trauma experienced by participants .....	49
4.3.1.1.1	Shock and sadness .....	49
4.3.1.1.2	Fear and stress.....	50
4.3.1.1.3	Disappointment and anger.....	52
4.3.2	Disclosure of HIV status .....	53
4.3.2.1	Theme 2: Barriers that prevented disclosure of status .....	53
4.3.2.1.1	Selective disclosure .....	53
4.3.2.1.2	Stigma and discrimination.....	55
4.3.2.1.3	Social isolation related to non-disclosure.....	57
4.3.3	Financial problems.....	58
4.3.3.1	Theme 3: Financial challenges experienced by the participants.....	58
4.3.3.1.1	Unemployment.....	59
4.3.3.1.2	Low sources of income .....	59
4.3.4	Social support.....	60
4.3.4.1	Theme 4: Perceptions of psycho-social support.....	60
4.3.4.1.1	Challenges experienced .....	60
4.3.4.1.2	Benefits of social support.....	63
4.3.4.1.3	Experiences of structured support groups .....	64
4.4	OVERVIEW OF RESEARCH FINDINGS .....	65
4.5	CONCLUSION.....	66

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

5.1	INTRODUCTON .....	67
5.2	RESEARCH DESIGN AND METHOD .....	67
5.2.1	Data collection .....	68
5.2.2	Data analysis .....	68

<b>Table of contents</b>	<b>Page</b>
5.3	SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS ..... 69
5.3.1	Emotional and psychological trauma experienced by the participants..... 69
5.3.2	Barriers that prevented disclosure of status..... 69
5.3.3	Limited financial support ..... 71
5.3.4	Perceptions of psycho-social support ..... 71
5.4	CONCLUSIONS ..... 73
5.5	RECOMMENDATIONS ..... 74
5.6	CONTRIBUTIONS OF THE STUDY ..... 75
5.7	LIMITATIONS OF THE STUDY ..... 76
5.8	CONCLUDING REMARKS..... 76
	LIST OF REFERENCES ..... 78

**List of tables****Page**

---

Table 4.1	Demographic information of participants (n=14) .....	42
Table 4.2	Data themes and categories .....	47



## List of abbreviations

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AFASS	Acceptable, feasible, affordable, sustainable and safe
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Anti-retroviral therapy
NDOH	National Department of Health
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
MTCT	Mother-to-child transmission
PMTCT	Prevention of mother-to-child transmission
TBA	Traditional birth attendants
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

## List of annexures

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- |            |                                                |
|------------|------------------------------------------------|
| Annexure A | Approval from Ethics Committee – UNISA         |
| Annexure B | Letter Seeking Permission to Conduct the Study |
| Annexure C | Letter of Consent from Department of Health    |
| Annexure D | Consent Form                                   |
| Annexure E | Interview Schedule                             |

## CHAPTER 1

### ORIENTATION TO THE STUDY

#### 1.1 INTRODUCTION

The HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) pandemic is currently over two decades old and continues to be a leading health challenge worldwide. The highest rate of HIV infections occur in women, babies and children. The commonest route of transmission that contributes to the high rate of HIV positive children under the age of 5 years is the mother to child transmission (MTCT). Mother to child transmission also known as vertical transmission, occurs when an HIV positive woman passes the virus to her baby. This route of transmission can occur during pregnancy, labour, delivery or breastfeeding (Page, Louw & Pakkiri 2006:3).

It is known that the HIV is transmitted, through bodily fluids and can be found in all bodily fluids including breast milk. It is possible for an infected mother to pass the virus on to the baby during birth, through breast-feeding, or through the child coming into contact with the mother's infected blood or blood products. Owing to the fact that mother to child transmission of HIV/AIDS can occur during or after birth, it is important that the mother is well informed about ways to prevent this from happening. The risk can be significantly reduced by good quality ante-natal care such as the prompt treatment of illnesses and the provision of antiretroviral treatment, a birthing process to ensure that the blood of the mother does not come into contact with the baby and ensuring exclusive infant feeding, be it breast feeding or bottle feeding (Whiteside 2008:2).

The South African National Department of Health introduced the prevention of mother to child transmission (PMTCT) of HIV/AIDS programme in 2001. The primary aim of this programme was to decrease the number of HIV infected babies born to HIV positive women (National Department of Health 2010:12).

## 1.2 BACKGROUND TO THE RESEARCH PROBLEM

The South African prevention of mother to child transmission of HIV/AIDS programme was conceptualised in 2000 and has been implemented at pilot sites since 2001, and nationally since 2002. Currently, prevention of mother to child transmission of HIV/AIDS services are offered in 100% of public hospitals and in more than 90% of primary health centres (National Department of Health 2008:12).

As stated by Bicego, Rutstein and Johnson (2003:1235-1247), HIV/AIDS is still a 'family crises' which marks the beginning of the deterioration of the family unit and the trauma in the emotional, psychological and material lives of both the mother and child. The researcher, being a midwifery lecturer, is in contact with patients on a regular basis during the clinical accompaniment of learners in the maternity units. These are some of the questions that came to mind during observations of women in the clinical setting that were on the prevention of mother to child transmission programme: Is there adequate family involvement for women that are on this programme? Are these women receiving adequate support at home once they leave the health facility? During case presentations and discussions with women on the prevention of mother to child transmission of HIV/AIDS programme, it was found that they were afraid to disclose their status to their partners or immediate family members.

According to the latest data from the Joint United Nations Program on HIV/AIDS, almost 60 million people have been infected with HIV/AIDS worldwide. In 2008, an estimated 2.7 million new infections were reported globally, with around 430 000 children born with HIV infection mainly related to mother to child transmission. Sub-Saharan Africa remains most affected by HIV infection, with over 67% of all people living with HIV infection worldwide, and approximately 91% of all new infections are among children. (UNAIDS 2009:2)

According to De Cock, Fowler, Mercier, De Vincenzi and Saba (2000:1175-1182), most children acquire HIV infection through mother to child transmission during pregnancy, labour and delivery or through breastfeeding. In the absence of any interventions, the risk of HIV transmission from mother to child is 15%-30% in non-breastfeeding women. A study by Newell (2005:2) indicates that breastfeeding approximately doubles the risk of vertical transmission in women with established HIV infection. In women that

breastfeed for 2 years, the additional risk of transmission through breastfeeding is approximately 15-20 % more.

These statistics led to questions such as: Are these woman supported regarding compliance to the preventative strategies set out in the prevention of mother to child transmission of HIV/AIDS programme, such as safe sexual practices, adherence to anti-retroviral therapy (ART) treatment and adherence to the infant feeding choices that were made within the prevention of mother to child transmission of HIV/AIDS context? Are these woman forced by the fear of discrimination and stigma to carry out mixed feeding, that is breast milk and formula feeds? Is it the pressure from the in-laws, family and society at large that lack the knowledge regarding prevention of mother to child transmission of HIV/AIDS and are thus not supportive enough? This sentence lacks sense. What is the pressure for? For prevention of mother to child transmission of HIV/AIDS to be successful there is a need to involve of family and significant others to provide the necessary support, which would encourage disclosure and compliance to treatment.

Medley, Garcia-Morena, McGill and Maman (2004:299-300) emphasised that disclosure of HIV status to sexual partners is an important preventative goal. Disclosure would lead to improved access to HIV prevention and treatment programmes, increased opportunities for risk reduction and increased opportunity to plan for the future. Evidence also showed that risk behaviour changes dramatically among couples where both partners are aware of their HIV status.

Although studies show that partner disclosure is a central concept in prevention of mother to child transmission of HIV/AIDS programmes, the findings that partner disclosure is associated with hardship adds evidence to previous studies that have shown that mothers fear for their families' social and economic future should they disclose their HIV status (Njunga & Blystad 2010:48-52).

However, in the context of South Africa where the majority of HIV-positive mothers are young single women who live in extended families, disclosure to the sexual partner alone is not an adequate condition for the success of prevention of mother to child transmission of HIV/AIDS. The optimal utilisation of prevention of mother to child transmission of HIV/AIDS interventions requires the support of the woman's partner and

other members of her family (Igwegbe & Ugboaja 2010:296-301). For prevention of mother to child transmission of HIV/AIDS to succeed, it is important to provide adequate information on prevention of mother to child transmission of HIV/AIDS interventions to the general population, the family, the in-laws, and male partners of HIV-positive pregnant women.

According to UNAIDS (2006), in South Africa close to 1 in 3 women who attend antenatal clinics are HIV positive. In KwaZulu-Natal, one of the worst affected provinces, as many as 40 to 60 % of pregnant women attending antenatal services are living with HIV infection.

To reduce the rate of mother to child transmission the involvement of the partner, family and community play a vital role in providing the necessary physical, emotional, social and financial support needed by the HIV positive women. Disclosure of HIV test results to a sexual partner is an important prevention goal for a number of reasons. This is supported by Kassaya, Lingerh and Dejene (2005:126), that the benefit includes expanding and sharing the burden of helping People Living with HIV/AIDS (PLWHA) beyond professional care providers, providing access for care and support programmes, planning for future care, and enhancing the quality of life of PLWHAs and their partners. In relation to prevention of mother to child transmission of HIV/AIDS, shared confidentiality is considered beneficial in order to prevent unwanted pregnancies and arrest the spread of HIV infection to uninfected partners. Another benefit is in assisting HIV infected women to plan for their future and their partners, to gain access and adhere to therapeutic regimens such as ART, and replacement feeding for infants. This study aimed to establish the link that the home environment has in the contribution to the success of the prevention of mother to child transmission of HIV/AIDS programme.

### **1.3 STATEMENT OF THE RESEARCH PROBLEM**

During contact and discussions with women on the prevention of mother to child transmission of HIV/AIDS programme, the researcher found that many women chose not to disclose their HIV status to their family due to fear of stigma and rejection; hence most women joined a support group within the institution.

### **1.3.1 Research questions**

The following were the study questions:

- What are the factors that influence the home environment of the women on the prevention of mother to child transmission of HIV/AIDS programme?
- What are factors that contribute to the lack of family involvement in the prevention of mother to child transmission of HIV/AIDS programme?
- What support services are available for HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme?
- How can problems experienced within the home environment be improved to contribute to a more successful programme of prevention of mother to child transmission of HI virus?

## **1.4 AIM OF THE STUDY**

The study aimed to establish the link of the home environment and its contribution to the success of the programme for the prevention of mother to child transmission of HIV/AIDS at a Provincial Hospital in KwaZulu-Natal.

### **1.4.1 Research purpose**

The purpose of this study was to explore whether a good home environment could have a positive effect and contribute to a successful prevention of mother to child transmission of HIV/AIDS programme.

### **1.4.2 Objectives of the study**

- To identify and describe the factors that contributed to a home environment that could have a positive effect and contribute to a successful prevention of mother to child transmission of HIV/AIDS programme.
- To explore and describe the challenges of the home environment faced by women on the prevention of mother to child transmission of HIV/AIDS programme.

- To assess the influence and effect that support received within the home environment has for the pregnant women that are on the prevention of mother to child transmission of HIV/AIDS programme.
- To make recommendations regarding the improvement of the home environment, for a successful prevention of mother to child transmission of HIV/AIDS programme.

## 1.5 SIGNIFICANCE OF THE STUDY

The HIV infection rate amongst infants and children continues to increase in KwaZulu-Natal (UNAIDS 2009). The study will identify factors within the home environment that contribute positively to the success of the prevention of mother to child transmission of HIV/AIDS programme, and the reasons for the poor involvement of partners and significant others within the home environment. Lastly, recommendations can be made on how to improve the level of support received within the home environment. This study will also contribute to the existing body of knowledge regarding the psychosocial support needs within the home environment of the women on the prevention of mother-to-child transmission of HIV/AIDS programme.

## 1.6 DEFINITIONS OF KEY CONCEPTS

**Human Immunodeficiency Virus (HIV).** The Virus that causes AIDS by weakening the hosts immune system (Wood 2008:8).

**Acquired Immuno Deficiency Syndrome (AIDS).** It is a collection of diseases and infections caused by HIV that result in damage to the immune system, which eventually causes death (Page et al 2006:2).

**Mother to child transmission of HIV infection (MTCT).** This is also known as Vertical Transmission, and occurs when an HIV positive woman passes the virus to her baby. This can occur during pregnancy, during labour and delivery or during breastfeeding (Page et al 2006:3)



**Prevention of mother to child transmission of HIV/AIDS (PMTCT).** It is a comprehensive strategy to reduce the risk of transmitting HIV virus from mother to child (Page et al 2006:3)

**Partner.** In this study, the partner is of male gender and is either married to, or is sexually involved with the women on the PMTCT programme

**Family.** In the context of this study family includes any person related to the women on the PMTCT programme by birth or through marriage, that the woman is living with

**Stigma.** An attribute that is significantly discrediting and is used to set the affected person or groups apart from the normalised social order, and this separation implies devaluation (*Oxford English Dictionary* 2011:444).

**Home environment.** Aspects of people's domestic lives that contribute to their living conditions, that can be physical, psychological and social

**Psychosocial support.** In this study support refers to the help, strength and encouragement given to the HIV positive women. It can be physical, social, emotional or financial forms of support that are received from the partner, family or community.

## **1.7 FOUNDATIONS OF THE STUDY**

According to Brink (2008:25), assumptions are basic principles that we accept on faith, or assume to be true without proof or verification.

The assumptions for this study were as follows:

- The fear of stigma and discrimination prevented women on the programme from prevention of mother to child transmission of HIV/AIDS disclosing their sero-status to their partners and family.
- The lack of knowledge and awareness of the prevention of mother to child transmission of HIV/AIDS programme contributed to the lack of involvement of family and the community.

- A good, supportive home environment where family members were involved in contributing to the efficacy of the prevention of mother to child transmission of HIV/AIDS programme would definitely result in its success.
- The infrastructure of the institutions and clinics where prevention of mother to child transmission of HIV/AIDS services were delivered were not user friendly and did not encourage the involvement of the partner, family and the community.
- Social, cultural and gender norms did not equip the women to yield power and be in control of their health and reproductive life.
- Women, especially in rural settings that were financially and socially dependent on men, were submissive and obligated to abide by the rules of the household, particularly those of the in-laws. That adversely affected the preventative strategies such as infant feeding, within the context. prevention of mother to child transmission of HIV/AIDS

## **1.8 RESEARCH DESIGN AND METHODOLOGY**

A qualitative, explorative, descriptive and contextual design was used in this study to explore the home environment and determine the support system available to the HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme, and establish the influence that this had on her compliance to treatment. The context of this study was the HIV positive women on the program prevention of mother to child transmission of HIV/AIDS me at a Provincial Hospital in KwaZulu-Natal.

Qualitative research involves an emergent design that is a design that emerges in the field as the study unfolds. It is elastic and flexible. The goal of most qualitative studies is to develop a rich understanding of phenomena as it exists in the real world (Polit & Beck 2010: 258).

In this study the researcher attempts to describe the influence of the home environment on the prevention of mother to child transmission of HIV/AIDS.

### **1.8.1 Research population**

The population of this study includes all women that has been counselled and tested HIV positive, and who have joined the programme for the prevention of mother to child transmission of HIV/AIDS at a Provincial Hospital for the period of this study.

