

Factors contributing to low follow-up of babies born to HIV positive mothers

AM Mogomotsi

Dissertation submitted in partial fulfilment of the requirements
for the degree Magister Curationis

Supervisor: Dr CS Minnie

School of Nursing Science

Faculty of Health Sciences

Potchefstroom Campus

North-West University

2012

ACKNOWLEDGEMENTS

Firstly, I want to express sincere appreciation to the trinity of GOD almighty, for having made it possible for me to achieve this. Glory to God.

Secondly, I want to thank the following who assisted me in the research process:

- Dr. C. S. Minnie, my research supervisor, for her patient support throughout the study.
- Ms. Naughty Poho, who assisted me at the beginning when my eyes were closed and she opened them to the research field.
- My friend and colleague, L. V. Monareng for her encouraging support and prayers to finish my studies.
- My friend and colleague Martha, for encouraging me to go on.
- Masedi, for assisting with technology when the laptop was giving problems.
- All the participants who were willing to share with me their experiences in their world of my research.
- How can I forget Dr. Petra, who trained me on data collection and was also my co-coder, thank you.
- Ms. Thato Manana for language editing.
- Ms Vos and Sylvia for their assistance in library with articles I needed.
- Prof. Casper Lessing for editing my references.

Thirdly I like to thank the North West University for financial support as bursaries.

Finally, but not least, I want to dedicate this research to: my husband, Molefe, who supported, prayed, encouraged and was always there for me, to run my errands towards the successfulness of this research. Tumelo, my youngest son, who drove me to Potchefstroom while his father was held up. Tshepo the elder son, who always supported me in prayers. My son in law- Phillip whom I always worried when things were not going well with the laptop.

ABSTRACT

Since the implementation of the prevention of mother-to-child transmission of HIV program in South Africa in 2001, infant deaths due to HIV and AIDS have still remained high. HIV-exposed infants need to be taken for follow-up, schedule at six weeks, for PCR HIV testing. When the infant is found to be HIV-positive, the antiretroviral treatment is commenced for life (DOH, 2010). This benefits them in that the earlier they start treatment, the higher their quality of life and their life expectancy will be. Health workers face a problem in that there are still mothers of HIV-exposed infants who do not return their babies for the 6 weeks of age follow-up schedule and their babies therefore do not benefit from the treatment and care.

The study looked at the reasons for the low follow-up of babies born to HIV-positive mothers according to HIV-positive mothers and nurses and counsellors and what strategies can be used by nurses and counsellors to encourage the mothers to bring their babies for follow-up.

To answer these questions, qualitative, exploratory and contextual design was used. Purposive sampling was done with participants who had knowledge about the research problem. HIV-positive mothers were individually interviewed and nurses and counsellors were interviewed in a focus group. Five individual interviews and three focus group interviews were conducted. The focus groups were interviewed twice for each question mentioned.

Responses were satisfactory with the following categories emerging from the findings: fear about disclosure, denial of status, insufficient knowledge about HIV, accusations about who is the actual “giver” of HIV and incongruent health education on HIV and AIDS and the management thereof in the case of babies with HIV, with specific reference to incorrect and/or insufficient information. Recommendations are made concerning these issues, so as to effect an increase in the follow-up of babies born to HIV-positive mothers.

Key words

PMTCT, low follow-up, HIV-positive mothers.

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ARV	Antiretroviral
ART	Antiretroviral therapy
AZT	Zidovudine
DOH	South African National Department of Health
NVP	Nevirapine
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MTCT	Mother to child transmission of HIV
PMTCT	Prevention of mother to child transmission of HIV
VCT	Voluntary counselling and testing
WHO	World Health Organization

TABLE OF CONTENT

Acknowledgements	ii
Abstract	iii
Abbreviations	iv
Table of content	v

CHAPTER 1 OVERVIEW OF THE RESEARCH PROJECT 1

1.1 INTRODUCTION.....	1
1.2 BACKGROUND AND RATIONALE.....	1
1.3 PROBLEM STATEMENT	7
1.4 OBJECTIVES.....	8
1.5 PARADIGMATIC PERSPECTIVE.....	8
1.5.1 Meta-theoretical assumptions	8
1.5.2 Theoretical assumptions	10
1.5.3 Theoretical Framework	12
1.5.3 Methodological assumptions	13
1.6 RESEARCH DESIGN AND METHODS	13
1.6.1 Design	13
1.6.2 Research Method	14
1.6.3 Data collection.....	16
1.6.4. Data analysis.....	17
1.7. TRUSTWORTHINESS.....	18
1.7.1 Credibility	18
1.7.2 Transferability.....	19
1.7.3 Dependability	19
1.7.4 Confirmability	19

1.8. ETHICAL CONSIDERATIONS.....	19
1.8.1 Approval.....	19
1.8.2 Informed consent	20
1.8.3 Rights of participants.....	20
1.9. FRAMEWORK OF THE RESEARH	21
1.10 SUMMARY.....	21
CHAPTER 2 RESEARCH METHODS	22
2.1 INTRODUCTION.....	22
2.2 RESEARCH DESIGN	22
2.3 RESEARCH CONTEXT	23
2.4 RESEARCH METHOD.....	25
2.4.1 Sampling	26
2.4.2 Data collection.....	29
2.4.3 Data analysis.....	37
2.5 MEASURES TO ENSURE TRUSTWORTHINESS	38
2.5.1 Credibility	39
2.5.2 Transferability.....	40
2.5.3 Dependability	41
2.5.4 Confirmability	41
2.6 ETHICAL CONSIDERATIONS.....	41
2.6.1 Protecting the rights of the participants	42
2.6.2 Principle of beneficence	45
2.6.3 Principle of justice	46
2.6.4 Protecting the rights of the research institution	46
2.6.5 Enhancing the scientific integrity of the study.....	47
2.7 SUMMARY.....	47

CHAPTER 3 RESEARCH FINDINGS 48

3.1	INTRODUCTION.....	48
3.2	DEMOGRAPHIC PROFILE OF PARTICIPANTS.....	48
3.2.1	Demographic information of participators in individual interviews	48
3.2.2	Demographic information of focus group participants	49
3.3	RESEARCH FINDINGS	50
3.3.1	Reasons why mothers do not bring their babies for the 6 weeksfollow-up.....	51
3.3.2	Strategies to encourage mothers to bring their babies for follow-up	84
3.4	SUMMARY.....	91

CHAPTER 4CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS 92

4.1	INTRODUCTION.....	92
4.2	CONCLUSIONS.....	92
4.3	LIMITATIONS.....	95
4.4	RECOMMENDATIONS.....	95
4.4.1	Nursing practice	95
4.4.1.1	Community involvement	
4.4.1.2	Resources	
4.4.2	Nursing education	96
4.4.3	Policy making	97
4.4.4	Nursing research.....	97
4.5	CLOSING REMARKS	97

REFERENCES 99

APPENDIXES

Appendix A Ethical approval from North West University	107
Appendix B Letter of request for permission from Department of Health	108
Appendix C Permission from Gauteng Department of Health and Social Development	110
Appendix D Ethical approval from Tshwane/Metsweding Research Ethics Committee	111
Appendix E Request for permission from the clinic	112
Appendix F Informed consent form for individual participants	113
Appendix G Informed consent form for focus group participants	116
Appendix H Demographic data form for individual participants	119
Appendix I Demographic data form for focus group participants	120
Appendix J Example of field notes for individual interview participant	121
Appendix K Example of field notes for focus group participants	122
Appendix L Transcript of individual interview	123
Appendix M Transcript of focus group interview	129
Appendix N Confidentiality agreement	136
Appendix O Area served by Phedisong 4 Community Health Centre	137
Appendix P Area served by Kgabo Community Health Centre	138
Appendix Q Area served by Boekenhout Clinic	139

CHAPTER 1

OVERVIEW OF THE RESEARCH PROJECT

1.1 INTRODUCTION

Infants of Human Immuno deficiency Virus (HIV) infected mothers (HIV exposed infants) need to be brought to a health facility at six weeks of age for polymerase chain reaction (PCR) HIV testing to determine whether they have been infected through mother-to-child transmission. If the infant is found to be HIV positive, he/she should have a confirmatory viral load test and urgently be referred for early initiation of antiretroviral therapy (ART) (Department of Health [DOH], 2010:25). This benefits infants in that, the earlier they start treatment, there is higher quality of life and improved life expectancy. In this research, the focus is on the reasons why HIV positive women do not bring their infants for the six weeks appointment and what midwives and counsellors see as the causes of delay for these infants not being brought to the clinic, as well as the strategies they use to facilitate the follow-up visits of these infants.

In this chapter, the background and rationale of the study is first addressed. This is followed by the problem statement, research question, objectives and research methods. Finally, trustworthiness and ethical considerations are discussed.

1.2 BACKGROUND AND RATIONALE

Since the initial recognition of the HIV disease and the consequent pandemic, by the end of 2009, an estimated 2.5 million children under the age of 15 years worldwide were living with HIV (Avert, 2010a). In sub-Saharan countries an estimated 22,5 million people were living with HIV at the end of 2009, including 2,3 million children (Avert, 2010b). In the study conducted by the South African National Department of Health in 2009 it was estimated that 29,4% of pregnant women were living with HIV

and the prevalence remained stable since 2006 (Avert 2010c). In Gauteng Province, an HIV prevalence of 29,8% among antenatal attendees was estimated in 2009 (Avert, 2010c).

Women in Sub-Sahara Africa are more easily infected than men. Evian (2000:193) states that in Africa, HIV infection has been spreading more rapidly in women than in men. Young women aged 15 to 24 are between two and six times more likely to be HIV positive than men of similar age (UNAIDS, 2006:88). Due to women being receptive sexual partners, uterine, cervical and vaginal conditions exist which promote HIV infection. These conditions include inflammation or damage of the vaginal wall, unnoticed sexually transmitted diseases (STD's) and period of menstruation which results in large, raw and exposed areas of the inner uterine lining, causing women to be more vulnerable to HIV infection (Evian, 2000:193).

Current interventions to reduce the risk of mother to child transmission (MTCT) include antiretroviral prophylaxis during pregnancy, labour and in the early neonatal period, caesarean section delivery before labour or rupture of membranes, avoidance of breastfeeding, shortening the breastfeeding period and/or encouraging exclusive breastfeeding (Newell, 2005:2). According to Sripipatana *et al.* (2007:S112) expanding access to interventions that effectively prevent MTCT of HIV is an urgent priority and one that must be maintained and strengthened in parallel with increasing availability of ARV treatment. Pregnant women who are diagnosed as HIV infected can serve as an entry point for families, promoting early diagnosis, particularly of women and young infants who have not yet become ill and linking them into long-term care (Sripipatana *et al.* , 2007:S112).

The newer strategies to limit the risk of MTCT of HIV have been highly successful. Shapiro *et al.* (2010:2292), found that only 1.1% of infants were infected with HIV-1 at six months of age when their mothers used antiretroviral therapy (ART) from early in the pregnancy through to six months of breastfeeding.

Infants younger than 18 months are diagnosed using the HIV PCR test that detects the presence of HIV within the human genes of white blood cells. The HIV ELISA or HIV Rapid tests that are commonly used for diagnosis in adults and children cannot be used for HIV diagnosis in infants as younger infants will test positive for the antibodies they received from their mothers during pregnancy, even though they are

not necessarily infected themselves. The maternal HIV antibodies can remain in the baby's blood until the age of 18 months (Stevens *et al.*, 2008:18).

To reduce HIV infection rates, the South African government implemented a Prevention of Mother-To-Child Transmission (PMTCT) programme in 2001 (McCoy *et al.*, 2002:1). This programme was revised in February 2008 and again in 2010 when clinical guidelines for PMTCT were released (DOH, 2010). According to these guidelines, all pregnant women attending antenatal care should be offered HIV counselling and testing routinely. Those who are found to be HIV positive should start at 14 weeks of pregnancy with a course of treatment of 300 mg zidovudine (AZT) taken orally 12 hourly, while waiting for the CD4 count results. If their CD4 count results are 350 cells/mm³ or less, or if they are staged as WHO clinical stage 3 or 4 (indicating significantly reduced immunity), they should start with the applicable regimen of ART as soon as possible. At the onset of labour, HIV positive women not on ART should receive 300 mg of AZT 3 hourly until the delivery as well as a single dose of 200 mg of nevirapine (NVP). After the birth they should receive single doses of 300 mg of Tenofovir (TDF) and 200 mg of Emtracitabine (FTC). The affected baby should receive 15 mg of nevirapine (NVP) syrup as soon as possible after birth, continuing daily for six weeks or for the duration of breastfeeding for those whose mothers are not on lifelong ART (DOH, 2010:3).

According to the Clinical Guidelines, at six weeks of age, all HIV exposed infants should be started with 2.5 ml of cotrimoxazole (prophylaxis against opportunistic infections) daily and tested for HIV using the PCR test. Infant NVP is discontinued except for infants who are breastfed by mothers who are not on lifelong ART. If the PCR test for the infant is negative, cotrimoxazole is stopped for the infant who is formula fed, but continued for the infant who is breastfed, until breastfeeding is stopped and the infant is HIV negative (DOH, 2010: 5).

Infants whose PCR test results are positive are promptly referred for ART (DOH, 2010:5). They are further investigated as soon as possible for RNA PCR (viral load), CD4 cell count, CD4 cell percent, and by undertaking a baseline clinical staging as part of their baseline assessment. Highly active antiretroviral therapy (HAART) should be initiated in HIV infected infants as per the paediatric guidelines (DOH,

2008: 59). HIV exposed infants should receive follow-up appointments according to the Integrated Management of Childhood Illnesses (IMCI) clinical case management guidelines, including weekly visits during the first month of life, monthly visits thereafter, until the age of twelve months, and three monthly visits between the ages of 12 months and two years unless the child is ill. In this case, the child should be seen more often (DOH, 2010:27). At six, ten and 14 weeks of age and at nine and 18 months, all children should be immunised according to the South African Expanded Program on Immunization (EPI) schedule. All HIV exposed infants not on ART should have a rapid HIV test at 18 months of age (DOH, 2010:28). To be able to successfully implement the government policy, HIV positive mothers need to bring their infants for follow-up appointments at the Primary Health Care (PHC) centres/clinics.

In spite of the introduction of the PMTCT programme, the study conducted by Sherman *et al.* (2004:167) showed that only one third of infants of HIV positive mothers were returned for follow-up appointments, and more than 70% were lost for follow-up care by four months of age. This means that these infants' HIV status is unknown and should it be positive, these infants will not benefit from the free continued care and social support that is provided at the PHC centres /clinics. Manzi *et al.* (2005:1242) also indicated that the progressive loss of follow-up visits of more than a quarter of their cohort study by the six month postnatal visit demanded a different way of acting if the PMTCT programme is to be successful.

Up to 2010, during pregnancy, each woman's card was marked with a code (indicating 'HIV neg', 'HIV pos' or 'not tested yet'), based on her own mother's name. The code can only be deciphered with a code-key (kept confidentially by the health professionals) if the woman is willing to share her mother's name. After the birth, the infant's Road-to-Health (RtH) card is marked with his/her grandmother's code, showing whether he/she is an 'affected baby', 'unaffected baby' or 'baby born to untested mother'. Ginsburg *et al.* (2007:2531) reported that the ability to knowledgeably track infants depends upon identification and the recording and reporting of visits.

In my experience, as a registered advanced midwife and working in a Community Health Centre, I observed that all pregnant women receive health education regarding HIV/AIDS, and PMTCT, voluntary counselling and testing. Those mothers who agree to go for voluntary testing are further pre-counselled, tested and post-counselled. Those who test positive receive further counselling and get PMTCT ARV therapy according to the Department of Health policy. They are further informed about the following:

- 1 MTCT of HIV infection which may occur during pregnancy, childbirth and through breastfeeding;
- 2 Nevirapine syrup which should be taken by the infant post delivery within 72 hours;
- 3 Cotrimoxazole which will be given to the infant at six week for prophylaxis;
- 4 Infant feeding so that they may make informed choices (exclusive breastfeeding or formula feeding);
- 5 That those mothers who do not choose exclusive breastfeeding will receive free commercial infant formula according to the age of the infant each month for six months;
- 6 The infant should be brought to the clinic for PCR testing at six weeks of age.

Irrespective of all these, preliminary statistics from the three primary health clinics of Odi sub-district in Tshwane District, Gauteng Province show that from January-June 2009, only 41.1% of infants born to HIV positive mothers were brought for follow-up visits (Gauteng Department of Health, 2009:1-2). This means that 59% are lost for follow-up care, thus the infants' HIV status is not known and they will not get treatment and support as envisaged by the PMTCT programme. Infants who are HIV infected are often only brought to the clinic in an advanced stage of the disease when their condition is irreversible, and dying from HIV/AIDS related conditions such as tuberculosis, pneumonia, and various gastro-intestinal diseases. If these infants were brought to health centres for follow-up visits, they could have benefited from treatment and support.

According to Jones *et al.* (2005:467), the PMTCT in South Africa has been unsuccessful in ensuring continued care of HIV exposed children due to an extremely high loss rate of follow-up visits. Identifying reasons for the poor follow-up rate of HIV exposed infants in PMTCT programs is a potentially important component of improved service delivery to HIV infected infants/children and their families. Their findings on loss of follow-up of HIV exposed babies were: lack of financial and fathers' support, babies looked after by a care-giver who might not know the importance of follow-ups of the baby and, babies who left the city to areas where there health care facilities are less accessible. A situational analysis of the PMTCT programme as implemented in pilot sites in South Africa suggested that socio-economic factors such as poor mobility, long distances and the cost of transport led to poor follow-up (McCoy *et al.*, 2002:467).

Manzi *et al.* (2005:1248) found in their study conducted in Malawi, that the problem with loss to follow-up was likely to be associated with the centralised hospital-based PMTCT implementation strategy in a large rural district completely without public transport. Furthermore, Jones *et al.* (2005:469) found that high unemployment rates, poor access to state financial grants and poor parental support may deny mothers the necessary resources to attend clinic visits. Adding to that, they mentioned that in cases where disclosure to fathers who are living with the mothers did not occur, regular attendance at clinics may be more difficult. Many children are living with caregivers other than their mothers and these caregivers may not understand the importance of continued follow-up, especially if there is no disclosure. The researchers acknowledge that part of failure to follow-up might have been due to high neonatal and infant mortality rates (Ioannidis *et al.*, 1999:773). Tejiokem *et al.* (2011:6) also supported the failure of infants to return for follow-up was due to mortality.

Personnel constraints, such as identifying and training personnel to carry out VCT and other PMTCT activities and sustaining the services also cause problems. Very often, existing health service providers are overloaded, suffer from burnout and are living with the stress of HIV/AIDS in their own lives and families (McKee *et al.*, 2004:215). In addition, Varga and Brookes (2008:798) found that nurse counsellors revealed high levels of psycho emotional stress because of their inability to cope with the counselling load and the needs of their PMTCT patients.

Although reasons for low follow-up rates were identified in different studies, the identified reasons do not seem applicable to the semi-urban district area of Odi sub-district which is the focus of this study. There are several clinics in each township, an adequate transport system and no farming industries. The researcher saw a need to do this research, so that the reasons that contribute to low follow-up rates in this area may be identified and addressed.

1.3 PROBLEM STATEMENT

There is a growing concern about infants born to HIV positive mothers being lost for follow-up care, without knowing about their HIV status and not benefiting from the support and treatment available. This is proved by the statistics from the three 24hours primary health clinics of Odi sub-district, where from January-June 2009, only 41.1% of infants born to HIV positive mothers were brought for follow-up visits, and 59% were lost for follow-up.

Knowledge regarding the factors that contribute to the low rates of follow-up for infants born to HIV positive mothers in the three primary health clinics of Odi sub-district in Tshwane District, Gauteng Province, will lead to the formulation of recommendations for the improvement of follow up rates and improvement of care for these infants.

From the above mentioned, the following questions arose:

1. What are the factors that contribute to the low follow-up of infants born to HIV positive mothers in the primary health clinics of Odi sub-district?

- according to HIV positive mothers; as well as
- according to nurses and HIV counsellors.

2. What strategies can be used to encourage HIV positive mothers to bring their babies for follow-up?

1.4 OBJECTIVES

The research question will be addressed through the following objectives:

- To explore and describe the factors contributing to the low follow-up rate of infants born to HIV positive mothers in the primary health clinics of Odi sub-district according to
 - HIV-positive mothers; as well as
 - nurses and HIV counsellors.
- To explore and describe strategies that can be used to encourage HIV positive mothers to bring their babies for follow-up according to nurses and HIV counsellors.

1.5 PARADIGMATIC PERSPECTIVE

In this section the following will be discussed: the meta-theoretical assumptions, theoretical assumptions and methodological assumptions.

1.5.1 Meta-theoretical assumptions

According to De Vos (2005:40), meta-theoretical assumptions refer to the researcher's personal beliefs regarding man and the environment in which he lives and is not testable. The researcher, as a Christian, based her meta-theoretical assumptions on a Christian worldview and they include the following concepts: man/person, environment, health and disease.

1.5.1.1 *Man/person*

Man/person is created by God in His image and is tripartite i.e., he/she is a spirit, has a soul (thoughts and emotions) and lives in a body. He has the will to choose, and

can choose to do right or wrong. The choices he/she makes will determine the consequences. If the choice made brought about negative results, he/she is given the option to repent and choose a better option for positive benefits. In this study man/person is the HIV positive mother who did not return her baby for the six weeks follow-up visit, the baby who is at risk of a fatal condition and nurses and counsellors who are rendering service to the mother and the baby.

1.5.1.2 *Environment*

This includes the internal and external environment of man/person. Internal environment includes her thoughts, emotions and beliefs. External environment includes the family, community (health care centre) and the society at large with which she interacts. The HIV positive mother's thoughts and emotions are wrestling with the decision of whether or not to take her baby to the health centre. The nurses and HIV counsellors at the health centre are trying their best to see the infant in order to give the care needed based on his/her condition.