### **1.8.2 Sample selection**

A non-probability sampling approach was chosen for this study. This type of sampling is usually more convenient and economical and allows the study of populations when the researcher is unable to locate the entire population (Brink 2008:131). The type of sampling method chosen for this study was purposive as it allowed the researcher to select the sample based on knowledge of the phenomena being studied. Sampling was done until data saturation occurred and no new data emerged.

The inclusion criteria for this study were:

- HIV positive pregnant women that have been counselled and who are on the programme for the prevention of mother to child transmission of the HI virus and AIDS.
- The women must be residents of the surrounding areas of the Provincial Hospital where the study is conducted and must be booked to deliver at that hospital.
- The women must be 18 years or older.
- These women must have a fairly good command of the English language.

The exclusion criteria were:

- Women that were not on the prevention of mother to child transmission of HIV/AIDS programme.
- Women younger than 18 years of age.

### **1.8.3 Sample size**

According to Brink (2008:136), in qualitative studies where the sample is purposive, too many subjects would cloud the issue and increase the complexity of the analysis

process. For these types of studies, the sample size is adequate when the meanings are clear and data are fully explored.

In this study the researcher intended to use a minimum sample size of 10-15 respondents. However sampling continued until data saturation was achieved.

#### **1.8.4 Data collection**

Data was collected using a semi-structured interview schedule, where Section A comprised of closed-ended short questions for demographic information, and Section B comprised of open-ended questions for the purpose of exploring phenomena related to the topic (Annexure E). Interviews were audiotaped and field notes were made. The central question that was asked was: "Describe your experiences of your home environment and the support you receive from your family and friends?", and this was explored further by using a prepared topic guide which included the following questions:

- Have you disclosed your HIV status?
- To whom did you disclose and how did they react?
- If no, what are the reasons for non-disclosure?
- How does having your partner or a family member involved help you with being on the prevention of mother to child transmission of HIV/AIDS programme?
- If you are not getting support from your family, what are your concerns about the lack of social support?
- What are the factors that prevent family from being involved in the prevention of mother to child transmission of HIV/AIDS programme?

#### **1.8.5 Data analysis**

Qualitative data analysis can be described as the non-numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relations (Babbie 2007:378). Interviews were audiotaped after permission was given by the participants, and they were transcribed verbatim for analysis purposes. Field notes taken during and immediately after the interviews were also used. The researcher analysed the transcriptions by reading the scripts over and over to seek meaning in the data. Data were then grouped into themes and categories. According to

Patton (2002:453), content analysis refers to the searching of text for recurring words or themes.

Data analysis was done manually. The initial analysis included identifying common themes and then linking major themes together under broader categories by checking for word repetitions. Coding was used to organise the data collected, and this was done for all of the recorded information. Coding involved inventing a name or code for the various clusters or categories identified. Once all of the data was coded, the researcher identified the most prevalent ones for each participant, in order to determine the final themes.

## **1.9 TRUSTWORTHINESS**

The aim of ensuring trustworthiness is to address ways to ward off researcher bias in the results of qualitative analysis. Qualitative data analysis requires clear, explicit reporting of data so that the reader will be confident of and can verify reported conclusions (Brink 2008:118).

The four strategies proposed to ensure trustworthiness in this study were credibility, dependability, confirmability and transferability.

### **1.9.1 Credibility**

This is concerned with the accuracy and truthfulness of scientific findings. The researcher asks: “Are the findings credible to the people studied as well as to the readers.” According to Brink (2008:118), the techniques used to achieve credibility include the following:

- Prolonged engagement – remaining in the field over a long period. The researcher planned to continue with data collection until data saturation occurred.
- Triangulation – This is using a variety of sources in data gathering. The researcher made field notes and made a tape recording of the interviews.
- Peer debriefing – where the researcher exposes themselves to a disinterested peer who probes the researcher’s biases, and explores meaning.

- Member checking – where the research participants review, validate and verify the researcher’s interpretations and conclusions. This can be done by periodic feedback sessions, where the results of data collections can be presented to participants to test if they agree with the interpretation.

### **1.9.2 Dependability**

As cited by Brink (2008:118), dependability is concerned with the consistency, stability and repeatability of the informants’ accounts, as well as the researcher’s ability to collect and record information accurately.

In this study, the researcher aimed to ensure that the data quality was checked for bias and that adequate participant checking was done periodically to ensure authenticity. This was done by ensuring that consistency was maintained when questioning and recording information during the interview. The written recording could also be cross-checked with the audiotape by an independent person in order to ensure reliability.

### **1.9.3 Confirmability**

This means that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigators’ interpretation and the actual evidence (Brink 2008:119).

To ensure confirmability, the researcher ensured that the study data was retained and made available for reanalysis by others. The tape recorder and notes would be available for audit by an outside person.

### **1.9.4 Transferability**

This is described as the degree to which the results of a study can be generalised to other settings. Thick description, a term used by qualitative researchers, refers to a rich and thorough description of the research setting and of observed transactions and processes (Polit & Beck 2010:326). This was achieved by ensuring that the study participants and the research design were described in detail. The demographic detail,

as well as the details of the interview and the details of the research design was described thoroughly.

## **1.10 ETHICAL CONSIDERATIONS**

### **1.10.1 Protecting the rights of the participants**

Individuals are autonomous agents that are capable of controlling their own activities. This principle of self-determination means that participants have the right to decide voluntarily whether to participate in a study without any prejudicial treatment (Polit & Beck 2010:122) In this study, participants were informed regarding their right to refuse to participate and that they could withdraw at any stage.

The principle of justice involves the right to fair selection and treatment (Brink 2008:33). This was ensured by the fair selection of subjects that were directly related to the study problem, and not because they were readily available or could easily be manipulated. Participants had to be on the prevention of mother to child transmission of HIV/AIDS programme and willing to be interviewed.

The process of ensuring anonymity refers to the researcher's act of keeping the subjects identities a secret with regards to their participation in the research study. All participants were given a number and this number was used when discussing data, thus ensuring anonymity as no names were used.

Confidentiality was of the utmost importance as the detailed information obtained during data collection was used by the researcher, and no unauthorised person was able to access it. When study results were published anonymity was maintained as no names were attached to any of the results.

The principle of beneficence is the right to protection from discomfort and harm. Participants were protected emotionally. Participants were not forced to divulge information that they did not want to and those that needed help, such as more counselling, were referred appropriately.

Informed consent was obtained prior to commencement of the study. Participants were given full information about why the study was conducted and what the study involved. Consent was voluntary and participants were not forced to participate.

### **1.10.2 Ethics pertinent to the research topic**

The topic of discussion in this study relating to HIV positive women was a personal and emotionally loaded area of discussion. Generally, persons affected by HIV were not readily willing to discuss their details due to the stigma and discrimination that is associated with this disease. The participant that was psychologically affected and was not coping with their status was referred for further counselling to the hospital counsellors. The researcher applied meticulous interpersonal skills during encounters with all participants, thus encouraging open communication. The purpose of the study was explained in detail to gain cooperation. Also, participants were reassured that all information was safeguarded and strict confidentiality and anonymity was maintained, as no names were used.

## **1.11 SCOPE AND LIMITATIONS OF THE STUDY**

The study was context specific to the culture and environment of the participants at this District Hospital and this limited the generalisability of the findings.

The study focused on exploring if there was any support received by HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme outside the health facility. This limited the study to this specific context and it therefore could not be generalised to the broader efficacy of the prevention of mother to child transmission of HIV/AIDS programme.

Another limitation could arise from unnoticed bias that may have arisen from the use of the data collection tool and data analysis due to the inexperience of the researcher conducting the study. Another limitation could result from information bias from incorrect information provided by respondents.



## **1.12 STRUCTURE OF THE DISSERTATION**

Chapter 1: Orientation to the study

Chapter 2: Literature review

Chapter 3: Research design and methodology

Chapter 4: Analysis, presentation and description of research findings

Chapter 5: Conclusions and recommendations

## **1.13 CONCLUSION**

A qualitative approach was used in this study to explore the support received by women on the prevention of mother to child transmission of HIV/AIDS programme, from within their home environment. The aim was to identify the types of support received, from whom the support was received, and the effect that this had on their compliance and adherence to the prevention of mother to child transmission of HIV/AIDS programme. This study was conducted at a District Hospital situated on the South Coast of KwaZulu-Natal, where pregnant women that were on the programme were interviewed. The following chapters will describe the methodology, data analysis and recommendations of the study.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This chapter focused on reviewing relevant literature on the prevention of mother to child transmission of HIV/AIDS and the impact that this epidemic has had on the women, their children and their families. It also looks at the social support that was received by these women, and the reasons for any lack thereof. The literature review highlighted the types, quantities and content of consulted sources, and also the way in which they were acquired.

The general purpose of a literature review is to gain an understanding of the current state of knowledge about the research topic (Johnson & Christensen 2004:61). For this study, literature was reviewed to gain more understanding on the role of the home environment and the support received or the lack thereof, and how this affected the women on the prevention of mother to child transmission of HIV/AIDS programme. The intention was also to identify the factors that contributed to the lack of family involvement and a poor support system.

#### **2.2 AN OVERVIEW OF THE PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV/AIDS PROGRAMME**

In South Africa, the prevention of mother to child transmission of HIV/AIDS Programme was conceptualised in 2000, and has been implemented nationally since 2002. Currently, prevention of mother to child transmission of HIV/AIDS services are offered in all public hospitals and in more than 90% of Primary Health Care Centres (National Department of Health 2008:12).

The primary aim of this programme is to reduce the number of HIV infected babies born to HIV positive mothers. The clinical care guidelines on prevention of mother to child transmission of HIV/AIDS have been reviewed and a few changes have been made to

the drug regimens over the years. Due to constant research in these areas scientists are continuously adjusting and implementing revised preventative strategies.

In 2008, 430 000 children under the age of **15** years became infected with HIV, mainly through Mother to child transmission. Approximately 90% of these MTCT infections occurred in Africa (UNAIDS 2009:12). The most common route for the transmission of HIV is that of, Mother to child transmission which contributes to the high rate of HIV positive children under the age of **5** years old.

The prevention of mother to child transmission of HIV/AIDS Clinical Guidelines (National Department of Health 2010:1) recognises that in order to prevent HIV among women and children, the four core elements are integral. These include:

- Primary prevention of HIV, especially among women of childbearing age.
- Preventing unintended pregnancies among women living with HIV.
- Preventing HIV transmission from a woman living with HIV to her infant.
- Providing appropriate treatment, care and support to women living with HIV and their children and families.

### **2.2.1 What is mother to child transmission?**

Mother to child transmission of HIV infection is also known as vertical transmission, which occurs when an HIV positive woman passes the virus to her baby. This can occur during pregnancy, during labour and delivery or during breastfeeding (Page et al 2006:3). Without treatment, around 15-30% of babies born to HIV positive women will become infected with the HIV virus during pregnancy and delivery. A further 5-20% will become infected through breastfeeding. Mother to child transmission rates of less than 2% are now reported from countries where antiretroviral prophylaxis, elective Caesarean section and refraining from breastfeeding can be applied, while in settings where refraining from breastfeeding is not feasible or safe, or where elective Caesarean section is also not a safe option, peripartum antiretroviral therapy can halve the risk to levels of approximately 10% at 6 weeks post-delivery (Newell 2005:1).

### **2.3 THE POTENTIAL RISK FACTORS FOR MOTHER TO CHILD TRANSMISSION OF HIV INFECTION**

The risk of Vertical Transmission is associated with a high maternal plasma RNA and viral load. The clinical staging and immunological disease progression also increases the risk of HIV transmission to the foetus. The maternal immune status is measured as the CD4 cell count. A lowered CD4 cell count results in a greater risk of the disease progressing and risk of transmission to the foetus.

Currently women that have a CD4 cell count of 350 cells/mm<sup>3</sup> or less are commenced on lifelong Antiretroviral Therapy (ART) within 2 weeks, and if the CD4 count is more than 350 cells/mm<sup>3</sup>, then they continue on the prevention of mother to child transmission regimen of Zidovudine (AZT) and a single dose of Nevirapine (sdNVP). (National Department of Health 2010:14-15).

Women who have reached the advanced stages of HIV infection require a combination of antiretroviral drugs for their own health. This must be taken every day for the rest of a woman's life and is highly effective in the prevention of mother to child transmission of HIV/AIDS.

Increased transmission has also been associated with prematurity, prolonged duration of the rupture of membranes and vaginal delivery. Maternal viral load is the strongest independent predictor of mother to child transmission. Intra partum transmission of HIV may occur through direct contact of the infant with the virus present in the genital tract. Breastfeeding doubles the risk of vertical transmission, especially in women with established HIV infection and in populations where breastfeeding continues into the second year. Breast milk RNA viral load is associated with plasma viral load. The risk of transmission through breast milk also depends on the child's age at complete cessation of breastfeeding, the stage of maternal disease, breast health and feeding modalities (Newell 2005:2).

## **2.4 PREVENTATIVE STRATEGIES FOR MOTHER TO CHILD TRANSMISSION OF HIV INFECTION**

### **2.4.1 Antiretroviral therapy within the PMTCT context**

The simplest of all prevention of mother to child transmission of HIV/AIDS drug regimens was tested in the HIVNET 012 trial, which took place in Uganda between 1997 and 1999. This study found that a single dose of Nevirapine (NVP) given to mothers at the onset of labour and to the baby after delivery halved the rate of HIV transmission. As it is given once only, single dose Nevirapine (sdNVP) is relatively cheap and easy to administer. A concern about the sdNVP was developing drug resistance. Therefore; there is a general agreement that sdNVP should only be used when no alternative prevention of mother to child transmission of HIV/AIDS drug regimen is available. Whenever possible, women should receive a combination of drugs to prevent HIV resistance problems and to decrease mother to child transmission rates even further (Stringer, Ekouevi, Coetzee, Tih & Creek 2010:293).

In November 2009, the WHO published revisions to its international guidelines that made more efficacious and complex drug regimens to prevent mother to child transmission of HIV. The regime implemented in KwaZulu-Natal consisted of AZT from 28 weeks of pregnancy and an sdNVP in labour, with the baby receiving NVP after birth and continuing on a 7 day course of AZT. In April 2010, the South African Department of Health and the National AIDS Council released revised clinical guidelines for the prevention of HIV. These guidelines include Highly Active Antiretroviral Therapy (HAART) for all HIV-infected pregnant women with CD4 cell counts of  $<350$  cells/mm<sup>3</sup>. In patients with a CD4 cell count of  $>350$  cells/mm<sup>3</sup>, AZT 300mg is given 12 hourly from 14 weeks of gestation. In labour, an sdNVP together with a stat dose of TDF (Tenofovir) + FTC (Emitracitabine) is taken and AZT is changed to 3 hourly doses (National Department of Health 2010:19). The infant regime for a woman on the prevention of mother to child transmission of HIV/AIDS programme includes NVP at birth and then daily for 6 weeks, and is continued as long as breastfeeding is done or until babies have tested negative at the 6 weeks check-up (Doherty, Sanders, Goga & Jackson 2010:63-67).

ART is one of the main focuses of the prevention of mother to child transmission of HIV/AIDS programme, but this alone will not make the difference in reducing the rate of mother to child transmission of HIV infection. Continuity of treatment at home needs to be supported by the family and community to ensure compliance and adherence to treatment. Routine follow up and counselling will assist the process of compliance, together with psychosocial support.

#### **2.4.2 Safer obstetrical practices**

An elective Caesarean section before the onset of labour and rupture of membranes significantly reduces the risk of transmission compared with vaginal and emergency Caesarean section deliveries (Newell 2005:1-5). In HIV positive women, a Caesarean section may be done to protect the baby from direct contact with the mother's blood and other body fluids. An elective Caesarean section can reduce the rate of Mother to child transmission by up to 50%. However, there is a need to weigh the risk of HIV transmission against the risks for the mother, for example, anaesthetic complications, post-operative complications and the risk of obstetrical complications during a subsequent pregnancy.

If the mother is on a combination of ARVs then a caesarean section will often not be recommended because the risk of HIV infection will already be very low. Caesarean section may be recommended if the mother has a high viral load in her blood. However, elective Caesarean section cannot be recommended as a routine intervention in most developing countries where resources are scarce (De Cock 2000:1847-1848). Rupture of membranes for over 4 hours is associated with an increased risk of mother to child transmission of HIV/AIDS. Therefore, avoidance of a routine artificial rupture of membranes is an intervention to prevent mother to child transmission of HIV/AIDS

Disinfections of the birth canal during labour with microbiocides are an intervention aimed at preventing mother to child transmission of HIV/AIDS infection through reducing exposure of the infant to infective cervicovaginal secretions. The use of chlorhexidine 0.25% where rupture of membranes exceeds 4 hours is associated with improved maternal and neonatal mortality.

Prolonged labour should be avoided as this will also reduce the risk of transmission to the baby. Other interventions that are associated with reducing the risk of mother to child transmission of HIV/AIDS in pregnancy and labour are avoiding all invasive procedures like chorionic villus sampling, amniocentesis and routine episiotomy as this deal with body fluid. Also, routine suctioning of the baby at birth must be avoided as damage to the mucosa can create an entry point for the virus. Thus, only babies needing suctioning at birth must have it done e.g. meconium exposed babies (WHO 2003:13).

### **2.4.3 Infant feeding options**

The new South African prevention of mother to child transmission of HIV/AIDS guidelines state that the programme adopts an approach to infant feeding that maximises child survival and not only the avoidance of HIV transmission. However, it appears that no decision has been made about which feeding practice will maximise HIV-free survival nationally. A choice between two feeding options (exclusive breastfeeding or exclusive formula feeding with free formula milk) is still recommended. The continued provision of free commercial infant formula is an incentive that can cloud feeding decisions (National Department of Health 2010:33). Research from South Africa has already shown that women are opting for formula feeding despite not having met the WHO AFASS (acceptable, feasible, affordable, sustainable and safe) criteria. (Doherty et al 2010:65).

According to Jones, Steketee, Black, Bhutta and Morris (2003:65-71), approximately 1.3 million child deaths per year (13% of deaths of children aged less than 5 years) could be prevented if universal coverage of exclusive breastfeeding was increased to 90% among infants aged less than 6 months. Compared with the use of breast-milk substitutes, breastfeeding has been consistently shown to reduce infant morbidity and mortality associated with infectious diseases in both resource-rich and resource-poor settings, particularly in the first months of life. Infants that are not breastfed, or where there is mixed feeding (breast and formula) have an increased risk of death from diarrhoea and pneumonia (Black, Morris & Bryce 2003:2226-2234).

In the study done by Doherty et al (2010:63-67), it was found that in prevention of mother to child transmission of HIV/AIDS sites across South Africa the inappropriate

choice to formula feed without WHO AFASS conditions being met carries a greater risk of HIV transmission or death than breastfeeding. Contamination of milk bottles with faecal bacteria was found at clinics and in the home. There was also evidence of poor formula preparation, with over-dilution occurring among 47% of home samples.

The prevention of mother to child transmission of HIV/AIDS guidelines recommend that every antenatal visit includes counselling on infant feeding, however several studies in South Africa have found that the quality of this counselling is poor and that AFASS conditions are not taken into account. In the context of weak counselling and unclear messages, the availability of free formula provides an incentive to choose this option, even when it is not appropriate, since free formula can be viewed as a cash transfer to poor households (Chopra, Doherty, Jackson & Ashworth 2005:357-363).

According to the WHO (2009:13-19), recommendations that HIV positive mothers take ARVs during breastfeeding to prevent transmission have been implemented into the prevention of mother to child transmission of HIV/AIDS programmes across South Africa. The challenge of repeated courses of ARVs on mother's health over the course of repeated pregnancies will require close monitoring.

Infant feeding decisions have significant implications for women, in that choosing one method over another may raise questions regarding a woman's HIV status from the partner, family and community. Despite counselling options being tailored to the economic constraints that HIV positive women face, many women prioritise the risk and social consequences of being stigmatised as a "bad mother" or being revealed to be HIV positive when deciding between replacement feeding or exclusive breast feeding for 6 months (Desclaux & Alfieri 2009:821). These are some of the challenges HIV positive women face that adversely affect their continued compliance to either ART or to the most appropriate choices of infant feeding practices.

A study done in Uganda and Tanzania indicated that many women in both these countries were being seen by traditional birth attendants (TBA). As they were the first contact persons during the antenatal period they could play an important role as a source of information about prevention of mother to child transmission of HIV/AIDS services and make appropriate referrals. Instead, it was found that in both countries the TBA's recommended breastfeeding women to introduce solid foods at 6 months and



liquids earlier at 3-4 months, which is not in keeping with the WHO Guidelines on exclusive feeding options. Common beliefs were that water is necessary for quenching thirst or that breastfeeding only will cause hard stools. These are some of the challenges that make it difficult to realise the international feeding guidelines (Harms, Schulze, Moneta, Baryomunusi, Mbezi & Poggensee 2005:258-265).

## **2.5 HIV COUNSELLING AND TESTING**

Antenatal services provide an important point of entry for women to learn their HIV status, especially because women in resource-poor settings often do not encounter the health system until they become pregnant or present themselves at the time of labour and delivery. According to Tarontola and Gruskin (2007:202-203), debates over HIV testing for pregnant women have drawn attention to which testing strategies best support safe delivery and the health and rights of mothers. The UNAIDS/WHO (2007:5) report provides guidance regarding provider-initiated HIV testing and counselling in health facilities, and recommends testing and counselling for all women of unknown HIV status who are in labour.

Approaches which focus on HIV testing during pregnancy also need to consider the ongoing risk of new HIV infection. In some high prevalence areas, pregnant women who initially tested negative later seroconverted while still pregnant or breastfeeding (Moodley, Esterhuizen, Pather, Chetty & Ngaleka 2009:1255-1259).

HIV positive women's desires to bear children can also be affected by testing protocols, the communication of test results and health care workers' attitudes. A study conducted by Oosterhoff, Hardon, Nguyen, Pham and Wright (2008:654-659) in Vietnam showed that if test results are delivered via a community notification system, women fear the violation of their privacy rights and are therefore less likely to seek or receive adequate HIV counselling.

According to the South African National Department of Health Policy Guidelines (National Department of Health 2008:16-23), all women are to be given routine information about voluntary HIV testing. Women are to be offered an HIV test and asked to provide verbal and written consent to the test. A woman can refuse an HIV test, and will then be given routine voluntary HIV counselling and testing options on every

subsequent clinic visit. HIV post-test counselling is to be offered to both HIV positive and negative women. The recent morbidity and mortality reports however indicated that only one third of neonates that were born to HIV positive mothers were receiving antiretroviral therapy. Also indicated in these reports was that half of the neonates that died in the children's wards had an unknown maternal HIV status

## **2.6 CHALLENGES EXPERIENCED BY HIV POSITIVE WOMEN**

### **2.6.1 Socio-economic status**

Women are more likely to be socially and culturally vulnerable to HIV infection because they tend to be economically dependent on men. Due to changes in industrialisation and socialisation there is an increasing number of women headed families. However, most of these families tend to be poorer than those of their male counterparts (Jackson 2002:93).

Osumba (2009:28) describes infected women as "isolated, unsupported, powerless, and invisible, primarily because of their status as women and the fact that the majority of HIV positive women are of colour and poor, which leads to further devaluation.

Jackson (2002:93) revealed that all over the world, women's human rights are violated every day. In many societies women do not have control over their sex lives as they are expected to do what their male partners ask them to do, which often involves unprotected sex. Unemployment is also higher among women than men. This can be attributed to the fact that most women have never been given an opportunity to acquire formal educational qualifications or to work, but have rather to concentrate on what is perceived as women's activities, such as cooking and taking care of children at home.

Power relations in the family consistently give women (especially young women and girls) a low status. Bearing children can increase one's status, but at the same time increases dependency on the extended family. These differences in power and independence inhibit women's capacity to make their own decisions regarding prevention of mother to child transmission of HIV/AIDS and other crucial issues (Skinner, Mfecane, Gumede, Henda & Davids 2005:115-123).

## **2.6.2 Vulnerability**

Many women live in poverty, lack education and economic opportunities, and suffer subordination to men. Many women remain powerless and are afraid to request condom use with their partners as they fear a violent reaction or abandonment by the man on whom they are entirely dependent for survival (Oosterhoff et al 2008:654-659).

Women and young girls also suffer from biological vulnerability. The risk of becoming infected with HIV during unprotected vaginal intercourse is 2-4 times higher for women than men. Women have a larger mucosal surface area exposed to their partner's semen, which has a higher concentration of HIV than the women's vaginal secretions. (Skinner et al 2005:115-123).

## **2.6.3 Stigma and discrimination**

The HIV/AIDS pandemic has always had the challenge of stigma and discrimination attached to this disease. This remains one of the main barriers to the success of the prevention of this disease. In order to receive the support and care that is necessary for the HIV positive woman, she has to first disclose her status. HIV is often associated with behaviours that may be considered socially unacceptable by many people and remains widely stigmatised. The difficulties women face when disclosing their HIV status to their partners can significantly inhibit their use of prevention of mother to child transmission of HIV/AIDS services. Women may reject disclosure as they fear blame, rejection or violence from their partners, including being ejected from their homes (Medley et al 2004:299-307).

According to the UNAIDS (2009:5) report, stigma and discrimination that is experienced by people living with HIV face many human rights abuses from partners, family and the community at large. This barrier discourages individuals from finding out about their HIV status. On the other hand, those that know that they are infected remain silent about their status and continue to infect others and may not seek the necessary care and treatment.

In a study done in Gauteng by Dorkenoo, Gumede, Maluleke and Shaik (2003:20) on pregnant women within the prevention of mother to child transmission of HIV/AIDS

programme, it was found that a stigma persists at the family and community level. Women indicated that their partners and other family members do not support them emotionally. At a time when those infected with HIV really need support the most; those that reveal their status are subjugated to victimisation and discrimination, and in some cases, the revelation has even resulted in their deaths. Community leaders have a key role to play in creating a non-stigmatised environment by focusing on care and support for the HIV positive women within the community (Hollos & Larsen 2008:159-173).

## **2.7 PSYCHOSOCIAL SUPPORT**

### **2.7.1 Role of the family and the community**

Women's decision to participate fully in a prevention of mother to child transmission of HIV/AIDS programme is influenced by the opinions of their partners, as well as other family and community members. Also, this decision is influenced by women's perceptions and fear of possible negative reactions by others. Partners, parents, in-laws and other relatives have varying degrees of influence relating to testing, disclosure and drug treatment, and often have significant authority over infant feeding. If women have to decide on their own and adhere to all the recommended practices, they are going against social norms. An example is infant feeding, where the recommended practice for the HIV positive women is breast milk substitutes or exclusive breastfeeding for 6 months and then early weaning, which are the normative practices. It is therefore difficult to reach most pregnant women with the full package of prevention of mother to child transmission of HIV/AIDS interventions (Peltzer, Skinner, Mfecane, Shisana, Nqeketo & Mosala 2005:26-40).

According to Basset (2002:347), the involvement and support from men is crucial if problem free prevention of mother to child transmission of HIV/AIDS interventions are to be observed. Men need to hear advocacy messages concerning their responsibility for caring for their families, and therefore to support their partners getting comprehensive pregnancy care, including. prevention of mother to child transmission of HIV/AIDS.

In the study done by Peltzer et al (2005:26-40), the dominant response of pregnant women was that people living with HIV/AIDS (PLWHAs) are not accepted by the community and are often spoken about in the community, resulting in other people

avoiding them. Some people are isolated in their own households, where they are not allowed to share the same household utensils with other family members.

Local communities, including faith-based organisations and persons living with HIV, have played a leading role in making prevention of mother to child transmission of HIV/AIDS a priority. In many resource limited settings, non-traditional service providers have taken over key activities such as HIV counselling, support for adherence to treatment, infant feeding counselling, nutrition support and home based care. This has helped relieve health care workers of a growing workload pressure. Local communities can provide essential support to HIV positive mothers who have to choose among infant feeding options. Promoting exclusive breastfeeding and the elimination of mixed feeding (which increases the risk of HIV transmission) can occur within prevention of mother to child transmission of HIV/AIDS services by using close links to community based maternal and child health and nutrition programmes (UNICEF 2008:12).

Community education and awareness campaigns on prevention of mother to child transmission of HIV/AIDS should reinforce male involvement and other family members, particularly mother-in-laws, who have influence over the options open to women who are HIV positive (Dorkenoo et al 2003:20).

A recent study by Harms et al (2005:258-265) indicated that TBAs' knowledge about mother to child transmission of HIV/AIDS and preventative measures was very poor. The TBAs in this study were found to be giving inconsistent and incorrect education and care to these women. The knowledge on the part of health care workers in general had considerable gaps, and was extremely poor in TBAs. Community based resource persons and TBAs have an important role to play in communicating messages, and as a link between the social environment of the women and the health facility. TBAs therefore also need to be trained regarding prevention of mother to child transmission of HIV/AIDS and infant feeding options.

## **2.8 BARRIERS TO PSYCHOSOCIAL SUPPORT**

### **2.8.1 Disclosure**

#### **2.8.1.1 *Barriers to disclosure***

According to Medley et al (2004:300), the most common barriers to disclosure mentioned by participants included the fear of abandonment, rejection, discrimination, violence, the upsetting of family members and accusations of infidelity. Women's fears of abandonment were closely tied to the fear of loss of economic support from a partner. In these settings where resources were extremely scarce and women's access to resources independent of their partner was uncommon, it was not surprising that fear of losing this instrumental support from a partner was a major consideration when deciding whether to share an HIV test result or not.

This non-disclosure in turn lead to lost opportunities for the prevention of new infections and for the ability of these women to access appropriate treatment, care and support services where they were available.

The stigma associated with disclosure leads to negative changes in self-concept and emotional reactions towards those who invoke the stigma. HIV positive individuals are likely to inform their significant others on condition that they perceive that the rewards of the disclosure outweigh the costs. The reasons for non-disclosure are justified by the disclosure's desire to reduce negative consequences, according to Driskell, Soloman, Mayer, Capistrant and Safren (2008:135-156).