1.5.1.3 *Health*

The World Health Organisation (WHO) defines health as a state of physical, mental and social wellbeing and not merely the absence of disease. The researcher includes the spiritual component of wellness. If one of these components is deficient, the others are affected. Therefore, the researcher believes that if the mother can be encouraged spiritually of her status and the effect on the baby, the HIV positive mother will be encouraged to bring her baby to the health centre/clinic at six weeks for HIV PCR testing to maintain their wellbeing.

1.5.1.4 *Illness*

Illness occurs when one of man's components is affected. This may be either the spiritual, physical, mental (psychological) or social aspect. In this study, the researcher sees the HIV positive mother as being ill either spiritually or psychologically which is reflected in her not bringing her affected infant to the health centre for a follow-up visit. The nurses and the counsellor are also affected

psychologically by not seeing the affected infant being brought to the health centre for further investigations, in this case HIV PCR to curb physical illness.

1.5.2 Theoretical assumptions

In this study, theoretical assumptions include the central theoretical statement, definition of key concepts and the theoretical framework applicable to this study.

1.5.2.1 Central theoretical statement

Understanding the reasons for the low rates follow-up visits of infants born to HIV positive mothers will contribute to the formulation of guidelines to improve the rate of follow-up and thus lead to more affected infants benefiting from the treatment, care and support available to them.

1.5.2.2 Theoretical definitions of key concepts

In this study, the following key concepts are clarified and their meaning provided within the context of this study:

- **HIV/AIDS**

HIV is an acronym for Human Immunodeficiency Virus and AIDS is an acronym for Acquired Immune Deficiency Syndrome. The virus is transmitted through blood, sexual intercourse or mother-to-child during pregnancy, delivery or breastfeeding. The virus attacks the immune system, by destroying many helper T-cells while the HIV replicates. The person develops opportunistic infections which result in full-blown AIDS. In this study, the nurse and HIV counsellor test the mother and the baby for HIV to prevent the progression of the disease.

- **HIV positive mother.**

In this study, an HIV positive mother is the woman who when tested with a rapid HIV test and a second HIV confirmation test, the results were both positive, during antenatal care, labour or immediately post delivery.

- **Exposed infant**

In this study, an exposed infant is the baby born to an HIV positive mother that may be HIV infected himself and is expected to be brought to a primary health care facility at six weeks for a follow-up visit in order to be tested for HIV.

- **Low follow-up**

In this study, follow-up means an HIV exposed infant is brought to the health facility/clinic for postnatal check-up, EPI or routine child health clinic where they will be identified at six weeks of age to be tested for HIV and therefore, low follow-up means that the number of infants brought for follow-up is less than expected.

- **Nurse**

A nurse is a person providing health services in terms of the Nursing Act, 2005 (Act No. 33 of 2005:34), having acquired qualifications as a nurse and registered with the South African Nursing Council. In this study, the nurse is the one who is directly involved with pregnant mothers and their infants.

- **HIV counsellor**

The HIV Counsellor is a person involved in the provision of health services to a user, but does not include a professional health care provider. In this study, the counsellor works directly with antenatal and postnatal mothers to counsel them for HIV testing.

- **Prevention of mother to child transmission (PMTCT)**

Mother to child transmission (MTCT) is the main source of transmission of HIV from the mother to the child during pregnancy, delivery or breastfeeding. In this case, the mother is the immediate source of infection. MTCT is a well-established mode of HIV transmission. PMTCT is the programme introduced to decrease the infection of infants born to HIV positive mothers. In this study, PMTCT means HIV testing of pregnant women, provision of ARVs to those that are HIV positive during the duration of pregnancy and, delivery and provision of treatment to their infants.

- **HIV PCR test**

This is the test used to detect the presence of HIV within the human genes of white blood cells. It is used in children below 18 months of age because they are still carrying their mothers' HIV antibodies which were transferred at three months of pregnancy.

1.5.3 Theoretical Framework

The point of departure for this study is the latest PMTCT policy (DOH, 2010).

The following interventions form part of the policy:

- all pregnant women should be offered HIV counselling and testing;
- those who tested negative should be offered a repeat HIV test at 32 weeks of gestation;
- Women who choose not to be tested should be offered HIV testing and counselling at each subsequent visit, labour or shortly after child birth;
- The CD4 cell count should be determined for all women who tested HIV positive;
- Women whose CD4 cell count is 350 cells/mm³ or less and women who are diagnosed with WHO stage 4 disease should be started with HAART;
- HIV positive women who tested positive and whose CD4 cell count is more than 350 cells/mm³ should be started with 300 mg of Zidovudine (AZT) daily from 14 weeks of pregnancy until delivery;
- HIV positive mothers should get a single dose of 200 mg of Nevirapine (sdNVP), 1 tablet (tab) of Truvada and 300 mg of AZT 3 hourly until delivery;
- Women who did not attend antenatal care or were not tested for HIV presenting in labour should be offered HIV testing and counselling in the first stage of labour and if positive, should be given the above triple treatment;

- If a woman who did not attend antenatal care or was not tested for HIV presents in hospital already in active labour, testing and counselling should be done immediately after delivery.
- The baby born to an HIV positive mother should be given NVP syrup from birth until six weeks if the mother is not breastfeeding and until breastfeeding is stopped if breastfeeding;
- HIV exposed infants should be brought to a health facility at six weeks of age for check-up, HIV PCR testing, cotrimoxazole prophylaxis treatment and reviewing of feeding method.

1.5.3 Methodological assumptions

Mouton and Marais (1994:16) explain the methodological assumptions as the researcher's understanding regarding the manner in which the scientific research should be planned, structured and carried out to comply with the demands of science. The researcher believes that the scientific research process is systematic, well ordered and reported in such a manner that the research community may have confidence in the research outcome.

1.6 RESEARCH DESIGN AND METHODS

1.6.1 Design

The proposed study was conducted as explorative, descriptive and contextual qualitative research. The aim was to capture the perspectives of HIV positive mothers (emic), nurses and HIV counsellors (etic) regarding the reasons that contribute to low follow-up of babies born to HIV positive mothers.

Qualitative research proposes to understand the response of the whole human being to a situation or situations. The participants communicate their experiences to the

researcher, who translates the communicated experiences into an understanding to the phenomenon under study (Burns & Grove, 2005:52).

This research is contextual in nature as the contributing factors regarding low follow-up of babies born to HIV positive mothers were only explored and described in a specific context.

1.6.2 Research Method

In this section, the context, population, sample, sampling process, data collection and data analysis are discussed.

1.6.2.1. Context

The study was conducted in the Odi sub-district of Gauteng province. This sub-district is a typical example of a sub-district experiencing a very low percentage of follow-up (41%) of babies born to HIV positive mothers. The Odi sub-district is comprised of three 24 hour CHC/clinics, six five-day clinics and one level-one hospital. Women who attend antenatal care in all these clinics deliver in the three 24 hour CHC/clinics. Those with complications are referred to the hospital, and those that need higher management are referred to a level three hospital in the region.

In all the CHC/clinics and hospitals, antenatal care is provided, with HIV counselling and testing (HCT) being offered to all pregnant women.

1.6.2.2. Population and sample

The target population in this study includes:

- a. HIV positive mothers of babies older than six weeks, attending the primary health care clinics of the Odi sub-district; and
- b. Nurses and HIV counsellors working in the 24 hours Primary health centre/clinics of the Odi sub-district

The selection criteria for the first population were:

HIV positive mothers who delivered in one of the three Odi sub-district clinics, who did not bring their babies for the six weeks follow-up and were willing to participate in the study.

The selection criteria for the participants for the focus group were:

Nurses registered with the South African Nursing Council (SANC) under the Nursing Act No. 33 of 2005 (South Africa, 2005:34) or, trained HIV-counsellors who were involved in rendering direct care to HIV positive mothers, who had at least two years of experience working with HIV positive mothers and were willing to participate in the study.

1.6.2.3. *Sampling process*

A purposive sampling approach was followed, where the sample which was selected from the population was chosen because the participants were able to provide as rich as possible information on the issue at hand (Brink, 2006:133).

The purposive sample from the first population occurred when mothers brought their babies to the primary health care clinics for reasons other than for the PMTCT programme. According to the integrated management of childhood (IMCI) clinical case management, all children should be routinely checked for their HIV status to see if they were exposed infants. Infants who were identified as exposed infants (according to the code previously explained) and were overdue for PCR testing, were given the care they needed and their mothers were then approached for recruitment to participate in the research in the following way. The nurses who were allocated to do IMCI, EPI services and identify the HIV exposed infants, then asked the mothers' particulars, informing them that there will be a researcher who will contact them. The researcher contacted them and recruited them for the research. At the time the researcher was busy with recruitment, coding was used but it is no longer in use. Instead, the status of the infant is written on the chart as it is.

As the researcher herself works at one of the primary health centres of the Odi sub-district, the nurses and the counsellors from that specific clinic were used in a focus group interview as a pilot to test the interview schedule and to determine if the core question was understandable as well as to stimulate free discussion. The focus group was also used to determine the effectiveness of the researcher as an interviewer and the use of a tape recorder in the interview process was tested. All the nurses and HIV counsellors who have worked in the other two primary health clinics for at least two years were asked to participate and those willing formed the sample.

1.6.2.4 *Sample size*

The sample size depended on data saturation, meaning that interviews were continued until no new findings were identified during the interviews (Strydom & Delport, 2005:328).

1.6.3 Data collection

Data was collected with individual semi-structured interviews with HIV positive mothers and focus groups with nurses and HIV counsellors. The question regarding the factors that contribute to the low follow-up of babies born to HIV positive mothers was asked to both the mothers and nurses and HIV counsellors. An opening question was used to open the interview: Why do you think mothers do not bring their babies to be tested at six weeks of age? The initial question was followed with additional probing questions to encourage the participants to clarify and expand their responses.

An appointment was made with mothers who expressed their willingness to participate in the study at a time and venue of the participant's preference. Data was collected from the mothers individually and privately by the researcher in a semi-structured interview. According to Brink (2006:151) an interview is a method of data collection in which an interviewer obtains response from a subject in a face-to-face

encounter, through a telephone call or by electronic means. The researcher used a face to face encounter as this type of interview was advantageous because the participant need not be learned, the researcher was able to observe non-verbal behaviour and mannerisms and misunderstood questions were clarified. The interviews were conducted in a non-threatening setting preferred by the participants.

The data from the nurses and HIV counsellors was collected from focus groups conducted by the researcher. The appointments for the interviews were arranged for a time and venue preferred by the participants. Participants were asked to describe their perceptions of factors that contribute to the low follow-up of babies born to HIV positive mothers. Brink (2006:152) defines focus group interviews as interviews with groups of about five to 15 people whose opinions and experiences are requested simultaneously. This method was advantageous in that it is flexible, there is a high response rate, and the interviewer/researcher used her interpersonal skills to facilitate cooperation and elicit more information. The method is inexpensive but the limitation however, was that it consumed more time. A semi-structured interview guide with open-ended questions to keep the discussion focused was used in the focus groups (Greeff, 2005:287).

The interviews were tape recorded and transcribed as soon as possible and field notes were taken. As the researcher was transcribing the data, she realised that there was limited data regarding the second research objective. Follow-up focus group interviews with the following core question were held: What strategies do you use to encourage these mothers to bring their babies back to the clinic for the scheduled follow-up at six weeks?