#### **2.8.1.2 *Benefits of disclosure***

Serovich, Lim and Mason (2008:25) stated that disclosing an HIV positive status can result in the gain of emotional, physical and social resources. The emotional benefits include social support, relief that comes from sharing a burdensome secret and the built in reward of educating others about HIV.

Nabilek (2009:2) states: "Disclosing one's HIV status may contribute to improved psychological well-being if those disclosed to respond in a helpful manner. It is also

likely that a group of HIV positive individuals could also provide a wide range of valuable resources, both physical and emotional. HIV positive persons can provide information about treatment options, financial assistance, sick care, emotional support and reassurance that one is loved and valued within the community despite their HIV positive status”.

According to the study by Bobrow (2008:54), disclosure of HIV status to sexual partners has many benefits, including: decreased anxiety; increased social support; increased access to prevention of mother to child transmission of HIV/AIDS and to care, treatment and support programmes; the ability to plan for the future; the chance for partners to be tested; and the opportunity to decrease risky behaviours.

### **2.8.2 Findings on factors influencing male involvement**

In a qualitative study on factors influencing men’s involvement in prevention of mother to child transmission of HIV/AIDS in Zambia, Tshibumbu (2006:24) found that the source and order of information flow on new programmes like prevention of mother to child transmission of HIV/AIDS were important for the involvement of men. Men consider themselves traditionally as bringers of health information to the family. If information on prevention of mother to child transmission of HIV/AIDS interventions is first given to women, this information is less trusted by men. Men prefer to receive the information directly from health workers and in gender specific groups, because cultural norms do not encourage mixing of men and women when discussing reproductive health issues. Also, men are less informed than women about mother to child transmission of HIV/AIDS and this disparity in knowledge could be attributed to the place and manner in which information is usually shared, which is mostly by female health workers at antenatal clinics, where men are unlikely to attend. This study also confirmed the importance of involving men in prevention of mother to child transmission of HIV/AIDS services, as women’s uptake of these services is considerably influenced by the attitudes of their male partners.

## **2.9 CONCLUSIONS FROM THE LITERATURE REVIEWS**

The studies referred to in this chapter confirm the influence that a supportive home environment will improve the uptake of the prevention of mother to child transmission of

HIV/AIDS interventions. Barriers of stigma and discrimination, fear of rejection, abandonment and a lack of financial and emotional support still appear to be issues surrounding HIV and the prevention of mother to child transmission of HIV/AIDS programme. It also confirms that women that are HIV positive face many challenges within the home and community environment. This indicates that the more support that a woman on the prevention of mother to child transmission of HIV/AIDS programme receives from significant persons, the better her compliance to the prevention of mother to child transmission of HIV/AIDS interventions will be.



## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **3.1 INTRODUCTION**

In this chapter, the researcher gives an accurate report of the research design and the methodology used in the study. The sampling method chosen as well as the data collection approach used in the study is described. The process that was followed for data analysis is also outlined in this chapter. Measures to ensure trustworthiness were applied, which included the strategies of credibility, transferability, dependability and confirmability.

#### **3.2 PURPOSE AND OBJECTIVES OF THE RESEARCH**

##### **3.2.1 Research purpose**

The purpose of this study is to explore and describe the support systems available within the home environment of an HIV positive pregnant woman, and the influence that this has in contributing to the success of the prevention of mother to child transmission of HIV/AIDS programme.

##### **3.2.2 Research objectives**

- To explore the link between the home environment and the contribution this has on the success of the prevention of mother to child transmission of HIV/AIDS programme.
- To assess the influence that support received within the home environment has for the pregnant and early post-partum women that are on the prevention of mother to child transmission of HIV/AIDS programme.
- To identify the factors that contributes to the prevention of family involvement. To make recommendations, that could improve family involvement for these women, that is based on the research findings.

### **3.3 RESEARCH DESIGN**

A research design refers to a series of decisions made by the researcher as to how the study will be conducted and implemented. The design focuses the researcher on the end product, that is the study as planned, and the results. (Mouton & Prozesky 2005:74). A qualitative, explorative, descriptive and contextual design was selected in this study.

#### **3.3.1 Qualitative design**

Qualitative research involves an emergent design that emerges in the field as the study unfolds. It is elastic and flexible. The goal of most qualitative studies is to develop a rich understanding of phenomena as it exists in the real world (Polit & Beck 2010:259).

Burns and Grove (2005:23) indicate that a qualitative design best promotes understanding of human nature, as narration facilitates understanding of the experience, and gives meaning attached to these experiences. In this study, the researcher was interested in the interactive and subjective nature of this design as it allows the participants to narrate their experiences with regards to the types of support received or the reasons for the lack thereof.

#### **3.3.2 Exploratory design**

Exploratory research seeks to explore a topic or a problem in order to provide familiarity. This also satisfies the researcher's curiosity and desire to understand the phenomena more clearly (Mouton & Prozesky 2005:79-82). In this study the researcher explored the influence of the home environment on the prevention of mother to child transmission of HIV/AIDS programme, in relation to the support or lack thereof that the women received from family and partners, and how this affected them both positively or negatively.

### **3.3.3 Descriptive design**

In descriptive qualitative studies, researchers tend not to penetrate their data in any interpretative depth. These studies present comprehensive summaries of a phenomenon or events in everyday language (Polit & Beck 2010:273). This allows the research participants to narrate their experiences. In this study the researcher describes the participants response by quoting specific narrations that were used to describe the phenomena.

### **3.3.4 Contextual design**

Holloway and Wheeler (2010:193) state that context refers to the setting or the location within which the phenomenon is studied. Specific conditions that may arise and be applicable to actions, time, space and environment are considered. The context of this study is the maternity unit of a public hospital where HIV positive women that are on the prevention of mother to child transmission of HIV/AIDS programme are admitted or seen as outpatients. This hospital is located in Ugu District on the south coast of Durban. It is a district hospital, situated in a rural area and has an average of 250-350 deliveries per month.

## **3.4 RESEARCH METHOD**

### **3.4.1 Population**

Population is described by Polit and Beck (2010:306) as “the entire aggregation of cases in which the researcher is interested” this can also be referred to as the target population, and within this there is accessible population which is composed of cases from the target population that are accessible to the researcher as study participants.

The accessible population for this study included all women that have been counselled and tested HIV positive. They must have joined the prevention of mother to child transmission of HIV/AIDS programme at the Murchison District Hospital for the period of this study.

### 3.4.2 Sampling and sampling technique

Sampling is a subset of people drawn from a larger population considered to be representative of the accessible population, and sampling technique refers to the process of selecting a portion of the population to represent the entire population.

The sampling design chosen for this study was non probability sampling, which is usually more convenient and economical, and allows the study of populations when the researcher is unable to locate the entire population.

The type of sampling method chosen was purposive as this allowed the researcher to select the sample based on knowledge of the phenomena being studied.

In qualitative studies where the sample is purposive, too many subjects would cloud the issue and increase the complexity of the analysis process. For these types of studies, the sample size is adequate when the meanings are clear and data are fully explored (Brink 2008:131-136).

In this study the researcher intended to use a minimum sample size of 10-15 respondents. Sampling continued until data saturation was achieved and no new data emerged. Data saturation was reached at 14 participants.

The inclusion criteria for this study were:

- HIV positive pregnant women that have been counselled and who were on the programme of prevention of mother to child transmission of the HIV/AIDS virus.
- The women must have been residents of the surrounding areas of the Provincial hospital where the study was conducted, and must have booked to deliver at that hospital.
- The women were 18 years or older.
- These women must have had a fairly good command of the English language.

The exclusion criteria were:

- Women that were not on the prevention of mother to child transmission of HIV/AIDS programme.

- No participant was younger than 18 years.

### **3.4.3 Data collection**

Data collection is a process whereby information pertaining to a phenomenon is sourced through instruments such as interview schedules and guides, questionnaires, records, artefacts, observations and field notes. Data collection in qualitative research refers to the collecting of information in the form of interviews because the researcher has interest in other people's stories, and the researcher then has the responsibility to create meaning from the data reflected by the participants (De Vos, Strydom Fouché & Delport 2005:287).

#### **3.4.3.1 Data collection approach and method**

Data were collected using a semi-structured interview schedule utilising closed ended short questions for demographic information and semi-structured open-ended interviews for the purpose of exploring phenomena related to the topic. Interviews were tape recorded and thereafter transcribed verbatim. Babbie (2007:264) describes an interview as a data collection encounter in which one person (interviewer) asks questions of another (respondent

Semi-structured interviews are free flowing with their structure being limited only by the focus of the research. They are conducted more like a conversation but with a purpose. In the semi-structured interview, the interviewer must ask a certain number of specific questions but can also pose additional probes. It includes both open and closed ended questions (Brink 2008:152).

Where clarity was needed, the researcher made use of communication techniques that included:

- Paraphrasing, where the researcher stated words in another form with the same meaning.
- Getting clarity on unclear statements, for example, "Could you expand more about that experience?"

- Reflection, reflecting back on something that was said so that the participant could expand, for example, “So you believe that your boyfriend will leave you?”
- Probing for responses. This is requesting an elaboration and is frequently used in open-ended questions. Probes must be completely neutral and in no way affect the nature of the subsequent response (Babbie 2007:267). Probing was done to persuade the participants to give more data on the issue being discussed and by allowing time for elaboration.

The advantages of interviews include the following:

- Interviews are frequently used in exploratory and descriptive research which is the most direct method of obtaining facts from the respondents (Brink 2008:151).
- Interpersonal interviews conducted on a face to face basis are usually preferred for a relatively small sample. It allows for both closed and open-ended questions (Brink 2008:152).
- It is a useful way of getting large amounts of data quickly.
- Useful when participants cannot be directly observed.
- Allows the researcher control over the line of questioning (Creswell 2009:179).
- Reduces the difficulties related to low literacy levels of respondents, which may be a factor in this study (Burns & Grove 2005:397).

The disadvantages included:

- It was time consuming and thus expensive.
- It was conducted in a designated place rather than a natural field setting. Polit and Beck (2010:341-345) state that there is the possibility of information bias as respondents could give answers just to impress the interviewer.
- This was overcome by rephrasing questions and picking up on non-verbal attributes, as well as ensuring that subjects were well represented and knowledgeable about the questions at hand.

### **3.4.3.2 Other data collecting methods used**

#### **Data recording**

Audio recording was used to ensure that interviews reflected the actual verbatim responses of the study participants. A tape recorder was used after written consent was obtained from the participants that allowed the researcher to record the interview. Written data recording was also done in the form of field notes, where the responses were recorded on the interview schedules.

### **3.4.3.3 Characteristics of the data collection instrument**

The interview schedule had Section A with closed ended questions for the demographic details of the participants. The questions addressed in Section A included the following:

- Age group of each participant.
- Highest level of education.
- Marital status.
- Duration of current relationship.
- Number of persons in household.
- Religious denominations.
- Employment history and sources of income.
- Number of pregnancies and number of live children.
- Gestational age of current pregnancy.

Section B of the guide had open-ended questions that were used to explore and gain more information related to the topic. The researcher's aim was to encourage respondents to talk freely about their experiences of the support received, or the reasons for the lack thereof. The central question asked in Section B of the guide was: "Describe your experiences of your home environment in relation to prevention of mother to child transmission of HIV/AIDS?" and this was further explored by using a prepared topic guide.

Other questions that were included in the prepared guide were:

- Have you disclosed your HIV status to any family member?
- If yes, who and what was their reaction?
- How does having a family member/partner involved help you with being on the prevention of mother to child transmission of HIV/AIDS programme?
- Describe the support that you receive from family.
- If you are not getting support from family, what are your concerns about this lack of support?
- What are the factors that prevent family from being involved in the prevention of mother to child transmission of HIV/AIDS programme?

#### **3.4.3.4 Data collection process**

The data collection process commenced following an Ethical Clearance from the UNISA Health Studies Higher Degrees Committee (Annexure A). Prior to commencing with data collection, permission was also asked and obtained from the KwaZulu-Natal Department of Health Research Committee, as well as from the relevant authorities of the Ugu Health District office and the District Hospital where the data was collected (Annexures B and C).

Participants that were eligible to participate in the study were first selected and the researcher then explained the details of the study and what was expected of them. Those participants that were willing to be part of the study were then taken to a private room where the consent form was read, explained and then signed. Each participant was told that participation was voluntary and that they could withdraw from the study at any time with no adverse outcomes. Confidentiality and anonymity was emphasised as each participant was recorded as a number and no names were used (Annexure D). Permission was also obtained to use a tape recorder during the interview.

A total of 14 participants were interviewed. Probing questions were used to clarify the meanings of responses and to illicit more information. The researcher made field notes during and immediately after the interviews.



### **3.4.3.5 Ethical considerations related to data collection**

Individuals are autonomous agents that are capable of controlling their own activities. This principle of self-determination means that participants have the right to decide voluntarily whether to participate in a study without any prejudicial treatment (Polit & Beck 2010:122). In this study, participants were informed regarding their right to refuse to participate and that they could withdraw at any stage.

The principle of justice involves the right to fair selection and treatment (Brink 2008:33). This was ensured by the fair selection of subjects that were directly related to the study problem and not because they were readily available or could be easily manipulated. Participants had to be on the prevention of mother to child transmission of HIV/AIDS programme and willing to be interviewed.

The process of ensuring anonymity refers to the researcher's act of keeping the subjects identities a secret with regards to their participation in the research study. All participants were given a number and these numbers are used when discussing data, thus ensuring anonymity as no names are used.

Confidentiality was of utmost importance as the detailed information obtained during data collection was used by the researcher and no unauthorised person was able to access it. When study results are published, anonymity will be maintained as no names are attached to any of the results.

The principle of beneficence is the right to protection from discomfort and harm. Participants were protected emotionally. Participants were not forced to divulge information that they did not want to. Those participants that were not coping and needed more help in the form of more information and support were referred to the hospital prevention of mother to child transmission of HIV/AIDS counsellor.

Informed consent was obtained prior to commencement of the study. Participants were given full information about why the study was conducted and what the study involved. Consent was voluntary and participants were not forced to participate.

### **3.4.4 Data analysis**

Qualitative data analysis can be described as the non-numerical examination and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relations (Babbie 2007:378). Interviews were transcribed verbatim. The researcher analysed the transcriptions by reading the scripts over and over to seek meaning in the data. Data was then grouped into themes and categories.

According to Polit and Beck (2010:273), content analysis refers to the searching of text for recurring words or themes. More generally, content analysis is used to refer to any qualitative data reduction and sense making effort that takes volumes of qualitative material and attempts to identify core consistencies and meanings. The core meanings found through content analysis are often called patterns or themes.

The data analysis approach used was content analysis using open coding. The interviews were transcribed and read several times to identify recurring themes and patterns among the themes. Tesch's data analysis approach was chosen. This involved breaking down the narrative data into smaller units, coding and naming the units according to the content represented. The coded material was grouped on the basis of shared concepts and meanings. The themes were then categorised and described, supported with verbatim quotes from the participants. (Creswell, 2009:183)

## **3.5 TRUSTWORTHINESS**

The main aim to ensure trustworthiness was by addressing ways to ward off researcher bias in the results of qualitative analysis. Qualitative data analysis requires clear, explicit reporting of data so that the reader will be confident of and can verify reported conclusions (Brink 2008:118). The four strategies proposed to ensure trustworthiness in this study were credibility, transferability, dependability and confirmability.

### **3.5.1 Credibility**

This is concerned with the accuracy and truthfulness of scientific findings. The researcher asks: "Are the findings credible to the people I am studying as well as to my

readers.” Brink (2008:118) asserted that the techniques used to achieve credibility included the following:

- Prolonged engagement – remaining in the field over a long period. The researcher continued with data collection until data saturation occurred.
- Triangulation – using a variety of sources in data gathering. The researcher made field notes as well as taped records of the interviews.
- Peer debriefing – where the researcher exposed herself to a disinterested peer who probed the researcher’s biases, and explored meaning.
- Member checking – where the research participants review, validate and verify the researcher’s interpretations and conclusions. This was done by periodic feedback sessions, where the results of data collections were presented to participants to test if they agreed with the interpretation. The researcher reflected and summarised the information at the end of the interviews to confirm that the information was interpreted correctly.

### **3.5.2 Transferability**

This is described as a degree to which the results of a study can be generalised to other settings. Thick description is a term used by qualitative researchers which refers to a rich and thorough description of the research setting and of observed transactions and processes (Polit & Beck 2010:492). This was achieved by ensuring that the study participants and the research design were described in detail. The demographic details, as well as the details of the interview and the details of the research design were described thoroughly.

### **3.5.3 Dependability**

As cited by Brink (2008:118), dependability is concerned with consistency, stability and repeatability of the informant’s accounts, as well as the researcher’s ability to collect and record information accurately. In this study the researcher ensured that the data quality was checked for bias and that adequate participant checking was done periodically to ensure authenticity. This was done by ensuring that consistency was maintained when questioning and recording the information during the interview. An

external independent person checked the tape-recording for reliability, and endured that the information was transcribed correctly.

#### **3.5.4 Confirmability**

This means that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigators' interpretation and the actual evidence (Brink 2008:119). To ensure confirmability, the researcher ensured that the study data was retained and available for reanalysis by others. The tape recorder and notes were made available for audit by an outside person to confirm that the data was correct.

### **3.6 CONCLUSION**

This chapter discussed the methodology used to conduct this study of the influence of the home environment on prevention of mother to child transmission of HIV/AIDS

A qualitative, explorative, descriptive and contextual design was used in this study to explore the home environment for the support system available for the HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme. Non probability sampling was chosen to conduct this study. The data was collected using a semi-structured interview schedule. The trustworthiness of data analysis was ensured by implementing the relevant strategies, and a presentation of the plans for further data analysis. The next chapter will focus on the data management and analysis.

## **CHAPTER 4**

### **DATA ANALYSIS**

#### **4.1 INTRODUCTION**

This chapter discusses the analysis and interpretation of data. The purpose of data analysis is to organise order on a large body of information, so that conclusions can be reached and communicated in a research report (Polit & Beck 2010:463). The research results are discussed and supported by published research work from literature, so as to demonstrate the usefulness and implications of the findings. The data was collected with the aim of answering the following questions:

- What is the nature of the support received within the home environment by the women on the prevention of mother to child transmission of HIV/AIDS programme?
- How can problems experienced within the home environment be improved to contribute to a more successful programme for the prevention of mother to child transmission of HIV/AIDS?
- What are the contributory factors that prevent family and community involvement for women that are on the prevention of mother to child transmission of HIV/AIDS programme?

#### **4.2 PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS**

Data were collected during July and August 2012. Data were collected using a semi-structured interview schedule with women that were admitted to the hospital and that were on the prevention of mother to child transmission of HIV/AIDS programme. A total of 14 participants were interviewed as data saturation was achieved and no new data was obtained. Interviews were audio taped after permission was given from those participants, and it was transcribed verbatim for analysis purposes. Field notes taken during and immediately after the interviews were also used. The researcher used communication techniques such as empathy, reflection, probing and clarification during data gathering. The researcher started data analysis by performing bracketing, and

removing all preconceived expectations about the phenomenon under study (Burns & Grove 2005:532).

Topics that emerged were given codes which were written next to each topic to allow for easy retrieval. Topics were then turned into categories, which allowed the grouping together of similar data. Once all the data were coded the researcher identified the most prevalent ones for each participant, in order to determine the final themes. Categories and sub-categories were present in each theme. A co-coder was engaged to analyse the data independently, and consensus was reached regarding the identified categories, sub-categories and themes.

#### 4.2.1 Sample characteristics

The demographic characteristics of each participant are displayed in table 4.1 below.

**Table 4.1: Demographic information of participants (n=14)**

Criteria	Characteristics	Frequency	Percentage
4.2.1.1 Age	18-25years	9	64.3%
	26-30years	3	21.4%
	31-35years	2	14.3
4.2.1.2 Highest level of education	In primary school	5	36%
	In secondary school	5	36%
	Completed Matric/Tertiary college	4	28%
4.2.1.3 Marital status	Single	13	93%
	Married	1	7%
4.2.1.4 Duration of current relationship	Less than 5 years	8	57%
	5-10 years	5	36%
	More than 10 years	1	7%
4.2.1.5 Religious affiliation	Christianity	13	93%
	No response	1	7%
4.2.1.6 Occupation and economic status	Employed	5	36%
	Unemployed	7	50%
	Students and unemployed	2	14%
4.2.1.7 Number of pregnancies	First	4	28%
	Second	5	36%
	Third	5	36%
4.2.1.8 Number of live children	0	7	50%
	1	3	21.4%
	2	4	28%
4.2.1.9 Gestational age of current pregnancy	7 months	1	7%
	8 months	2	14%
	9 months	9	64.3%
	Term (40weeks+)	2	14%

#### **4.2.1.1 Age**

The majority of participant's ages ranged from 18-25 years, which equated to 64.3% of the total and 3 participants that ranged in the 26-30 year group (21.4%), while only 2 fell in the 31-35 group (14.3%).

The youngest participant was 18 years old and the oldest was 35 years old. A study done in Nigeria showed that pregnant women aged between 25 and 35 years were 1.9 times more likely to accept counselling and testing than younger women. The younger unmarried pregnant women were less willing to use HIV counselling and testing and prevention of mother to child transmission of HIV/AIDS services due to fear of the reactions from their families and communities if they tested positive (Okonkwo, Kimberly, Alabi, Umeike & Nachman 2007).

#### **4.2.1.2 Highest level of education**

The lowest grade completed was grade 3 by 1 of the participants, and 2 of them had completed Matric. The same 2 participants have commenced Tertiary education and were still in the process of studying. Only 1 of the 14 participants indicated that they will go back to school after the baby is born to continue with grade 11.

Willis (2002:29) maintained that prevention of HIV should focus on educating young people about sex and sexuality, since it is well known that sex is responsible for more than 85% of HIV transmission.

An individual's level of education has been found to be associated with the likelihood of the acceptance of HIV counselling and testing. A survey in Uganda by Banjunirwe and Muzoora (2005) showed that women educated beyond the seventh grade and literate women were three and two times more likely to accept testing respectively.

Osumba (2009) went further to suggest that low education and literacy could also prove to be a barrier to the access and use of counselling and testing services in the prevention of mother to child transmission of HIV/AIDS programmes.

### **4.2.1.3 Marital status**

Of the participants 93% were single, with only one that was married. Although a few of the relationships were longer than 5 years, no marriages were in the plans. This data clearly indicated that being single did not protect one from contracting HIV/AIDS, but rather increased the risk as long as one was involved in unprotected sexual activities.

According to a study done by Ehlers (2010:21), it was found that receiving sex education after becoming sexually active, might have limited value for younger girls to protect themselves against unplanned pregnancies and sexually transmitted disease, including HIV infections.

### **4.2.1.4 Duration of current relationship**

The most common duration of relationships was 5 years and less, which accounted for 8 of the 14 participants. The shortest relationship was 1 year. Three of the total number of participants was involved with a new partner who is a different father for the current pregnancies.

Four participants had a relationship longer than 5 years, where 2 of them were 7 years long, with no plans of marriage. None of the unmarried participants were living with their boyfriends. The 1 participant that was married was living with her husband. The duration of a relationship does not necessarily indicate faithfulness to each other, and the fact that the participants live away from their boyfriends could contribute to multiple partners. Four of the 14 participants found out that their partner was already HIV positive and knew about it, but only mentioned this when they themselves disclosed to them that they were HIV positive. One participant was infected from a previous relationship and had not disclosed the fact to her current partner. This data confirms that multiple relationships and unfaithfulness among sexual partners contribute to the increased number of HIV infections on a continuous basis. A study done in Zambia by Ngoma and Himoonga (2008:27-35) revealed that female respondents had more sexual partners compared to their male counterparts, which could possibly be attributed to the high poverty levels present, and the need for financial dependence.



#### **4.2.1.5 Religious affiliation**

The majority of participants were Christians, with only one participant specifying the denomination as she was a Jehovah's Witness. One participant had no response and was unsure. Only 2 of the total number of participants went to church regularly.

#### **4.2.1.6 Occupation and economic status**

Out of the 14 participants, only five (36%) had jobs and managed on their incomes. The other participants were unemployed and some of them never really tried to go out and work. Two of them were students still studying but not really financially independent as adults, as they relied on money from family members that were earning low incomes. The data reveals a huge financial problem and poverty. Three of the participants shared their experiences of how little money was sometimes available for food, and that it was very hard to survive. A few of the participants mentioned that their mom or granny had a little vegetable garden that helped to sustain their income and provide food.

The grants that were received seemed to be the majority source of income. Three of the participants relied totally on the pension grants from the "Gogo" or Grandmother, while 2 of them relied on their mother's pension grants. The grants received for previous children of their own or for their sister's children were also the only source of income for 3 of the participants. One of these participants was pregnant with her third child as she was receiving grants for her two other children, and she saw this pregnancy as her means of getting more money. The data revealed that the unemployment rate among the participants contributed to the poor living conditions, poor eating habits and general poverty, and the dependence upon boyfriends that were assisting with any financial aids.

Willis (2002:20) reported that youth, especially females, engage in sexual activities for economic reasons and may engage in unprotected sex with older men. Poverty directly or indirectly creates vulnerability to HIV/AIDS, with a resultant complex and mutually reinforcing inter-relationship between HIV/AIDS and poverty. The majority of the poor are women and they often sell their bodies in order to survive.

#### **4.2.1.7 Number of pregnancies**

Four of the participants were pregnant for the first time, and 5 were having their second babies. Five of them were pregnant for the third time. Out of the 10 multigravida patients, 4 of them were diagnosed HIV positive in the previous pregnancy. This data reveals that being HIV positive does not mean that further pregnancies are avoided.

The risk of transmission to the baby is increased when the CD4 count is low, as was in the case of 2 participants that were on the full regime of antiretroviral treatments. According to the National Department of Health, Clinical Guidelines, women with CD4 cell counts of 350 cells/mm<sup>3</sup> or less and WHO HIV staging of 3 or 4 should receive lifelong antiretroviral treatment, both for their own health and to reduce the likelihood of mother to child transmission (National Department of Health 2010:17).

#### **4.2.1.8 Number of live children**

Five participants were in their second pregnancy, and out of these 5 there were 3 women with no live children. One of them had had her first pregnancy terminated by an abortion, one had had a miscarriage, and the other had lost her child as a result of diarrhoea and vomiting below one year of age. There was 1 woman that was pregnant for the third time but had no live children due to pregnancy losses from abnormalities, and this current pregnancy at 9 months was also an intra-uterine death, but she seemed to have accepted this loss and was coping emotionally.

#### **4.2.1.9 Gestational age of current pregnancy**

The majority of the women were above 7 months gestation and 2 of them were already at term and due to deliver at any time.

### **4.3 DATA THEMES AND CATEGORIES**

The structure of the data consisted of 4 categories and themes and 10 sub-themes. Sub-themes were developed as the analysis proceeded and were present in each theme.

Table 4.22 represents an overview of the structure of the data as it emerged during data analysis, illustrating the themes, sub-themes and categories. Discussion was based on the schematic condensation of data in the table, and highlighted by direct quotations from the participants and relevant literature.

**Table 4.2: Data themes and categories**

Category	Theme	Subtheme	Frequency
4.3.1 Emotions	4.3.1.1 Emotional and psychological trauma experienced by participants	4.3.1.1.1 Shock and sadness	6
		4.3.1.1.2 Fear and stress	8
		4.3.1.1.3 Disappointment and anger	6
4.3.2 Disclosure of HIV status	4.3.2.1 Barriers that prevented disclosure of status	4.3.2.1.1 Selective disclosure	9
		4.3.2.1.2 Stigma and discrimination	12
		4.3.2.1.3 Social isolation related to non-disclosure	5
4.3.3 Financial problems	4.3.3.1 Financial challenges experienced by the participants	4.3.3.1.1 Unemployment	9
		4.3.3.1.2 Low sources of income	13
4.3.4 Social support	4.3.4.1 Perceptions of psycho-social support	4.3.4.1.1 Challenges experienced	12
		4.3.4.1.2 Benefits of social support	4
		4.3.4.1.3 Experiences of structured support groups	12

### 4.3.1 Emotions

#### 4.3.1.1 Theme 1: Emotional and psychological trauma experienced by participants

##### 4.3.1.1.1 Shock and sadness

Participants generally expressed shock and sadness when they first found out that they were HIV positive. Most participants found out during the current pregnancy, and only

one knew she was infected from the last pregnancy. Some described their shock and sadness as using the following quotes:

“I was very unhappy and felt bad when I found out. Where did this HIV come from? I cannot believe that I seriously got HIV and I keep thinking about it and the disease and dying”.

“I am too shocked still and cannot talk to anyone about it. I can't believe it, hey! What will people say and how will I accept that he...gave this disease to me, really I can't”.

“I felt very depressed and just cried and cried...it was very hard to accept my results, and now I worry about this baby, it is very difficult...”.

Being diagnosed with a fatal disease like HIV/AIDS can be devastating for anyone, and in pregnancy there is the added fear of transmission to the unborn baby.

“I felt very bad and was very sad, but I'm already pregnant and can't do anything now. I don't know what I'm going to do, but because of the baby I'm keeping calm”.

Ndala-Magoro (2010:18) stated that the psychological impact of HIV/AIDS is important to explore as this has major implications for the manner in which the person affected copes with the disease. After being diagnosed, those who have just tested positive experience arrays of emotions such as shock, grief, anger, sadness, embarrassment and fear. These similar emotions were expressed by many of the participants in this study as well.

#### *4.3.1.1.2 Fear and stress*

Many participants described that disclosure of their HIV status to their family or partners was very stressful and that they were scared as to how they would react. Many of the participants had knowledge of HIV and knew someone that was infected, and this was stressful to them as they knew how sick they could become and that they would eventually die from this disease. Most participants were sad and embarrassed about getting a disease that is not easily accepted by society at large. The worries and stress

stemmed from always thinking about the disease, its outcome and the shattered future plans and hopes for their children.

“I am worried in case I also die, then who will look after my children...plus this baby too, the father drinks a lot of alcohol and he is always fighting and making noise and he don't care about us”.