1.6.4. Data analysis

The open coding method was used to analyse the data collected from the individual as well as the focus group interviews. The three types of codes that were used are:

A. Descriptive codes – It is the simplest method of classification of data and will be used in the initial data analysis.

B. Interpretative codes - As the researcher gains insight into the processes under discussion, he or she begins to sort out statements and the participants' terms are used to attach meaning to these statements.

C. Explanatory notes - These codes are part of the researcher's attempt to unravel the meaning inherited in the discussions. These codes can be more general, for example, patterns, themes and causal links (Burns & Grove, 2005:549).

1.7. TRUSTWORTHINESS

To ensure the trustworthiness of this study, the researcher will follow the criteria identified by Guba (as described by De Vos 2005:346- 347).

1.7.1 Credibility

Credibility seeks to find truth about the findings and was enhanced by the following procedures in this study

- **Triangulation of sources**

Data was collected from mothers through individual interviews as well as nurses and HIV-counsellors through focus groups in order to obtain diverse views (emic and etic) of the phenomenon under study.

- **Referential adequacy**

Audio tapes as well as field notes were used to provide good records during data collection.

- **Peer briefing**

The researcher discussed the findings with the supervisor and colleagues who are knowledgeable in qualitative methods in order to review perception, insight and analyses.

1.7.2 Transferability

As the study is contextual in nature, the findings cannot be generalised. However, the theoretic framework and context will be described in detail to enable the reader to decide if the findings are transferable. In this research, transferability will be enhanced through triangulation where multiple informants and data-gathering methods are used to increase the study's usefulness for other settings (De Vos, 2005:346).

1.7.3 Dependability

Dependability refers to consistency of the research findings (Babbie & Mouton, 2001: 278). In this study the researcher accounted for differing conditions by providing a rich description of the context in which the research was conducted (De Vos, 2005:346).

1.7.4 Confirmability

Confirmability refers to objectivity. It is concerned with establishing that the data represent the information provided by the participants, and not the biases of the researcher. An audit trail was kept to determine if the conclusions, interpretations and recommendations can be traced to the sources and if they are supported by the inquiry. The transcriptions of the interviews were also checked against the original recordings on audiotapes (Babbie & Mouton, 2001: 278).

1.8. ETHICAL CONSIDERATIONS

1.8.1 Approval

Approvals from the Ethics committee of the University of North West (NWU) Potchefstroom campus (Appendix A), Gauteng Provincial Department of Health (see

Appendix B) as well as the Tshwane/Metsweding Research Ethics Committee (Appendix C) were obtained to conduct the study in the three 24 hour clinics of Odi sub-district of Gauteng Province.

1.8.2 Informed consent

Informed consent was obtained from all participants prior to data-collection (Appendix F and G). The participants received clear and full information regarding the study, including the aim and expectations from them and that they were free to choose to participate or to stop the process without any harm. On choosing to participate, they had to sign a consent form.

1.8.3 Rights of participants

During the process of the study, the rights of the participants were protected at all times by implementing the following principles (Brink, 2006:32-33):

- Principle of respect of persons - The HIV positive women are prone to stigma and are vulnerable therefore special arrangement was made during recruitment - see 1.6.2. In this study their decision to participate or terminate was respected. Information shared was kept confidential and the participants' identities were kept anonymous. All tape recordings, transcriptions and notes were kept under lock and key.
- Principle of beneficence - Although the participant did not directly benefit from the study, she helped that other mothers will be better supported and other babies benefit from the strategies flowing from this research. During the interview, the participants were protected from discomfort or harm, be it physical, emotional or psychological. A professional counsellor was available to assist in cases of emotional or psychological discomfort and appropriate referral was done for needs aroused, for example, in one case the participant's baby was HIV positive and was not yet started with treatment and she was referred to hospital according to the new protocol.

- Principle of justice - The researcher selected participants fairly according to the research plan. She always kept the times agreed upon. She respected the right to privacy of the participants at all times by keeping information collected confidential. Permission was asked from the participant in cases where her information needed to be shared, for example, with a member of the multi-disciplinary team.

1.9. FRAMEWORK OF THE RESEARCH

The study is reported in the following chapters:

Chapter 1: Orientation to the study

Chapter 2: Research design and methods

Chapter 3: Research findings and literature control

Chapter 4: Conclusions, limitations and recommendations

1.10 SUMMARY

In this chapter, an overview of the study was given, discussing the background and rationale of the study, followed by the problem statement, research question and objectives. This was followed by research design and methods, trustworthiness and ethical considerations.

CHAPTER 2

RESEARCH METHODS

2.1 INTRODUCTION

In this chapter the researcher dealt with the right choices of the research design that will be appropriate to the study to achieve what the study was intended for. These include the study methods of collecting data, and of data analysis. (Babbie, 2007:378). The research method includes discussions on: population, sampling and sampling technique, and data collection methods and how data was analysed. The discussion also describes how trustworthiness was ensured and ethical considerations taken into account.

2.2 RESEARCH DESIGN

Burns and Grove (2007:553) defines the research design as an overall plan for conducting a research, a blue print to guide the planning and implementation of a study to address the objectives and answer the research questions so as to achieve the intended goal. The research design of choice for this study was explorative, descriptive and contextual qualitative in nature.

According to Struwig and Stead (2001:7), the major purpose of exploratory research is to develop and clarify ideas and it involves gathering a great deal of information from a small sample. For this study, the researcher explored reasons for the low follow-up rate of babies born to HIV-positive mothers, through individual interviews with HIV-positive mothers and focus group interviews with nurses and HIV-counsellors.

Brink (2006:64) indicates the importance of context in that a research problem does not exist in a vacuum but is embedded in a particular context. This research was

done specifically and only on HIV-positive mothers and nurses and counsellors of the 24-hour clinics of Odi sub-district. The researcher managed to get reasons for the low follow-up rate in this area.

Langford, (2001:139) define qualitative research as an objective way to study subjective and holistic nature of humans, aiming to examine and understand the whole of a phenomenon using non-statistical methods of analysis. She adds that qualitative research focuses on process by which concepts are given meaning in a given context rather than on the measurement of the concepts and their relationships. The researcher's questions regarding reasons for low follow-up of babies born to HIV-positive mothers were adequately answered by the participants through explorative, descriptive and contextual qualitative design.

The qualitative method was found to be more appropriate and effective in exploring and focusing on the qualitative aspects of meaning and understanding of reasons for low follow-up rate of babies born to HIV-positive mothers from the view point of research participants in the context in which the action took place (Brink, 2006:113).

2.3 RESEARCH CONTEXT

The researcher chose to do the research in Odi sub-district because this was one of the sub-districts in Tshwane district, Gauteng Province, with a low follow-up rate of babies born to HIV- positive mothers. The sub-district has a district hospital, Odi hospital, three 24-hour clinics/health centers (Phedisong 4 Community Health Center (CHC), Kgabo CHC and Boekenhout Clinic).

Phedisong 4 CHC (see Appendix O) is situated in the semi-urban area of Ga-Rankuwa. Ga-Rankuwa is made up of 20 units and has three 5-day clinics, which also attend to antenatal clients. Deliveries are undertaken only in the CHC. It is next to Mabopane, Soshanguve, Rosslyn and close to a rural part of Madibeng district in North West Province - divided only by the main road from Ga-Rankuwa. There are many shacks belonging to stand owners and their tenants. The tenants are mostly foreigners, with most of them utilizing services in Ga-Rankuwa clinics. Most of them are from Zimbabwe and are in the country to seek jobs. The Academic hospital level

3, Dr George Mukhari Hospital, is closer to Phedisong 4 CHC than the other two 24-hour clinics, where these clinics refer complicated cases.

Kgabo CHC is situated in Winterveld (see Appendix P). This is a semi-rural area with many shacks. Most people live with extended families and there is a lot of unemployment of young men and women. There are a lot of shacks and muddy houses for stand owners and their tenants. Many of the tenants are foreigners and there is communication breakdown with the health workers due to language differences. It is a very big place and it has 3 five-day clinics which attend to ante natal care clients. It is next to Soshanguve and Mabopane with their clients coming for ANC to this CHC.

Boekenhout Clinic is in Boekenhout (see Appendix Q). This area is partly rural and partly urban. It has 2 five-day clinics which attend to ANC. Boekenhout also has stand owners with many tenants in one yard, also mostly foreigners. The clinics also attend to many foreigners and the language barrier is a challenge. It is too close to Mabopane and Soshanguve with many of the population attending health services in Boekenhout Clinic.

In the Perinatal Care Survey of Tshwane/Metsweding: 2009, Pattinson *et al* (2010:26-32) reported the obstetric statistics for the three 24-hour service clinics of Odi sub district as shown in Table 2.1.

Table 2.1 Obstetric statistics for the three 24-hour clinics/health centers

Clinic	ANC Attendance	VCT done	HIV + women	PCR done	PCR positive
Kgabo	377	359	53	103	4
Phedisong 4	199	190	56	56	3
Boekenhout	274	272	54	97	5
Total	750	721	163	256	12

From Table 2.2 below, the improvement brought about by the monthly discussions of the Tshwane sub district PMTCT forum, initiated to improve loss of follow-up of babies born to HIV- positive mothers, is clear.

Table 2.2 The prevalence of HIV-positive mothers and babies for the period of July to September 2011 in the Tshwane sub district PMTCT Forum

Clinic	Dates	Total deliveries	Missing stats
Phedisong 4	Jan 08 to April 10	1165	Nov 08, Jun – Jul 09, Nov 09, Jan 10
Kgabo	April 08 to April 10	2041	Jul 08, Jun 09, Nov 09, Jan 10
Boekenhout	April 08 to April 10	1208	Nov 2008, June 2009, Nov 2009, Jan 2010. (July 2008 incomplete)

The number of babies tested is higher than those of the mothers being positive as the infant's number included both the babies being brought at six weeks (babies born from mid-May to mid-August fall within the six weeks follow-up for the above period) including the babies who are repeated at four months as an internal policy, repeating PCR test as well as those being brought later than six weeks for different reasons.

2.4 RESEARCH METHOD

Research method according to Polit and Beck (2008:765), refers to the logical process which is followed during the application of scientific methods, procedures and techniques when a particular phenomenon is investigated. This means, it is the way in which research is planned, structured, and implemented to comply with the criteria for science. The researcher followed the research method which was applied as well as methods of ensuring trustworthiness and research ethics as discussed below.

2.4.1 Sampling

Sampling involves selecting a group of people, events, behaviours or other elements with which to conduct a study (Burns & Grove, 2005:341). This includes research population, sampling technique and sample selection, sample and sample size.

2.4.1.1 Population

A research population, sometimes referred to as target population, is the entire set of individuals or elements, who meet the sampling criteria. The accessible population is the portion of target population to which the researcher has reasonable access (Burns & Grove, 2005:342). In this study there were two populations:

- 1) all the HIV-positive mothers who did not bring their babies for 6 weeks follow-up, attending the three 24-hour primary health clinics of Odi Sub-district in Tshwane District of Gauteng Province; and
- 2) all nurses and HIV-counsellors working in the three 24-hour primary health clinics of Odi sub-district in Tshwane district of Gauteng Province for at least two years.