“It is very stressful because I don't want my children to find out, so I have to hide it from them, because they can also suffer and be treated badly if others find out. I checked them at the clinic and they both negative and have a future and I have to help them...” (Sad look)

“What about the future, I'm too scared to tell anyone, and I know that I'm dying. When I get sick and thin then everyone will know. It is too stressful”.

One participant had lived through both her parents being infected and eventually dying from AIDS related illness. She described her experience as:

“I know all about this disease as I had both my parents that had HIV and I know how sick they became...(sigh) and now for me to go through the same fears and trauma of having seen my parents suffer and die with no support. I am scared that the same (means the suffering) will happen to me”.

After being diagnosed as HIV positive, most individuals perceive the positive diagnosis as a death sentence. This fear often cripples the individuals as he/she becomes preoccupied with thoughts of death rather than maintaining a healthy lifestyle to keep themselves alive. Their negative psychological experiences, such as isolation, fear, depression and anxiety are intensified by the perceived lack of support from family, friends and society due to the stigma attached to the disease. Women often do not know what the reactions of others will be if they disclose their status (Mdlalose 2006:10).

Fear about the future was the most common emotion that these women had to deal with. The main concern was about their families; especially their children and what would happen to them when they got sick or when they died. This fear resulted in a lot of anxiety and depression for many respondents.

#### 4.3.1.1.3 *Disappointment and anger*

Disappointment was experienced in different ways by various participants, such as when they tested HIV positive, the response from family upon disclosure, when their partners admitted that they were aware that they themselves were HIV positive, and in instances where their partners did not want to be tested. Participants that did not disclose their status and those that chose selective disclosure were more worried about disappointing the significant persons in their lives:

“I can’t tell granny because she will be disappointed in me, and she is too old to worry now about me. I know she will be angry too because this is my 2<sup>nd</sup> baby and I’m only 19 years...its already so hard at”.

Disappointment and anger were also expressed when partners disclosed that they had known of their own HIV positive status, and then subsequently abandoned them after confessing their status.

“I was angry because when I told my boyfriend, he admitted that he is positive and he knew long ago, I can’t do anything now because I’m already pregnant, but after the baby is born I’m going to see how I’m going to handle it”.

“After I told him that I’m positive he left and I’m not sure why he runs away. I felt very disappointed because he never come to see me... he can be helped, but he don’t want treatment”.

One participant was so angry after finding that she was HIV positive that she felt like killing her boyfriend.

“I was so angry when I found out that I’m HIV positive and I knew that I got it from my boyfriend because he is my first boyfriend. I even thought of getting a gun and shooting him for doing this to me. I can’t talk to him now because I’m still very angry”.

Of the participants 28% found out that their boyfriends were already HIV positive and only told them after they had disclosed their status and 21% revealed that their partners

refused to have an HIV test, while others did not disclose the information to their partners or partner testing was not discussed.

At the onset of a chronic illness such as HIV/AIDS, anger is often a classic reaction. The anger is usually directed towards people who are thought to be responsible for bringing the disease to the individual who has been diagnosed as HIV positive (Ndala-Magoro 2010:20).

#### **4.3.2 Disclosure of HIV status**

##### ***4.3.2.1 Theme 2: Barriers that prevented disclosure of status***

The second major theme related to the issues surrounding the barriers to disclosure and included selective disclosure, stigma and discrimination and social isolation. The impact of an HIV positive diagnosis on the social lives and economic activities of the participants was the main reason for the refusal of most participants to fully disclose their HIV status. In a study done by Wright and Mwinituo (2010:36-47), the findings revealed myths about methods of HIV transmission, leading to negative public attitudes including stigmatisation, discrimination, humiliation, blame and rejection, which resulted in anxiety, suicidal ideations, low self-esteem and sleeplessness.

##### ***4.3.2.1.1 Selective disclosure***

The most important reason for not wanting to disclose to certain people was the fear of being stigmatised by others who lack basic knowledge about HIV/AIDS. The fear was especially prominent when faced with the need to disclose to parents or siblings. This was evident by the large number of respondents (57%) that did not disclose to family with whom they lived.

The majority of the participants (64%) stated that they had disclosed their status to their boyfriend, while 57% of the same participants had also told a friend or a family member. The family members involved included either their granny, mom, both parents or aunts and uncles.

According to Mdlalose (2006:78), women disclosed their status to trustworthy and supportive people who would empathise with them and provide them with advice on how to cope with their disease. They did not disclose to people with whom they did not have a good relationship, as they feared that these people would later discriminate against them and stigmatise them.

One participant had no intention of disclosing to anyone at home, but her younger sister had found out by accident, so she had had to disclose the truth to her:

"Because my parents died from HIV and I know how difficult it was for me and my sisters, I decided not to tell them yet, but my younger sister (4 years younger) saw my results in my antenatal book and asked me questions. She was so shocked and wanted to know how did this happen...so I had to tell her, but I am not ready to tell my older sister because she can be difficult and may use it against me during any fights".

Three of the participants that had disclosed to their boyfriends had also told a friend, but not anyone that they were living with. These participants felt that a friend was more supportive and understanding and that it was easier to talk to them:

"I only told my friend, first she was so shocked and didn't believe it...so she saw my results. She is a good friend and supports me and talks nicely and listens to me"

"I told a friend that lives away from my home, and she is so kind and always phone to see how I'm doing and advise me".

Some participants chose not to disclose to parents or grandparents, in order to avoid stress to their health, as they already had health problems related either to HIV, chronic conditions or age-related problems.

The reasons for non-disclosure at home were expressed by the following quotes:



“Too scared to tell ‘Gogo’, she will be disappointed. She helps to look after me and she is all I got.”

“Mom is also HIV positive and she is sick so I don’t want to stress her”.

Similar findings were found in a study by Mdlalose (2006:73) that stated that some women decided not to disclose their status due to a fear of worsening other people’s health, especially their parents that already had chronic illnesses like hypertension. They felt that such news would place extra burden on their parents and that they would rather protect their parents from worry and stress.

Some participants had similar experiences after disclosure to their boyfriends and feared losing them:

“When I was HIV positive I told my boyfriend he was shocked but then was okay. He cried and said we will be fine. We courting for 4 years, but now after I told him he is not sleeping with me and I don’t see him coming anymore”.

“Ever since I told him he got angry and went away and don’t come and see me now”.

“Too scared, cannot tell anyone at home (crying), and too scared to lose my boyfriend. This is my first and only boyfriend.”

According to a study by Wright and Mwinituo (2010:36-47), it was found that several barriers existed to HIV/AIDS disclosure. Disclosure is by nature personal and individualistic. This study indicated that some participants, after considering the circumstances around their social and interpersonal relationships within a highly stigmatising environment and the zeal to continue to engage in their social and economic activities, were unwilling to disclose either fully to the public or partially (telling relatives, friends or spouses

#### *4.3.2.1.2 Stigma and discrimination*

Generally the responses were that there is still stigma and discrimination surrounding this disease. Most of the participants made no indication of disclosing to anyone out in

the community for fear of discrimination. The data also revealed that although there was that fear of disclosure at home associated with disappointment and abandonment, a few did tell someone in the household. The stigma was more related to the community and their negative reactions to this disease. This is evident by the following responses:

“There is no support, too much gossip, people don’t understand”.

“I do home based care and work with people that also have HIV and I help them, but I won’t tell them because they won’t allow me in the house. They won’t want me to TOUCH them, because they will think I am going to make them more sick”.

“I also sell some vegetables from my garden and if the people find out then they will not buy my things because they will think I’m dirty”.

These responses that were received indicate that people are still exposed to the stigma and discrimination associated with HIV/AIDS, and the general lack of knowledge related to transmission of the disease.

Disclosure is intimately related to how communities stigmatise or accept HIV and how individuals perceive themselves, their identities, and their roles within the community (Nabilek 2009)

Associated stigma was also indicated by the following:

“I can’t talk about it...people judge you, sometimes I feel like everyone is looking at me and they know that I got HIV. This is why people hide their disease”.

Stigma and discrimination against people living with the disease mean that they face many human rights abuses from partners, family and the community at large. This barrier discourages individuals from finding out about their HIV status. On the other hand, those that know that they are infected remain silent about their status and continue to infect others and may not seek the necessary care and treatment (UNAIDS 2009).

One of the participants that had lost both her parents from HIV infection expressed her experience of how her parents suffered and that no one supported them when they

were ill. This negative reaction from others, both family and the community, has resulted in her not wanting anyone to know about her status, for fear of the associated stigma.

“When my parents were very sick, the neighbours and family too did not even come and help us because they knew they had HIV”.

The difficulties women face when disclosing their HIV status to their partners can significantly inhibit their use of prevention of mother to child transmission of HIV/AIDS services. Women may reject disclosure as they fear blame, rejection or violence from their partners, including being ejected from their homes, according to Medley et al (2004:299-307). The one participant that told her husband about her status indicated the violence that she was exposed to:

“Ever since I told this man, he drinks more and more and every time there is fighting and noise in the house. One day he even chased me out of the house because he is blaming me”.

#### *4.3.2.1.3 Social isolation related to non-disclosure*

Due to the fact that most participants practiced selective disclosure and were not completely open about their status, they experienced some degree of social isolation. This obviously indicates that if the community at large is unaware of this disease, then there will be little evidence of the support or the lack thereof that will be encountered. One of the participants that did not disclose to anyone strongly believes that no one will support her if she reveals her status and expressed her concerns about disclosing her status for fear of social isolation:

“No one knows how hard it is. I know if I tell anyone they will blame me. (Tears) Very hard. I can't even tell anyone at work (works at Wimpy), if people at work know then they will treat me badly and won't accept me, and I need the job”.

One of the participants stated that ever since she disclosed her status to her boyfriend he keeps away and they have not been intimate again. This partner was one of those that knew that he was HIV positive and did not disclose the fact to the participant.

“He knew he was sick too but didn’t tell me and now he left like it is my fault”. He gave it to me (means HIV) and now he is gone. Now I have to worry about this baby and how I am going to manage without any help”.

Other forms of social isolation experienced were the concerns of the boyfriends, family or the community isolating them and the loneliness that they felt. Some of the participants were very emotional and cried during the interview. They were supported appropriately, and felt better talking about their feelings.

“I can’t talk about it, I know my boyfriend will dump me...and then what will I do?...and my family will scold me and what if they don’t accept me..., because my mother was so angry when she see I’m pregnant, I’m too scared of losing everyone”.

This reveals that in order to be able to receive support, whether it is from family, partners or the community, one has to be able to talk freely and openly about one’s own status. Education of the family and communities is the key to obtaining acceptance and understanding of this disease, and thus increasing the psychosocial support needs. In the study done by Peltzer et al (2005:26-40), the dominant response of pregnant women was that people living with HIV/AIDS (PLWHAs) are not accepted by the community and are often spoken about in the community, resulting in other people avoiding them. Some people are isolated in their own households, where they are not allowed to share the same household utensils with other family members.

Community education and awareness campaigns on prevention of mother to child transmission of HIV/AIDS should reinforce male involvement and other family members, particularly mother-in-laws, who have influence over the options open to women who are HIV positive (Dorkenoo et al 2003:20).

### **4.3.3 Financial problems**

#### **4.3.3.1 Theme 3: Financial challenges experienced by the participants**

The majority of the participants experienced financial problems as they were dependant on family members, partners or social grants as their only means of survival.

#### *4.3.3.1.1 Unemployment*

Out of the 14 participants that were interviewed, 5 of them were employed and earned a salary. The other 64% of the participants were unemployed and depended on the family, social grants or their partner for financial support. Unemployment is higher among women than men. This can be attributed to the fact that most women have never been given an opportunity to acquire formal educational qualifications or to work, but to rather concentrate on what is perceived as women's activities such as cooking and taking care of children at home (Jackson 2002:93).

#### *4.3.3.1.2 Low sources of income*

Generally, income was limited for all of the participants interviewed, and they had insufficient food and experienced poor living conditions. Participant 7 explained that she lives in one big room that is divided by curtains, and that 6 of them share this room. Their only source of income is from small jobs that the mom does to buy food. The difficulties experienced with regards to money can be seen with the following quotes:

“There are times there is no food, no money crying) we are battling at home.”

“If I don't sell enough vegetables then there is no money. Sometimes there is nothing to eat, but I try to get something for my other child (8 year old)”.

“This man only buys drink and if I don't give him the money then he fights. Sometimes there is nothing to eat...I have to give my children porridge in the night”.

Of the participants 30% that lived with their “Gogo” (grandmother) depended totally on her pension for survival. One respondent that lived with the granny stated:

“I can't find a job, it's very hard for money, we are battling. She has a small vegetable garden that helps with food”.

Other forms of income were social grants for their mother and the other children in the family, as was seen with 3 of the participants. One participant had 2 of her own previous

children that she received grants for, and 2 participants that lived with an older sister received grants for the sisters' children, which was the only source of income. The other 21% of the participants had either a parent or sibling that was employed, that managed the household. All of the participants experienced financial problems and low income. The common problem expressed was that of limited food, and the hard times when there was no food. Many participants were emotional when they explained their financial constraints. Only 4 of the participants mentioned that the partner sometimes helps with money. This financial dependence was also the reason why they still remained with this partner.

"I am not talking to him now and I won't tell him, because I need him, because he helps me with money. I can't lose him now because I can't manage to have this baby if he don't support and help me".

Power relations in the family consistently give women (especially young women and girls) a low status. Bearing children may increase one's status, but at the same time increase dependency on the extended family. These differences in power and independence inhibit women's capacity to make their own decisions regarding prevention of mother to child transmission of HIV/AIDS and other crucial issues (Skinner et al 2005:115-123).

#### **4.3.4 Social support**

##### ***4.3.4.1 Theme 4: Perceptions of psycho-social support***

This theme indicates how the participants perceived the support that was received from significant people in their lives, the challenges faced and what benefits this provided for them. The categories discussed here are the challenges experienced and the benefits of the social support received.

###### *4.3.4.1.1 Challenges experienced*

The first challenge was that of the lack of psycho-social support from the partners. There were 8 participants that stated that they had disclosed their status to their boyfriends, and that 4 of these boyfriends were already HIV positive, while 3 of them

refused to test and the status of the last one was not known. Two participants indicated that their partners had left them and cut all ties once they had disclosed their status:

“I’m not sure why he runs away, he can be helped and take the treatment too”.

“This is my first boyfriend and I know he gave me the infection but he is in denial. He doesn’t want to go and test. He also doesn’t use a condom, so I can’t say anything”.

The ignorance or denial of the male partners’ role in the transmission of HIV is a serious concern. The WHO report on new HIV infections in 2005 confirmed that most women were infected by their husbands or partners (WHO 2007:3).

The second challenge was the effects of selective and non-disclosure of the HIV status. Participants that did not disclose to anyone stated that:

“I hide and take my pills and no one must see, but sometimes I forget and no one there to remind me”.

“I don’t want my children or anyone to find out, and I worry that my children will also suffer and how they can also be treated badly by their friends and in school”.

Some of the participants stated that if others knew that they were HIV positive there would be too much gossip and “*no freedom*” in the community. Many of them experience poor support and attend the clinic alone, feeling that people don’t understand because there is little knowledge of this disease.

One participant stated that she will disclose her status to her family and boyfriend after the baby is born, because she needs to worry about the baby:

“I need to keep calm, I don’t want to stress my baby. I will only tell them after. I don’t need to be stressed because I don’t know how they will react”.

One of the participants that saw both her parents die from the effects of being HIV positive expressed her fear of suffering as they did in the following quote:

“I’m not strong, I’m going through the same fear and traumas of having seen both my parents suffer with no support from family or the community.”

The general challenge expressed by most was that of the lack of social and financial support by either their partner, family or the community.

The lack of knowledge with regards to the preventative strategies in the prevention of mother to child transmission of HIV/AIDS programme was also evident in this study. One participant did not fully understand the treatment received and needed to be educated further.

“I will only tell my boyfriend when I start taking treatment to prevent this disease”.

This participant did not understand that the ARVs that she was already taking was the treatment that she referred to.

Another participant was very knowledgeable about the disease and the CD4 cell counts, but was afraid about the stigmas attached to the disease.

*“I know my CD4 count is low (it is 158) but I am still going to breast feed my baby because people will talk and ask a lot of questions if they see me giving a bottle”.*

“My CD4 count is low and I am taking all the treatment, but my boyfriend, his CD4 is high so he is not on treatment... No, we don’t use the condom because he don’t want it”.

These types of responses confirm that there are still many challenges that face prevention of mother to child transmission of HIV/AIDS and in particular, and the need for constant education and information is absolutely crucial to reduce mother to child transmission of HIV/AIDS ..

Infant feeding decisions have significant implications for women, and choosing one method over another may raise questions regarding a woman’s HIV status from the partner, family and community. Despite counselling options being tailored to the economic constraints that HIV positive women face, many women prioritise the risk and



social consequences of being stigmatised as a “bad mother” or being revealed to be HIV positive when deciding between replacement feeding or exclusive breast feeding for 6 months. (Desclaux & Alfieri 2009:821-829).

Many women live in poverty, lack education and economic opportunities, and suffer subordination to men. Many women remain powerless and are afraid to request condom use with their partners as they fear a violent reaction or abandonment by the man on whom they are entirely dependent for survival (WHO 2003:6).

#### *4.3.4.1.2 Benefits of social support*

The first benefit that was identified by a few participants was that of emotional and psychological support received from those that knew of their viral status. Two of the respondents (only 14.3%) had no problems and claimed to have had ample support because they were open and told all family members, partners and people in the community. This was expressed by the following statements:

“People understand, nothing is hidden and talking helps sharing. By living healthy I’m able to assist my baby. Family helps to encourage you.”

“I believe if you hide it depresses and “eats” you up. I spoke up and even the church helps you. Family and people help to encourage and build you and no stress”.

“People understand my status, and it makes me understand my modules of treatment. It helps prevent transmission of the HIV to my baby”.

This obviously indicates that in order to receive support you need to disclose your status. One participant stated that talking and sharing helps with managing and living a healthy life. Three of the participants that could not disclose to a family member, but were able to talk to a friend also stated that it helps to talk to someone and that they listen and encourage you. The other positive experience expressed by 1 participant was that of confidentiality. This participant said that she had only told her grandmother that she lived with and that her grandmother was supportive:

“I told Gogo and she supports me by not talking about my HIV (means confidentiality), and she looks after me by cooking and see that I take my tablets”.

Another benefit was that of compliance to treatment. Three of the boyfriends that are also HIV positive are on treatment, and they help by accompanying their participating girlfriends to the clinic and by taking their antiretroviral treatment together. Quotes depicting this are:

“I feel happy; we always together and we remind each other to take the treatment”.

“We go to the clinic together, and I feel happy that we always together. We also use the condom to protect the baby”.

The participant whose mother was also on antiretroviral treatment received support from her.

“My mother is also HIV positive and we both go to the clinic together, and she cooks for me. Mom will also help me with the baby. I am coping with HIV and there are no problems at home”.

This type of support helps with healthy living and contributes to both maternal and foetal wellbeing. Another positive experience expressed was that the support and help that was received in hospital from the Sisters and other patients was very good, and that they helped them to understand how to prevent infection to the baby.

“I only talk to the nurses and other patients in the hospital and we share our stories and give advice to each other...this helps a lot”.

“The staff in the hospital is very supportive and they treat us nicely. They teach us how to protect our baby and how to take the tablets”.

#### *4.3.4.1.3 Experiences of structured support groups*

Most participants (86%) indicated that the support is much better in the hospital than at home because of joining the support programme that is provided within the hospital. This is the Mothers 2 Mothers (M2M) support group, where HIV positive mothers help other mothers to cope by providing support, encouragement and education. This support group is very successful at the hospital where the research was conducted.

“When we join the PMTCT programme we are allowed to also join a support group. This helps me a lot to talk about how I feel with others that understand and have the same problems as me. People at home don’t understand and can’t help us”.

The study done by Ndala-Magoro (2010:82) found that women who joined a support group felt a new sense of hope for the future. They started making plans for the future, looking forward to raising their children and seeing them through school. They felt that having someone to share experiences with and being listened to contribute to their emotional wellbeing.

From the analysis of the above data it can be seen that there are multiple benefits to having a good psych-social support system when faced with the challenges of being HIV positive. Support that is received within the institution seems to be very beneficial to the participants that use these support groups.

Nabilek (2009:37-38) states that disclosing one’s HIV status may contribute to improved psychological well-being if those disclosed to respond in a helpful manner. It is also likely that a group of HIV positive individuals could also provide a wide range of valuable resources, both physical and emotional. HIV positive persons can provide information about treatment options, financial assistance, sick care, emotional support and reassurance that one is loved and valued within the community despite their HIV positive status.

#### **4.4 OVERVIEW OF RESEARCH FINDINGS**

The average age of the participants interviewed was 22 years, with all having some form of schooling and 93% of them being single.

This study revealed that one of the major issues still surrounding HIV/AIDS and prevention of mother to child transmission is that of non-disclosure, selective disclosure and the stigma and discrimination that surrounds this disease. Out of the 14 participants that were interviewed, only 2 felt comfortable about disclosing their HIV positive status to all of their family members, their partner, a friend and selected persons in the community. The experiences of those that disclosed to persons within the home

environment received various forms of emotional, psychological, physical and financial support from a parent, partner or grandparent. The support received from the sexual partners varied from complete psycho-social support to total abandonment. The common finding with regards to disclosure to the partner was the revelation that they were aware of the fact that they were also HIV positive and had failed to disclose this fact prior to this disclosure. One of the major challenges that all of the respondents faced was that of limited financial support due to low incomes and the dependence on pension and social grants as the only source of income. The low incomes led to limited access to good nutrition and poor living conditions. Where positive experiences were reported, the partners or parents that were also HIV positive assisted in treatment compliance and accompaniment to the clinic. The stigma perceived by the community at large still exists and this generally prevents persons from being open about their status.

#### **4.5 CONCLUSION**

Four major themes and 10 sub-themes were identified and described in detail in the analysis of the data in this chapter. Direct quotations from the participants were used to highlight the findings and discussion. Literature quotations were also used to show the relevance of the findings. This data analysis confirms that in order for the prevention of mother to child transmission of HIV/AIDS programme to be effective, the psychosocial support by significant persons must be improved and the need for constant education and knowledge of the community at large is of vital importance. The last chapter will discuss the findings further and appropriate recommendations will be made.

## **CHAPTER 5**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This chapter discusses the summary of the research findings, in line with the study objectives, and the conclusions based on the findings of the study. It also provides recommendations drawn from these findings and the limitations of the study.

#### **5.2 RESEARCH DESIGN AND METHOD**

A qualitative, explorative, descriptive and contextual study was used in this study to explore the home environment for the support system available for the HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme, and the influence that this has on her compliance to treatment. The context of this study was the HIV positive women on the prevention of mother to child transmission of HIV/AIDS programme at a Provincial Hospital in KwaZulu-Natal.

The population of this study included all women that have been counselled and tested HIV positive and who have joined the programme on prevention of mother to child transmission of HIV/AIDS at a Provincial Hospital for the period of this study.

A non-probability sampling approach was chosen for this study. This type of sampling is usually more convenient and economical and allows the study of populations when the researcher is unable to locate the entire population (Brink 2008:131). The type of sampling method chosen for this study was purposive, as this allowed the researcher to select the sample based on knowledge of the phenomena being studied. Sampling was done until data saturation occurred and no new data emerged.

### **5.2.1 Data collection**

Data were collected using a semi-structured interview schedule with Section A for closed-ended, short questions for demographic information and Section B with open-ended questions for the purpose of exploring phenomena related to the topic. Interviews were audio taped where it was allowed and field notes were made as well. The central question that was asked was: “Describe to me the support you receive from your family and friends?” and this was explored further by using a prepared topic guide which included the following questions:

- What is the influence of the home environment on women on the prevention of mother to child transmission of HIV/AIDS programme?
- What are the factors that contribute to the lack of family involvement for women on the prevention of mother to child transmission of HIV/AIDS programme?
- How can problems experienced within the home environment be improved to contribute to a more successful programme on prevention of mother to child transmission of HIV/AIDS?

### **5.2.2 Data analysis**

Qualitative data analysis can be described as the non-numerical examination and interpretation of observations for the purpose of discovering underlying meanings and patterns of relations (Babbie 2007:378).

Interviews were transcribed verbatim. The researcher analysed the transcriptions by reading the scripts over and over to seek meaning in the data. Data were then grouped into themes and categories.

According to Patton (2002:453), content analysis refers to the searching of text for recurring words or themes. Data analyses were done manually. The initial analysis included identifying common themes and then it was linked to major themes under broader categories by checking for word repetitions. Coding was used to organise the data collected for all recorded information. Once all data were coded the researcher identified the most prevalent ones for each participant in order to determine the final themes.

## **5.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS**

### **5.3.1 Emotional and psychological trauma experienced by the participants**

The findings revealed that more than half of the respondents (57%) experienced various forms of emotional and psychological trauma that was expressed as shock, fear, disappointment and anger. These emotions were experienced either when they were first diagnosed as being HIV positive, on disclosure or the reason for non-disclosure, or when they found out that their partner was already HIV positive and did not disclose his status. Many participants expressed disappointment and embarrassment because of getting a disease that is stigmatised and not readily accepted by society.

These findings revealed a strong association between being diagnosed as HIV positive and the psychological impact this has on the women, as well as the stress it causes on the current pregnancy. The worries and stress stemmed from always thinking about the effect of the disease on their health and the shattered future plans and hopes for their children. It is also evident that there is a need to be able to disclose to significant others, in order to receive the necessary support that is critical for proper utilisation of all the benefits of the prevention of mother to child transmission of HIV/AIDS services. In a study conducted in Addis Ababa – Ethiopia, knowledge of prevention of mother to child transmission of HIV/AIDS services is high, but having knowledge about prevention of mother to child transmission of HIV/AIDS does not necessarily guarantee attitudinal change to subsequent use of prevention of mother to child transmission of HIV/AIDS services. Adequate knowledge on how to prevent Mother to child transmission of HIV to pregnant women and their families as well as the necessary support will increase the uptake of these services. (Mekonnen 2009:43).

This study indicates similar evidence that the involvement of the partner and significant others is a major factor in positively influencing the uptake of the prevention of mother to child transmission of HIV/AIDS services.

### **5.3.2 Barriers that prevented disclosure of status**

The barriers that were found in this study included stigma and discrimination and the fear of social isolation. The majority of the participants (64.3%) expressed selective

disclosure either to only the boyfriend and or a friend or to a family member as well. The impact of being HIV positive and the effect it has on the social and economic lives of these participants was one of the contributory factors for either selective disclosure or non-disclosure. The findings revealed that those participants that did not disclose their disease within their home environment (50%) were afraid to disappoint their family member or because either the parent was also sick with HIV (21.4%), or the granny that they lived with was too old (14.3%) and they did not want to stress them. The remaining 14.3% lived with siblings and were too afraid of the negative reactions that may be received and the lack of financial support that they depended on.

Stigma and discrimination was the major barrier experienced by 85.7% of the participants. These participants revealed that there is still a lot of stigma out in their communities and this was evidenced by the fact that only 2 (14.3%) participants were open about their status at home and in the community. The majority feared being rejected, blamed and socially isolated within the communities. One participant that sold vegetables indicated that if anyone knew that she was HIV positive then they would not buy from her.

These findings revealed a strong negative association between disclosure of an HIV positive status and stigma and discrimination. This was therefore a major barrier preventing full disclosure. This then resulted in a poor support system in both the home and community for the women on the prevention of mother to child transmission of HIV/AIDS programme. Participants that disclosed to their partners expected some benefit in the forms of social, emotional or financial support, but this was not the case in 14.3% of the respondents. These women conveyed their experiences of rejection where the partners abandoned them, blamed them and physically or emotionally abused them. It was evident that disclosing to a friend was better received and that the support received was beneficial to coping with the disease. One participant expressed how her friend motivated her to take her treatment and always reinforced positive living and protection of her baby from HIV. According to a WHO (2003:6), on women's experiences of HIV sero-disclosure it was found that disclosing to a male partner may lead to psychosocial support and, in some cases, abuse or violence, whereas disclosing to a sister, aunt or a friend had a better outcome. Although disclosure to a partner may reduce risky sexual behaviour, we need to look at how women can be supported to disclose to other people who can also offer care and support.



### **5.3.3 Limited financial support**

The findings revealed that 64% of the 14 participants were unemployed and depended on a family member, a social grant or the partner for financial help. This financial dependence resulted in selective and non-disclosure of their status for fear of not receiving any financial help. There were 35.7% of the participants that did not disclose their status to their partners because they needed their financial assistance to survive. This study also indicated that some women (21.4%) continued to have children although they were aware of their status, as they received a social grant for each child, which helped them to support themselves and the family. It was evident that the low sources of income that these participants received had an impact on their quality of life and health. A few participants expressed their poverty, where sometimes they had no money to buy food and their children had to eat porridge for supper. Other problems experienced were that it was sometimes difficult to go to the clinic as there was no money and they had to work or sell vegetables in order to get money to buy food. These factors indicated that the stressful financial burdens that these women faced directly impacted on their health and underutilisation of the prevention of mother to child transmission of HIV/AIDS services. The women's economic dependency on men, poverty, and their limited decision making power, both within the family unit and the community, highly affects their utilisation of prevention of mother to child transmission of HIV/AIDS services. Also, women are overloaded with domestic work and other activities to generate income. As a result, they become busy and do not get enough time to attend to their health and to seek prevention of mother to child transmission of HIV/AIDS services adequately (Mekonnen 2009:46).

### **5.3.4 Perceptions of psycho-social support**

This study revealed two aspects to psycho-social support. On the one hand, the findings indicated some of the challenges experienced by participants and the lack of support given to them, while on the other hand 2 participants (14.3%) expressed their positive psycho-social benefits of full disclosure within their home and community.

Of the participants 85.7% experienced various challenges, ranging from total abandonment by their partners after disclosure, the fear of stigmatisation due to the lack of community education and understanding regarding prevention of mother to child

transmission of HIV/AIDS, and the feared loss of psycho-social and financial support from family if they disclosed the fact that they had contracted HIV.