2.4.1.2 Sampling technique

Burns and Grove (2007:40) defines sampling technique as the process for selecting events, a group of people, behaviours or other elements with which to conduct a study where the population cannot be managed because of its size. In this explorative, descriptive, contextual qualitative research, the researcher selected the participants purposefully, whom she believed were knowledgeable informants on the subject of low follow-up of babies born to HIV-positive mothers and would bring rich information to the study.

- **The criteria followed to select research participants**

The selection criteria for individual interviews (mothers)

- HIV-positive mothers who delivered in one of the three 24-hour Odi sub-district clinics and did not bring their babies for 6 weeks follow-up.
- HIV-positive mothers who were willing to participate in the study and gave either verbal or written consent.

The selection criteria for focus group participants

1: nurses who:

- were registered with the South African Nursing Council (SANC) under the Nursing Act No. 33 of 2005 (Republic of South Africa 2005:34).
- were involved in rendering direct nursing care to HIV-positive mothers.
- had at least two years of experience working with HIV-positive mothers.
- were willing to participate in the study and give written consent.

2: HIV-councillors who:

- have been counselling for at least two years in the same clinic with pregnant mothers.
- were willing to participate in the study and give written consent.

- **Sampling procedure for individual interviews**

For this explorative, descriptive, contextual qualitative study on low follow-up of babies born to HIV- positive mothers, the researcher conducted purposive sampling approach. The following process was followed to select participants for the individual semi-structured interviews:

After permission was granted to conduct the study at the clinics, the researcher informed the nurses who were allocated to do IMCI and EPI about the study. They acted as mediators by identifying the research population. According to the IMCI clinical case management, all children should be routinely checked for their HIV status to see if they were exposed babies as explained in Chapter 1.3 Babies who were identified to be exposed infants, and were overdue for PCR testing, were given the service they needed. The nurses then asked the mothers' particulars and informed them that there would be a researcher who will contact them telephonically for those who had phones or visit those who had no phones at their homes. .

The researcher contacted identified individual potential participants personally to find out if they were interested in participating in the study. The mothers who were willing were then selected based on their interest to participate. All of the participants were informed that they could withdraw from the study if they felt uncomfortable with the process at any stage and that there would be no negative repercussions. Information was provided about what the study was about, what would be expected from them and that a counsellor was available if needed for any discomfort or stress. All the participants gave their informed consent either verbally or written.

- **Sampling procedure for focus group interviews**

In this study, the sample for focus groups from the 3 clinics consisting of nurses and HIV-counsellors met the inclusion criteria. Arrangements to contact the potential participants were made through the supervisor at the sub-district. The facility managers were informed by the researcher about the study and appointments scheduled with them for focus group interviews which were conducted in the clinics. The researcher approached the participants individually to discuss with them about the research procedures to be followed, purpose of the study and objectives and to obtain an informed consent from them. Those willing to participate were included in the group.

2.4.1.3 Sample size

In this study the sample size was determined by data saturation when no more new information emerged. In the first sample, the total number of 5 individual semi-structured interviews was done with HIV-positive mothers, which was stopped when additional sampling provided no new information according to the guidelines of Burns & Grove (2007:348). The second sample was stopped after the 3rd focus group interview, when no new themes emerged from the interview. The group size varied between 5 and 8 individuals assembled to answer questions on a given topic. Groups of this size allow everyone to participate. Since fewer than five participants tend to result in inadequate discussions, it was critical to recruit the appropriate number of participants for each of the focus group (Burns & Grove, 2007:379).

2.4.2 Data collection

Data collection is defined by Langford (2001:94) as a formal procedure of gathering data necessary to address a research problem or research objectives. Data can be provided through self-reported accounts of participants, observation and biophysiologic measures (Polit *et al.*, 2001:263). In this study, self report approach, through semi structured interviews, was used.

In the following section, research setting, data collecting instruments, pre-testing interview guide and interviews will be discussed

.

2.4.2.1 Research setting

Research settings are the physical locations or specific places where data collection occurs. Based on Burns and Grove (2007:29-30) in-depth qualitative study is likely to be done in a naturalistic setting or field which is an uncontrolled, real life situation or environment. Such settings can be at people's homes or places of work (Polit & Beck, 2008:57).

Individual semi-structured interviews' settings were arranged with mothers at a place convenient and comfortable for them, either at the participant's home or at the clinic. Some participants were given money for transport while others were collected by the researcher from their homes. Focus group setting was in the clinic where the nurses and HIV-counsellors work since they were on duty. These were held at Phedisong 4, Boekenhout and Kgabo Primary Health Care/Clinics, in Odi sub-district of Tswane District, Gauteng Province.

It is the responsibility of the interviewer to create a suitable and conducive environment for the participants to sit comfortably, and maintain eye contact with all participants, so that they will be able to express themselves freely. (Burns & Grove, 2005:543). The researcher made sure that the venues for the focus groups were easily accessible and provided a non-threatening climate. The venues were prepared before the participants arrived. These venues provided privacy, comfort and were free from distractions such as noise or other interruptions and people moving in and out.

A boardroom/office/kitchen in a quiet place was prepared as arranged with the managers for this purpose, with a table and chairs around it for the convenience of the conversation and possible eye contact with one another, and to support interaction among participants and easy recording of discussions and comments (Greeff, 2005:294). A 'do not disturb' notice was placed on the door to make people aware that there were interviews in progress.

2.4.2.2 *The data collection instruments*

For this study, the researcher used interviews to collect data. The interviews merely extend and formalise conversation with a purpose (Greeff, 2005:292; Holloway, 2005:152) Interviews are defined by Henning *et al.* (2004:53) as a mechanism to source data from participants through structured conversations. If used

methodologically and applied according to strict principles of objectivity and neutrality, interviews will yield information that represents reality more or less “as it is” through the response of interviewees. According to Rubin and Rubin (1995:145), an interview consists of four kinds of questions which are: demographic, open ended, probing and follow up questions.

Demographic questions for individual interview participants (see Appendix H) were used to provide the following profile information: age, parity, religion, standard of education, marital status and whether employed or not. The demographic information for focus group participants (Appendix I) included: age, gender, religious affiliation and courses done related to HIV and AIDS.

The main data collection instruments were interview guides for individual and focus group interviews. The central question posed to each individual and to the focus groups, was:

- What are the factors that contribute to the low follow- up of babies born to HIV-positive mothers?
- What strategies do you use to encourage the mothers to bring back their babies for 6 weeks follow-up?

This second question was posed to the focus group.

After training in interview skills, the researcher acted as an interviewer for individual interviews and as a facilitator for focus groups collecting data, making observations and writing notes.

2.4.2.3 *Pre-testing the interview guide*

Pre-testing of the interview guide according to Polit and Beck (2008:762), is conducted in order to identify possible weaknesses, especially on the questions asked and responses provided by the participants. According to Seidman (1998:32)

pre-testing of the interview guide gives the researcher an opportunity to try out the interview design and questioning with a small number of participants who are not part of the main study. The purpose of conducting pre-testing in this study was to evaluate the comprehension of questions, the duration of the interview, to test the interview skills of the researcher as well as the use of the audio-recording device.

A small scale study was conducted with a group of 5 nurses in a focus group to pre-test the semi-structured interview guides, interview skills and the skills on the use of the taping facilities. Although the researcher decided to adjust the questions, the trial run interviews did produce rich data and were therefore included in the analysis.

2.4.2.4 *Data collection process*

The following process was followed in conducting interviews:

All ethical requirements had been met prior to collecting data – see 2.6. The researcher then arranged and communicated the date, time, duration, and venues of the interview well in advance for both the individual and focus groups interviews. This was done to prepare the participants psychologically and emotionally. The settings were well arranged as described under section 2.4.2.1. The documents such as informed consent form (see appendices F and G), demographic form (appendices H and I) and journal for taking notes were prepared for the interviews. The role of the researcher was to ensure that the interview process is managed successfully. The researcher arrived early at the venues where interviews were to be held. The researcher welcomed the participants and an introduction was done as an ice breaking mechanism. Participants were requested to switch off their cell phones or to place them in silent mode to avoid interruptions.

The researcher explained the ethical issues, the general purpose of the research, the specific purpose of the interview and possible benefits such as counselling sessions available if needed, as stated in the informed consent letter (Appendix F

and G). Each participant then signed to give their informed consent for participation. The researcher reached an agreement with the participants concerning the approximate duration of the interview sessions.

- **Individual interviews**

In this current study, semi-structured individual interviews were conducted with a purposively selected sample of HIV-positive mothers who did not return their babies for 6 weeks follow-up for HIV-testing. With the individual interviews, the researcher conducted one-on-one interviews with the participants. The demographic data form (Appendix H) was collected from the participant and thereafter an open ended question, “What do you think makes mothers not bring their babies for 6 weeks follow-up for HIV-testing?” was posed.

Each participant was encouraged to express and deliberate on their ideas freely, with the researcher listening and clearly indicating her interest in their opinions. Each participant was initially allowed to communicate uninterrupted in her way of thinking and speaking, followed by promptings, probing, follow-up questions and remarks designed to elicit responses that demonstrated the participant’s conception of the identified concept. Throughout the interviews, the researcher used verbal and non-verbal communication, not forgetting to keep eye contact and expressing phrases such as “OK”, “I hear what you are saying” and “thank you”. These made the participant more open and free, and as a result she gave data that was useful.

The researcher guided the participant towards focusing on the issues at hand rather than on unrelated issues. In cases where the participant raised an issue that was outside the topic discussed, she was asked to hold it and to continue with it after the interview. Interviews were audio-taped as agreed upon with each participant. This was used to assist the researcher to concentrate better on what was said as some information could be easily missed.

The researcher kept field notes (see Appendix J) during and after interviews. Field notes according to Langford (2001:155), are written accounts of what the researcher sees, hears, experiences and thinks during the data collection and analysis processes. According to Polit and Beck (2008:754), these observations include the participants' responses to probing questions through non-verbal behaviours and cues. Therefore, the researcher in this study used field notes as a written account in the reflexive journal of what was seen, heard, experienced and thought about during the course of the interview.

At the end of the interview, each participant was asked if there were any questions or further comments to assist in the closure of the interview. Each participant was then thanked and allowed to disperse if she was satisfied. The tapes were marked properly with pseudonyms, using the dates of the interview and the number of the interviewee, for example, 19/09/10/1.

Methodological notes at the end of each session were written which assisted with the interpretative attempts to make meaning out of the observations. Personal notes about the researcher's own reflections and experiences about low follow-up rate of babies born to HIV positive mothers were written by the researcher to aid the researcher to bracket her own feelings and gain more insight into the basic experiences of the participants. The aim of keeping these notes was to compliment the audio recordings done during interviews (De Vos, 2005:298).

- **Focus group interview**

A focus group interview is defined by Brink (2006:152) as "an interview with a group of 5 to 15 people whose opinions and experiences are requested simultaneously". According to Burns and Grove (2007:379), one of the assumptions underlying the use of focus groups is that the group dynamics can encourage people to express and clarify their views in ways that are less likely to occur in a one-to-one interview. The group by virtue of its construction offers a protection to individuals who may feel

vulnerable in a one-to-one interview. Focus groups have been found to be helpful when dealing with sensitive topics especially in the work place. They also have the advantage of being inexpensive, flexible, stimulating, cumulative, elaborative and capable of producing rich data (Streubert-Speziale & Carpenter, 2003:29; Stringer, 2004:11). In this current study, semi-structured focus group interviews were conducted.

The participants of the focus groups were asked to complete the demographic data form (Appendix I). The researcher facilitated and guided the participants through a set of questions using a semi-structured interview guide in which she was trained and confident in. To commence the interview in each group, the researcher asked an open-ended question designed to introduce the topic and to encourage the participants to be free and open. To answer the research question the following question was asked: What do you think are the reasons that cause HIV-positive mothers to not bring their babies for 6 weeks follow-up for HIV testing? The question was followed by probing questions, based on the discussion. The researcher listened attentively, showing interest in the groups and putting in an effort to understand the meaning of their experiences as they provided from their perspective the reasons for low follow-up of babies born to HIV-positive mothers' point of view.

The researcher 'led the group', and made sure that each one of the participants got a chance to say something, and was careful to ensure that no one participant dominated the discussion. Expressions to encourage participants in their responses and to encourage them to volunteer more information were used and field notes were taken as explained under individual interviews.

The interview was terminated when no more new information emerged and new data yielded redundant information (Polit & Beck, 2008:768). Participants were given an opportunity to ask questions. The participants were informed of the need for follow-up interviews should there be aspects that are not clear enough or need further probing for saturation purposes (Terre Blanche *et al.*, 2006:129). The participants were thanked for sharing valuable information with the researcher and for their time.

Refreshments were served thereafter. In order to limit the risk of bias, the researcher used a reflexive journal to record her own feelings, experiences and opinions about reasons for low follow-up of babies born to HIV-positive mothers to avoid subjectivity.

- **The process of recording the interviews**

The following process was followed in tape recording the interviews:

- In the case of an audiotape, two recorders were taken along, one using batteries and the other using electricity in case of power failure, electric disturbances, flat batteries, or any other unforeseen reason, to ensure that discussions were captured in totality.
- The tape recorders were pre-tested to make sure that they were working properly. The extension cord was brought along in case the room had an electric socket or the socket gives a problem on the day of the interview which was tested before the interview.
- The tape recorder was placed between the researcher and the participant/s, or in the centre in the case of focus groups for better capturing of the conversation after permission to do so was obtained from the participants.

Both the individual and the focus group interviews were marked properly with dates and pseudonyms, such as, the date of the interview, the number of the focus group and the number of the participants, for example, 10/10/10/F1/5. The taped data provided the researcher with an opportunity to listen to it as often as was necessary to ensure that understanding of the meaning derived from the interviews has been achieved (Lincoln & Guba, 1985:271).

The following process was followed by the researcher and the co-coder to analyse data.

2.4.3 Data analysis

According to Burns and Grove (2005:548), in a qualitative study, volumes of data are gathered and these must be stored in an organised way for easy retrieval. Data management in qualitative research entails reducing the volume of data to facilitate examination, a process referred to as data reduction (Burns & Grove, 2005:548). For this purpose two co-coders were used, that is the researcher and an experienced co-coder, and the following three types of coding were used: Descriptive, Interpretative and Explanatory codes.

2.4.3.1 Data analysis method

In preparation for data analysis, each of the audio-taped individual and focus group interviews recorded (see appendices L and M) were transcribed verbatim by the researcher herself shortly after the interview in Setswana and then translated to English (Streubert-Speziale & Carpenter, 2003:28). One data set was re-translated in Setswana and found to be almost similar to the first. The transcripts were read and recorded soon after each interview. The interviewer listened to the tapes and evaluated her own interviewing approach. The researcher noted irregularities on how questions were asked and improvements were made in interviews that followed. Field notes were read and wrote on the verbatim transcriptions relevant to the interview. The transcribed interviews were validated by an experienced qualitative researcher after translation to English.

The open coding method was used to analyse the data collected from the individual interviews and focus groups and this was done by the researcher and the co-coder. The three types of codes that were used are:

- **Descriptive codes**

Descriptive codes classify elements of the data by using terms that describe how the researcher organises the data (Burns & Grove, 2005:549). The descriptive codes

such as fear, denial, doubt, uncertainty and more emerged in the initial stage of data analysis.

- **Interpretative codes**

Interpretative codes, as Burns and Grove (2005:549) state, usually developed later in the data collecting process as the researcher gains insight into the ongoing process and begins to move beyond simply sorting statements. The participant's terms are used to attach meaning to these statements. In this study the following were interpretive codes that emerged: emotional experiences, internal conflict and cognitive aspects. All the transcribed interviews were read and re-read in order to classify data (see table 3.3 and 3.4). In all final results the two coders met to discuss results and reach consensus.

- **Explanatory codes**

Explanatory notes are part of the researcher's attempt to unravel the meanings inherent in the situation. These codes connect data to the emerging theory and the codes used may be specific to the theory or be more general. In this research the following explanatory codes emerged: organisational reasons, internal reasons, external reasons, HIV specific and infant related reasons.

The co-coders met to discuss the final results, taking out some sub-categories which we did not agree upon and left what we agreed upon. After the data was organized and reduced into different codes, it was then analysed. This was followed by a review of literature to guide the interpretation and integration of the findings in order to draw meaning and conclusions from the results of the study (see Chapter 3).

2.5 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness according to Lincoln and Guba (1985:290) refers to the quality value of the final results and conclusions reached in a qualitative research. In qualitative

studies scientific rigor is measured by its trustworthiness or the extent to which the findings are true to the data collected and analysed. Scientific research aims at generating valid and reliable explanations about phenomena (Babbie & Mouton 2001:138).

Lincoln and Guba (1985:291-292) developed four criteria according to which trustworthiness is evaluated which are truth value or credibility, transferability or applicability, dependability or consistency and confirmability or neutrality.

2.5.1 Credibility

Credibility according to Lincoln and Guba (1985:291), refers to confidence in the truth of the data, its integrity and interpretation. It involves carrying out the investigation in a way that is believable. The following methods are suggested by Lincoln and Guba (1985:291-293) to improve and document credibility in a study.

- **Triangulation**

Triangulation refers to the use of multiple methods to collection and interpretation of data about a phenomenon to draw conclusions about what constitutes the truth (Polit & Beck, 2008:768). In this study the researcher used triangulation when she used the same question in individual interviews and focus groups in order to obtain diverse views of the phenomena under study. Demographic data and interviews as data collection methods were used. There was rigorous consultation with the co-coder to meet investigator triangulation. Literature review and control was also done as a method of triangulation.

- **Peer debriefing**

Peer debriefing refers to holding sessions with peers to review and explore various aspects of the inquiry (Polit & Beck 2008:548-549). The researcher presented the different chapters, interview guide and references of this investigation into reasons

for low follow-up of babies born to HIV positive mothers to research supervisor and colleagues who are knowledgeable in qualitative methods to give constructive inputs.

- **Member checking**

Member checking according to Lincoln and Guba (1985:293) is the most important method for validating the credibility of qualitative data. Similarly member checking entails giving the research participants an opportunity to determine whether the initial findings and interpretations are consistent with their views and experiences which they shared with the researcher. Member checking can be done informally during data collection and formally after the data has been collected and analysed (Polit & Beck, 2008:545). The researcher went back to the respondents of the 3 focus groups to ask the second question, “What strategies can be used to encourage the women to bring their babies to the clinic for follow-up at 6 weeks?” As this question was answered, richer additional information was given on reasons why mothers do not bring their babies for follow-up.

2.5.2 Transferability

Though the study is contextual in nature, the results cannot be generalised. However the theoretic framework and context were described in detail to enable the reader to decide if the findings are transferable. In this research, transferability will be enhanced through triangulation where multiple informants and data-gathering methods were used to increase the study’s usefulness for other settings (de Vos, 2005:346). The researcher involved information-rich participants, mainly mothers who did not bring their babies back for follow-up at the scheduled time. Other participants were the nurses and HIV-counsellors who work directly with these mothers and their babies, who contributed towards transferability by conducting purposive sampling, involving participants who shared a wealth of insights with the researcher.

2.5.3 Dependability

Dependability in qualitative research refers to consistency of the research findings (Babbie & Mouton, 2001:278). Lincoln and Guba (1985:295) argues that dependability or consistency of findings can only be attained once credibility has been established. In this current study the researcher planned to give enough information for an audit to be undertaken.

2.5.4 Confirmability

Confirmability refers to the degree to which the findings are the products of the product of the focus of the inquiry, and not the biases of the researcher. An audit trail was kept to determine if the conclusions, interpretations, and recommendations can be traced to the sources and if they are supported by the inquiry. The transcriptions of the interviews were also checked against the original recordings on audiotapes (Babbie & Mouton, 2001: 278).

The scientific methods and procedures employed in this study were described in detail. Information gathered from individual and focus group interviews and field notes were verified through literature control to determine whether similar finding were identified in other studies. Themes, categories and sub-categories were given to the independent coder who is skilled in qualitative research procedures to examine them so that consensus may be reached between her and the researcher.

2.6 ETHICAL CONSIDERATIONS

According to Polit and Beck (2008:168), qualitative research like all forms of research is subject to a code of ethics for the protection of human subjects. The nature of the study at hand is sensitive since the interview is on mothers who are HIV positive, and the HIV status is regarded as a very personal issue. To conduct a

study on such sensitive issues poses a number of ethical challenges. In this study, ethical consideration involved protection of the rights of the participants, the institutions involved and ensuring the scientific integrity of the study.

It was the responsibility of the researcher to obtain Ethics approval by the Ethics committee of the North-West University (Appendix A), the permission to conduct the research from the Gauteng Province and Odi District Provincial Department of Health and Social Development (Appendix C) and approved Clearance Certificate from Tshwane/Metsweding Region Research Ethics Committee (Appendix D).

2.6.1 Protecting the rights of the participants

In this study, the researcher ensured that the participants who willingly consented to participate were not exposed to harmful situations, either psychologically, emotionally or socially. The researcher avoided exploitation, coercion or manipulation of the participants as some of them were familiar with her. This was important especially in this regard because the researcher was well known to participants as an authority in the field of investigation. In the study the rights of the participants were protected by observing the following ethical practice such as, obtaining informed consent, demonstrating respect for confidentiality and anonymity, protecting the right to withdraw from the study, showing respect for human dignity, maintaining privacy and ensuring the principle of beneficence and justice (Polit & Beck, 2008:170-177). Use of mediators in sampling is explained in paragraph 2.4.1.2, under the heading, sample procedure for individual semi-structured interviews.

- **Informed consent**

People are autonomous beings and have the right to self-determination which involves consent or freedom to freely decide whether to participate or not to participate in research. Autonomy is interlinked with giving voluntary informed consent and capability to control ones activities and therefore it would be unethical to

coerce prospective participants to participate in a study (Burns & Grove 2007:201, 217).