The study highlighted the lack of community education and understanding regarding the prevention of mother to child transmission of HIV/AIDS services. Some participants expressed the fact that they attend the clinic alone and have to hide their treatment by taking it at home so that no one becomes aware of their status. What was evident with 14.3% of the participants was a lack of knowledge with regards to the ART treatment that they were already on. Only 14.7% had an idea of their CD4 cell counts, and displayed inadequate knowledge regarding preventative infant feeding strategies. Another challenge was the decision to breastfeed rather than bottle feed because they perceived being seen as HIV positive because of the disease's association with bottle-feeding.

The stigma associated with disclosure leads to negative changes in self-concept and emotional reactions towards those who invoke the stigma. HIV positive individuals are likely to inform their significant others on condition that they perceive that the rewards of the disclosure outweigh the costs. The reasons for non-disclosure are justified by desire for the act of disclosure to reduce negative consequences (Driskell et al 2008:135-156).

The participants that indicated receiving some form of psycho-social support were those that disclosed their status. 28.6% of the participants reported that the people that they had told helped to support them by encouraging them and that this helps them to comply with their treatment modules. Two of these respondents (14.7%) were completely open about their status to family and the communities that they lived in. One participant reported that her church was very supportive and encouraging. This implied then that sharing this burdensome disease with a significant person helps them to cope with the stress better. Another benefit that was evident was that 21.4% of the boyfriends of the participants were also HIV positive and on treatment, and that the knowledge of each other's status helped them to support each other, to attend the clinic together and to remind each other to comply with their strict treatment regimens.

These results indicate that in order to receive the appropriate psycho-social support and maintain compliance to the prevention of Mother to child transmission of HIV/AIDS preventative strategies, status disclosure is required. This helps a person to cope better

and to live a more positive lifestyle, where they are motivated and encouraged to adhere to treatment. Serovich, Lim and Mason (2008:23-31) stated that “disclosing an HIV positive status can result in the gain of emotional, physical and social resources. The emotional benefits include social support, relief that comes from sharing a burdensome secret and the built in reward of educating others about HIV”.

Participants that did not disclose to anyone in the home environment felt that they were receiving adequate support within the institution, either from the nursing staff or from the support groups that they had joined. This contributes positively for a woman that is on the prevention of mother to child transmission of HIV/AIDS programme as she is able to share her experiences and learn from others with similar problems. This support is, however, limited to within the institution only, and there is no continuity at home where the real challenges of adherence to treatment and other problems are experienced.

#### **5.4 CONCLUSIONS**

The findings of this study reveal that although there is knowledge and awareness of the prevention of mother to child transmission of HIV/AIDS programme that is provided for women at the antenatal clinics, there is the problem of interpretation of this information which is somewhat unclear, especially for those with a low literacy level and resultant communication barrier. The area where the study was conducted is a rural township and many of the participants (35.7%) had only been to a primary school, which contributed to the poor education, unemployment and poverty factors. It was evident from a few of them that they sometimes did not have money for food or transport to get to the facility. Lower levels of education affected the financial independency of the participants because even those that worked were earning very little to sustain themselves and their families. Some depended solely on a state grant for survival. These are contributory factors to the under-utilisation of the comprehensive prevention of mother to child transmission of HIV/AIDS services available, and relate to a lack of understanding of the key concepts to reducing mother to child transmission of HIV/AIDS.

This study also showed that socio-cultural factors within the home environment such as stigma and discrimination, gender inequalities, lack of support, abandonment and social isolation all played a major role in affecting the utilisation of prevention of mother to child

transmission of HIV/AIDS services among pregnant women. Another major constraint was the poor acceptance of people living with HIV in the family as well as in the community. This resulted in non-disclosure for fear of similar discriminations.

On a positive note, this study indicated that those women that disclosed their status to a partner or family member reaped positive rewards such as motivation, encouragement, accompaniment to the clinic, as well as someone to share their stressors with, which together all contributed to compliance to treatment and effective utilisation of the prevention of Mother to child transmission of HIV/AIDS services.

## **5.5 RECOMMENDATIONS**

Recommendations for strategies to improve the support systems of the home environment for women on the prevention of mother to child transmission of HIV/AIDS programme include the following:

- To increase the knowledge and awareness about the prevention of mother to child transmission of HIV/AIDS programme and its preventative strategies to the communities at large, by using opportunities such as community gatherings, social events, and religious functions to provide these awareness sessions and regular updates.
- Continuous health education and sensitisation regarding prevention of mother to child transmission of HIV/AIDS and specific education on overcoming stigma and discrimination of PLWHA. The involvement of influential persons, religious leaders and teachers to disseminate this knowledge and updates on an on-going basis would facilitate this.
- To encourage HIV positive women to bring their male counterparts in during antenatal attendance so that counselling can be given to them as a couple. This would make the preventative strategies and compliance more readily accepted and supported.
- Prevention of mother to child transmission of HIV/AIDS counsellors should be available on all maternity units, clinics and other facilities where mother and child target groups attend, so that on-going health education and counselling is given.
- All staff working closely with mothers and children or teenagers should receive training in prevention of mother to child transmission of HIV/AIDS and be given

regular refresher courses on counselling so that there are no missed opportunities to disseminate this information.

- Health facilities should adapt their pregnancy clinics and wards to be more accommodating to allow male involvement, by sending out messages to communities that males are welcomed with their partners, that couple counselling is provided and that confidentiality and privacy will be maintained.
- Support groups that consist of women that are on the prevention of mother to child transmission of HIV/AIDS programme and living positively can be encouraged to take the support and education to the people out in the communities; this will have a positive effect if information comes from a person directly involved in this disease. Issues such as the benefits of psycho-social support within the home environment must be emphasised.

## **5.6 CONTRIBUTIONS OF THE STUDY**

- This study contributes to the existing body of knowledge on HIV/AIDS and prevention of mother to child transmission of HIV/AIDS better and the effects that psycho-social support or the lack thereof has on the woman and her family when she is enrolled on the prevention of mother to child transmission of HIV/AIDS programme.
- The study indicates the necessity for on-going community education and involvement in supporting women that are on the prevention of mother to child transmission of HIV/AIDS programme that needs to be campaigned for by Government and policy makers.
- Another contribution of the study is the need for short courses on HIV/AIDS and prevention of mother to child transmission of HIV/AIDS that need to be provided to relevant stakeholders in the communities such as Religious leaders, Traditional healers, Chiefs and other prominent people that would assist with educating others and providing support to these women. As evident from the study findings many women do not have adequate support at home and seek help from the community.

## **5.7 LIMITATIONS OF THE STUDY**

The findings of this study cannot be generalised to other areas, as it was limited to one Provincial Hospital. Also, the participants in this study were from a rural community and thus cannot be generalised to an urban area.

- Sampling was limited to a few participants and only to those that came in to the hospital, which could affect the bias during sampling.
- Another limitation could have arisen from the unnoticed biases arising during the interview and the inappropriate use of the instrument due to inexperience of the researcher.
- Participants could have responded dishonestly to please the researcher and to avoid open discussions.
- A few participants had poor communication skills and language barriers due to low literacy levels, and this could have also contributed to the incorrect or unclear interpretation of the information provided.
- A few participants did not want the interview to be recorded and felt intimidated by the tape recorder, so notes were made, and this could have led to missed non-verbal responses from observation during the interview.

## **5.8 CONCLUDING REMARKS**

From this study it can be concluded that receiving psycho-social support within the home environment and the community has proven to be a key to successful implementation of the prevention of mother to child transmission of HIV/AIDS preventative strategies in reducing mother to child transmission of HIV/AIDS. Disclosure of one's status is another critical element for one to be able to receive any support at all. To overcome the negativity, stigma and discrimination associated with this pandemic, there has to be continuous health education and dissemination of knowledge regarding HIV and, prevention of mother to child transmission of HIV/AIDS and acceptance of the available treatment and preventative strategies that are in place. To realise the benefits of HIV transmission risk reduction, prevention of mother to child transmission of HIV/AIDS programmes have to achieve adherence to antiretroviral drug prophylaxis. Evaluation of many prevention of mother to child transmission of HIV/AIDS programmes, however, reveals that adherence is still a challenge compromising the

effectiveness of the programmes. Disclosure of HIV status is seen as the major obstacle, as it is found that women that do not disclose their status to anyone are less likely to adhere to ARV prophylaxis

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**UNIVERSITY OF SOUTH AFRICA  
Health Studies Higher Degrees Committee  
College of Human Sciences  
ETHICAL CLEARANCE CERTIFICATE**

**HS HDC/40/2012**

Date of meeting: 30 April 2012                      Student No: 0809-611-2

Project Title: Influence of the home environment on the Prevention of Mother to  
Child Transmission (PMTCT) of HIV/AIDS

Researcher: Asha Sewnunan

Degree: MA Health Studies                                      Code: DIS702M

Supervisor: Dr LM Modiba  
Qualification: D Cur  
Joint Supervisor: Mrs ND Ndou

**DECISION OF COMMITTEE**

Approved

Conditionally Approved

  
**Prof E Potgieter**  
**CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE**

  
**Dr MM Moleki**  
**ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

*For*

**PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES**



**HEALTH**  
KwaZulu-Natal

**PORT SHEPSTONE NURSING CAMPUS**

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Cell: 083 783 1864

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Enquiries: Mrs A. Sewnunan

08<sup>th</sup> May 2012

Department of Health  
Kwa Zulu Natal  
Head office  
Natalia, PMB

The Research Team  
Attention: Mr. Xolani Xaba

Dear Mr Xaba

**Re: Permission to conduct Research in the maternity unit at Murchison Hospital in Ugu District**

I, Asha Sewnunan, the Midwifery HOD at the Port Shepstone Nursing Campus is currently doing my Masters Degree through Unisa.

I am required to conduct a research study which is part of the requirements for completion of the degree.

My topic is as follows: **Influence of the home environment on the prevention of mother to child transmission (PMTCT) of HIV/AIDS.**

I am doing a qualitative study whereby voluntary participants that are on the PMTCT programme will be interviewed. A consent form will be signed after explaining the purpose of my study to all participants that volunteer to be interviewed. The purpose of this study is to assess the support that a woman that is on the PMTCT receives at home and how this benefits her and the baby. Every precaution will be taken to ensure that no harm comes to any participant.

Please find enclosed with my letter of request, a copy of my proposal, questionnaire and consent form and a copy of my ethical clearance certificate.

Your permission, support and co-operation to conduct the study at Murchison Hospital will be greatly appreciated

Thank you,

Yours sincerely

Asha Sewnunan



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

Health Research & Knowledge Management sub-component  
10 – 103 Natalia Building, 330 Langalibalele Street  
Private Bag x9051  
Pietermaritzburg, 3200  
Tel.: 033 – 3953189  
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Email.: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

Reference : HRKM 60/12  
Enquiries : Mr X Xaba  
Tel : 033 – 395 2805

Dear Mrs A. Sewnunan

**Subject: Approval of a Research Proposal**

1. The research proposal titled "Influence of the home environment on the Prevention of Mother to Child Transmission (PMTCT)" was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby **approved** for research to be undertaken at **Murchison Hospital**

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

  
\_\_\_\_\_  
**Dr E Lutge**

Chairperson: Provincial Health Research Committee

Date: 16/05/2012

## **ANNEXURE D**

### **CONSENT FORM**

#### **DEAR PARTICIPANT**

You have been selected to participate in a study to explore the link between the home environment and its contribution to the success of Prevention of Mother to Child Transmission of HIV/AIDS at the Port Shepstone and Murchison Hospitals in Ugu District.

The study will be conducted by Mrs. A Sewnunan from the Port Shepstone Nursing Campus.

The study may benefit you and other women on the PMTCT programme to identify the factors in the home environment that could assist to improve the support for women on this programme.

Permission has been obtained from the relevant authorities to conduct this study. All you have to do is to respond to questions that will be asked for about 20 minutes. You are free to ask any questions about the study at any time if you need more information.

Your participation in this study is voluntary and you are under no obligation to participate. You have the right to withdraw at any time and this will not affect your care and treatment at the hospital. You will not be paid for your participation but will receive a little gift from the researcher.

All information collected from you will be kept confidential. No names will be used. Your questionnaire will be given a number and only the researcher will have access to this information. Your identity will not be revealed at any time during or after the study. All data will be kept securely and will be destroyed after the study has been completed.

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

The study described above has been explained to me and I voluntarily consent to participate in this study. I have had an opportunity to ask questions.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date



## ANNEXURE E

### INTERVIEW SCHEDULE

#### 1. SECTION A: DEMOGRAPHIC DETAILS

1.1 In which age group do you fall?

1.1.1 \_\_\_\_\_ 18 -25 years

1.1.2 \_\_\_\_\_ 26 -30 years

1.1.3 \_\_\_\_\_ 31 – 35 years

1.1.4 \_\_\_\_\_ 36 – 40years

1.1.5 \_\_\_\_\_ 41 – 45 years

1.1.6 \_\_\_\_\_ 46 – 50 years

1.1.7 \_\_\_\_\_ other

1.2 What is the highest level of education you completed?

1.2.1 Never attended school \_\_\_\_\_

1.2.2 Attended primary school \_\_\_\_\_ Grade/std \_\_\_\_\_

1.2.3 Attended secondary school \_\_\_\_\_ Grade/std \_\_\_\_\_

1.2.4 Attended college or university \_\_\_\_\_

1.2.5 Tertiary qualification completed \_\_\_\_\_

1.3 What is your marital status?

1.3.1 Married \_\_\_\_\_

1.3.2 Single \_\_\_\_\_

1.3.3 Divorced \_\_\_\_\_

1.3.4 Separated \_\_\_\_\_

1.3.5 Widowed \_\_\_\_\_

1.4 How long are you living with your current partner?

1.4.1 Less than 5 years \_\_\_\_\_

1.4.2 5 to 10 years \_\_\_\_\_

1.4.3 More than 10 years \_\_\_\_\_

1.4.4 Other, specify \_\_\_\_\_

1.5. Who else lives in the same household with you? Specify?

\_\_\_\_\_  
\_\_\_\_\_

1.6. What religion do you belong to?

\_\_\_\_\_

1.7 Are you employed? If not, what is your source of income?

\_\_\_\_\_

1.8 Who else contributes to the family income?

\_\_\_\_\_

1.9 How many pregnancies did you have? \_\_\_\_\_

1.10 How many children do you have that are alive? \_\_\_\_\_

1.11 Did any of your babies die? How? \_\_\_\_\_

1.12 How many weeks pregnant are you currently? \_\_\_\_\_

**2. SECTION B: THE HOME ENVIRONMENT AND LEVEL OF SUPPORT RECEIVED**

2.1 The central question will be:

Describe your experiences of your home environment in relation to prevention of mother to child transmission of HIV/AIDS

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2.2 This will be explored further by using a prepared interview guide that will include the following questions:

2.2.1 Have you disclosed your HIV status to any family member?

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2.2.2. If yes, what was the reaction, and did they support you

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2.2.3 If no, what was the reason for not disclosing your status?

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2.2.4 How does having your partner or a family member involved help you with being on the PMTCT programme?

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2.2.5 Describe the support you receive from your partner and family?

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2.2.6 If you are not getting support from your family, what are your concerns about the lack of social support?

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2.2.7 What are the factors that prevent family from being involved in the PMTCT programme?

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THANK YOU FOR YOUR CO-OPERATION