In this study, although participants were selected through the use of the purposive sampling method, they were empowered in such a way as they could make an informed decision and to consent voluntarily to participate in the study. Participants were given full information about the study as to what its requirements, purpose and benefits are. The nature and implications of participation were explained and the participants were informed of their rights (Appendices F and G) after which the informed consent was obtained. For the individual participants, the information letter was read in English, and then explained in simple terms in the participants' mother tongue for them to understand. The letter was read throughout, and the participants' understanding was asked and clarifications made where necessary. The managers of the focus group participants were not informed about what was said in the interviews.

- **Right to withdraw from the study**

Participants were informed that they could refuse to participate or withdraw from the study even after signing the consent form or at any time when they experienced discomfort during the research process without penalty or victimisation.

- **Anonymity and confidentiality**

Management of data collected from participants in research should occur in such a way that the participants' identity is protected and information and responses cannot be linked (Burns & Grove, 2007:534). The principle of anonymity refers to the researcher's ability to keep informants nameless, whereas confidentiality refers to ability to keep data sources safe against unauthorised persons without the participants knowledge (Burns & Grove, 2007:531; Polit & Beck, 2008:747).

In this study, the researcher organised the data records in a manner that would ensure that there would not be a link between participants and their contributions during the interviews. In addition to this, the audio-tapes and transcripts and demographic data forms were locked in a safe at the School of Nursing Science of the North West University Potchefstroom campus for 5 years after the report is released, to prevent any unauthorised person from having access to the data.

The following measures were taken to ensure anonymity and confidentiality:

- Pseudonyms were used on the interview schedule response sheet instead of the participants' real names.
- Code numbers and pseudonyms were used in the analysis of data.
- Participants' names and contact details were not revealed in the research report and would also not be revealed in the publication of the study.
- The data was shared with only those who were actively involved in the analysis of the data and not any unauthorised person.
- Tapes and transcriptions will be erased five years after the research has been completed and the required publication/s has been effected.

- **Respect for human dignity**

Since human HIV-status is a personal issue, it was necessary for the researcher to demonstrate respect for each participant's unique views and refrain from being discriminatory or judgmental. Questions were asked in a simple and respectful manner. Participants were given the opportunity to express themselves fully without feeling humiliated and interruption unless where clarity was needed. The researcher avoided to ask personal questions and responded humanely towards their showing emotional disturbances.

- **Maintaining privacy**

According to Burns and Grove (2007:550), privacy refers to freedom to determine the time, extent and general circumstances under which information will be shared

with or withheld from others. Issues of being HIV-positive are regarded by some people as private and not to be discussed openly. For the recruitment of HIV-positive mothers, a mediator was used to tell them that someone would either visit or phone them (see section 2.4.1.2).

In this study, the researcher made sure that privacy was maintained during the individual interviews by conducting interviews at the participants' venue of choice. Focus group interviews were held in a boardroom that was away from interruptions and a kitchen where a 'do not disturb' sign was placed at the door to avoid exposing the participants from the onlookers.

2.6.2 Principle of beneficence

One of the fundamental ethical principle in research is that of beneficence which entails doing good and "above all, do no harm" such as psychological, physical, emotional, spiritual or any other harm to study participants (Burns & Grove 2007:531). Interviewing people on issues of their HIV-positive status may bring about discomfort and emotional distress. In this current study the researcher took care to establish an emotionally safe environment and ensured that focus groups participants respected each other's views and opinions. According to the researcher, considering the risk-benefit ratio, the benefits of this study outweighed the risks. The participants were protected from exposure to emotional distress because of the nature of the study. A counsellor, who was an employee in one of the study institutions, was made available for the participants who would require support or debriefing it as a result of suffering emotional stress due to their participation.

Explanation was given to the participants that there would be no direct benefits to them in this study but their participation would provide rich information through which recommendations would be made to improve the rate of follow-up of babies born to HIV-positive mothers in the future.

2.6.3 Principle of justice

According to Polit and Beck (2008:173), the principle of justice refers to fairness and equity which includes the participant's right to fair treatment and right to privacy.

- **Fair selection and treatment**

Participants who are to be involved in a study should be selected based on research requirements and not on their vulnerability or compromised position. It is the researcher's responsibility to protect the rights and interests of participants and ensure that they are not exploited for the advancement of knowledge science and research. Participants who withdraw from the study even after agreeing, should be treated in a non-prejudicial manner. Promises made by researchers to participants must be honoured and be afforded courteous and tactful treatment at all times (Polit & Beck, 2008:173-174).

In this study, individual and focus group interview participants were purposefully selected on the basis of their knowledge and experience of the study topic. Knowing the researcher might have compromised the position of the participants. The participants for individual interview were selected purposefully as mothers brought their babies to the clinics for other reasons.

2.6.4 Protecting the rights of the research institution

The rights of the research institutions were protected by obtaining informed consent and permission from the clinic management and the research committees of the suggested research settings. The researcher complied with the conditions which they set. An Ethical Certificate, which was obtained from the ethics committee of the North West University (Potchefstroom campus), was shown to the institution.

2.6.5 Enhancing the scientific integrity of the study

Scientific integrity refers to honest practices commonly accepted within the scientific community for conducting and writing research reports. To avoid plagiarism all sources and references used in the study were acknowledged. The research findings and presentation were done without manipulating data and information obtained from the participants during collection and analysis.

Acknowledgement of those persons who contributed towards the successful completion of this study was done. Strategies and measures which the researcher applied to enhance the trustworthiness of this study served to ensure its scientific integrity. The results of the study were shared with the institutions that granted the researcher the permission to do data-collection as well as the scientific community, by publishing findings.

2.7 SUMMARY

In this chapter the research design and methodology were described. The research process was discussed in detail, especially in terms of the research approach which was the qualitative paradigm and the research design which was explorative, descriptive and contextual design. The research setting was introduced. The research methodology included procedures such as determining the population, sample and sampling technique, data collection, data analysis, establishing trustworthiness and ethical considerations.

The data collection methods used as in-depth individual interviews, focus group interviews and field notes, were discussed. The data collection instruments were semi structured interview guides of one question for individual interviews and two questions for focus groups which were followed by probing questions. The analysis of data entailed open coding. Methods of ensuring trustworthiness of data and ethical considerations were described in detail.

A summary of the themes, categories and subcategories that emerged from collected data is presented in the next chapter.

CHAPTER 3

RESEARCH FINDINGS

3.1 INTRODUCTION

In this chapter results of the findings are discussed, justified by the participants' comments and literature. The demographic information of the participants is addressed firstly. The findings related to the first objective to explore and describe factors contributing to low follow-up of babies born to HIV-positive mothers in the primary health clinics of Odi sub-district and are discussed. Lastly, the findings related to the second objective to explore and describe the strategies of the health workers in the clinics to encourage the mothers to bring their babies for follow-up, are addressed.

3.2 DEMOGRAPHIC PROFILE OF PARTICIPANTS

3.2.1 Demographic information of participators in individual interviews

Demographic data from the five women who participated in the individual interviews was collected to get the picture of the participants. Questions asked were about age, parity, religion, level of education, employment and marital status. Three of the participants had four children, one had three children and one had two children. Two were not affiliated to any type of church. All of the participants had passed matric. They were all unemployed, and two of them were married. The illustration of the

demographic data for the participants in the individual interviews is provided in table 3.1

Table 3.1 Demographical information of individual participants

Age	2 were between age 31 – 40 3 were between age 21 - 30
Parity	3 had 4 children 1 had 3 children 1 had 2 children
Religion	1 was a Christian 2 were Protestants 2 belonged to no religion
Level of education	All matriculated
Employment	All were unemployed
Marital status	2 were married 3 were single

3.2.2 Demographic information of focus group participants

A total of 24 participants were involved in the focus groups. Seventeen participated in the first round of 3 focus group interviews: 13 nurses and 4 counsellors. The first and second focus groups had six participants each while the third one had 5 participants.

There were 24 participants in the second round of focus group interviews. When arrangements were made some of the previous participants were on leave, but other potential participants that were available, were recruited and signed informed consent.

The following is the demographic information of the focus group participants: Only three participants were under 30 years, eight were between 31 and 40 years of age, another eight ages ranged from 41 to 50 of age while five were between 50 and 60 years. Most were 40 years and older. All participants were females. Twelve of them were of Protestant belief; five considered themselves Christians while six did not indicate any religious affiliation.

With regard to HIV/AIDS related courses, twelve of the participants attended all three relevant courses (VCT, PMTCT and Lactation management course), but four of them did not attend any of the courses. The demographic information of the focus group participants is also presented in Table 3.2.

Table 3.2 Demographical information of focus group participants

Age	3 were between 21 – 30 years of age 8 were between 31 – 40 years of age 8 were between 40 - 50 years of age 5 were between 50 – 60 years of age
Gender	All were females
Religion Affiliation	12 were Protestants 5 were Christians 6 did not indicate any affiliation
HIV related courses VCT, PMTCT & Breastfeeding	12 completed all 3 courses 3 completed 2 of the courses 4 completed 1 of the courses 4 have not done any of the courses

3.3 RESEARCH FINDINGS

In this section themes and categories that emerged after the researcher and the independent co-coder analysed the data separately and reached consensus after

several discussions, will be discussed. Five themes and 17 categories emerged from the analysed data (figure 3.1).

Relevant quotations from both individual and focus group participants' expressions are used to support the themes. The quotes are numbered to enable a document audit. Numbering of quotes indicates the number of the individual participant (IP2) and the page from which the quotation comes, e.g. IP2/1, while for focus group participants it will be the number of the focus group (FG3), the participant number= /6, and the page number from which the quotation comes /11 e.g. FG3/6/11.

The discussion after the quotes incorporates literature to refute or confirm the finding of this study. The discussion of the findings related to the first question will be followed by the discussion addressing the second question.

3.3.1 Reasons why mothers do not bring their babies for the 6 weeks follow-up

The first question "Why do mothers not bring their babies for the 6 weeks follow-up?" was asked from participants of both the individual interviews with mothers and the focus groups with health workers.

Table 3.3 Themes related to reasons why mothers do not bring their babies for the six weeks follow-up for testing

Theme	Category
3.3.1.1 Internal reasons	• Emotional experiences • Cognitive aspects • Own being • Internal conflicts • Traditional beliefs
3.3.1.2 External reasons	• Relationship with life partner • Own family • Community • Consequences of disclosure of status • Language barriers between health workers and patients that are emigrants
3.3.1.3 Classical indicators of HIV	• A HIV- positive baby implies a HIV-positive mother

	• The clue when you regularly visit the same clinic • The use of formula milk
3.3.1.4 Organizational reasons	• Health facility staff • Mistrust in the capability of the health facility
3.3.1.5 Baby-related reasons	• Baby ultimately the main concern • Baby is a burden

3.3.1.1 Internal reasons

The word ‘internal’, according to Oxford Advanced Learners Dictionary (1993:656), is described as a problem of the mind and not outwardly expressed. This theme was expressed by participants as they described their emotional experiences, cognitive aspects, own being, internal conflicts and the role of religion as to why babies were not brought for the 6 weeks follow-up.

Table 3.4 Theme 1: Internal reasons

3.3.1.1 Internal reasons	• Emotional experiences • Cognitive aspects • Own being • Internal conflict • Traditional belief
--------------------------	--

• Emotional experiences

Oxford Advanced Learners Dictionary (1993:394), describes ‘emotion’ as a strong feeling of any kind, fear given as an example. Emotional experiences found to cause mothers not to bring their babies for the 6 weeks follow-up were fear about disclosure and denial of status.

➤ Fear about disclosure

Participants verbalized that it was disturbing to be told of the baby’s status. For them being positive, was tolerable because the partner could live with her without knowing her status but felt that if the baby tested positive, the family becomes aware of their

positive status. They were scared of the possible consequences, and that kept them from bringing their babies to the clinic at the due time - at 6 weeks of age. This was expressed as follows:

“Isn’t it now when you are HIV-positive, you think that maybe the baby is also HIV and some have not disclosed in the family that she is HIV” (IP1/1);

“Isn’t it I fear the mother will fear that if she brings the baby to the clinic the sisters will test her and find that there is a disease and when she return to the family and start to explain that the baby is sick. You will find that they start to judging her differently her and her baby” (IP3/1).

This finding is supported by a study conducted by Chopra *et al.* (2005:361), where it was found that the level of disclosure appeared to be low in most PMTCT settings, mostly due to fear of consequences.

According to the participants, it was better not to take the baby for testing, because that would disclose her status to the partner and/or family.

“... you will find that the family does not know and they will see the baby taking medication and will want to know what is wrong with the baby” (IP2/1);

The finding in this study compares with what Peltzer *et al.* (2008:456) who found that the taking of nevirapine by the mother and the baby was strongly associated with disclosing the HIV status to the partner. This in turn caused mothers not to take the baby to the clinic or doing it all secretly.

“At time she is afraid that you will find out that the baby is ill and the family will think differently on her” (PI2/1).

In their study “Wamepotea” (They Have Become Lost) in Western Kenya, Braitstein *et al.* (2011:e43) also found that one-third of all the children lost to follow-up was mostly due to fear of disclosure and discrimination. According to the study conducted by Chikonde *et al.* (2009:148) women found that weaning children at six months, home visits by staff and receiving HIV-linked food assistance were visible signs of disclosure and that led them to drop-out of PMTCT.

In the focus groups, it was verbalized that mothers feared to disclose the status of their babies, to keep their own status unknown. This was expressed in the following excerpts:

“Before I discharged her, she said, ‘give me the milk quickly before those people come’ “ (FG1/R3/3);

“Can we go and test the baby today? She refuses and refuses, she fears to face that issue that if I can find my baby being fears to face reality” (FG1/R4/5).

Although in some studies positive benefits were reported after disclosure of HIV-positive status, Medley *et al.* (2004:300) in their study about rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries, revealed a number of potential risks from disclosure for HIV-positive women including: blame, abandonment, violence, anger, stigma and depression.

“.... Some have a problem of being afraid to see people and some fear the family. Isn't it she did not tell the family of what is happening. She gave her baby to the mother She does not tell her mother anything because she is afraid her mother will know her status” (FG3/1 1)

“.... here in our place the problem is that it is full of foreigners.... Among them two or three or four are married to the same husband being many. So they do not disclose. And because this is the younger wife, she did not disclose to the elder wife, and the elder one to the younger wife. They did not tell the father because the father is the bread winner.” (FG2/5/4).

Mephram *et al.* (2011:744) agree with this finding that in polygamous relationships issues of disclosure are difficult as the HIV status of one individual may impact on the health of the others.

The participants found it difficult to disclose their status to their partners and families.

➤ Denial of status

The denial of status was clear from the behaviour of women who are HIV positive by the following expressions:

“They hide” (IP1/3);

“....she doesn’t say a thing” (IP2/4);

“....when you first hear that you are positive it is not simple to accept and some just sit and say that this baby is not sick and therefore I am not taking him and it is their minds telling them that they are not sick so why should I go there” (IP4/2)

...you can see it on her face that she is telling lies....she is lying...she will rather tell you lies.

“....not being able to accept that you are HIV....” (IP5/1)

This finding is confirmed by Lemly et al. (2007:531) in their study about factors related to medical appointment attendance after childbirth among HIV-infected women in the Paris region, namely that women felt forced to lie in the interest of secrecy, so that their status might not be revealed to the community.

“.... they encourage you to know the consequences of not coming but anyway we as people do not take it the same way. The other one feels that there is no such a thing. A lot of people do not believe. And I can see them that they do not believe. They will tell you that there is no such a thing, it is lies, the clinics are lying. She will just say I do not have it so how will my baby contract it, or if I have it why should my baby contract it....”(IP4/3).

Health workers complain of mothers who lose their cards, or change the coding on their cards and of some who visit different clinics because they were diagnosed HIV-positive, as a denial of the status. These statements were confirmed by participants in the focus group as follows:

‘ If they can be diagnosed that they are positive, they do not accept, they have a denial that they will move from place to place. So that is why sometimes these babies die because she does not accept that she is positive you see? She will only accept when she is deteriorating. Yes, but you would have diagnosed her on time

and she would have got treatment on time and CD4 count send on time and managed to see that they are low, you see?” (FG3/R8/5);

“ Like as we were saying that a person can tell you that I tested and I am negative and even when you check, her code is positive. Having tested positive and she says I am negative” (FG1/R3/3);

“Or sometimes it is denial, he tested before isn’t it that you know? You can test at Clinic A and they say positive and you say, they are mad those ones let me go to Clinic B. When you reach Clinic B they say positive. Before you can accept you have to go all around” (FG3x2/R6/4);

“.... I realized that some of these mothers realized that they are positive most of them when they are pregnant. So most of them have a denial that is so serious that make them fail to follow the program that has been well explained to them and well understood.” (FG1/4/5)

Medley *et al.*(2004:304) state the importance of women’s acceptance of their HIV-positive status after being tested for HIV willingly, to benefit from the interventions that can reduce HIV perinatal transmission.

- **Cognitive aspects**

These aspects included ignorance about the importance of visits, confusion/different sources of information and insufficient knowledge about HIV. Participants verbalized ignorance about the importance of the visits, insufficient knowledge of MTCT of HIV, as well as confusing information from health workers.

- **Ignorance about the importance of visits**

Participants showed little knowledge about MTCT and the effects thereof. The importance of bringing their babies for follow-up did not mean a lot to them. The

seriousness of their infants' condition is not taken into consideration. This was verbalized in these statements:

" Some just sit and say that this baby is not sick and therefore I am not taking him So why should I go there. I go there I am going to find that he is also positive It is no more pleasant and therefore you feel that it is better just to sit" (IP4/1);

"... sometimes she tells me that she forgets" (IP5/1);

In agreement with the findings in this study, the study about medication adherence for HIV-positive women caring for children (Wood *et al.*, 2004:911), one participant stated that she did not feel sick and therefore could not take medication, and taking medication reminded her that she had it (HIV) and she kept forgetting.

These results are also supported by Braitstein *et al.* (2011:e42) when in their study, some reasons given for low follow-up were family of the child, or work commitments, or the caregiver, or having forgotten the appointment, which shows much ignorance about the importance of follow-up visits to health facilities.

➤ **Insufficient knowledge about MTCT of HIV**

HIV-positive mothers need adequate information to make the right decision about their health and that of their babies. This information can be obtained from, among others, health workers. This was reinforced by the mothers when they verbalized their insufficient knowledge about HIV, and that they needed to learn from the health workers. This is exemplified in the following excerpts:

"Isn't now when you are HIV, you think that the baby is also HIV" (IP5/1);

".... At times I think she did not get the right information properly basically they did not tell her in detail about HIV and pregnancy and how it affects the baby" (IP5/2).

This finding was confirmed by Peltzer *et al.* (2008:456) when in their study, 36.7% of their participants incorrectly believed that a baby born to an HIV-positive mother will also be infected. Chopra *et al.* (2005:361) agree that even though mothers were counselled, there was still inadequate knowledge of MTCT. This is also supported by Bajunirwe and Muzoora (2005) where in their interview with mothers it became clear

that knowledge about the possibility of the virus being passed on to an unborn baby (12%) and the virus being passed from mother to child (8%) was lacking.

“Like when you are at the clinic for pregnancy care there should be lessons that focus only on HIV that informs. Even though the others are not positive but that lesson should strictly focus on HIV and inform people. I also didn’t know in the beginning but what helped me is that when I began to go to the clinic they straight away send me to the hospital and when I got to the hospital I meet sisters who took their time to inform me” (IP5/2);

Mothers expressed their keenness to have knowledge and understanding about PMTCT but those who need to educate them (nurses and counsellors), expressed their need to get more information about PMTCT.

➤ **Confusing information**

Participants were concerned about different information from health workers which caused confusion:

“I went to the clinic at six weeks. I found one sister. I told her that I have brought the baby for six weeks. I know at the hospital the way they informed me I must bring the baby to get tested. So she told me I think some of the sisters are not all informed about HIV. She told me that things have changed lately, the baby should be tested at nine months. But I was not happy about that and there was no way in which I could go back to hospital. I then went again the following day. When I came there I found another sister and explained to me saying: Have you come here for the six weeks? I explained to her that I came for six weeks and this and that happened and she was also surprised. I also told her that I was also amazed because I knew that the procedure should be like that” (IP5/2).

• **Own being**

An HIV-positive mother may have self-stigma, condemning herself about what people would think about her. Sub-categories that emerged are: Being undisciplined, self-deceit about the problem, shyness about HIV and self-blame about HIV.

➤ **Being undisciplined**

The participants in the focus group of mothers accused the mothers of being undisciplined, as expressed in the following:

“.... our community is irresponsible. And they have this thing of becoming dependent. They don't take responsibility in their lives. They want somebody else to take responsibility in their lives” (FG1/3/4);

“And again these people want a burden to be upon us. That is why every time we are worried. That is why even now we met here because we are worried because we think it is our burden and they also know that it is our burden and they have offloaded it from them” (FG1/5/6).

➤ **Self-deceit about the problem**

One participant expressed self- deceit about the problem as follows:

“The other one feels that there is no such a thing. Like it is like a dream when they tell you.... She does not think the way she should be thinking because it is possible for the baby to be infected as there are many mistakes that can happen when the baby is born And I can see them that they do not believe. They will tell you that there is no such a thing, it is lies, the clinics are lying. If I have it why should my baby contract it. The other one will tell you that it was only TB.” (IP4/3).

This finding is confirmed in the study by Painter *et al.* (2004:544) where some participants denied their HIV-positive status with reasons like ‘I do not touch sharp objects that belong to others, I have known only two men in my life and they are not positive, in my first test I was negative’.

➤ **Shyness about HIV**

One of the delays to bring the babies for follow-up at a set time was verbalized by participants as being shy as follows:

".... These mothers are shy of their situation and the treatment, one they have received from the nurses. You become shy that what if even this baby when I go there I am going to find that he is also positive I think is being shy like it is not simple to accept that I am positive (IP4/1);

"I was shy of coming in contact with those people because I felt everybody knew about me and my condition so I did not return and went to another clinic" (IP4/4);

"Some is the shame of what people are going to say"(IP1/1);

The study of Anderson and Doyal (2004:101) about women from Africa living with HIV in London, revealed that they were so ashamed to let the African community know their status, that they led a secret life and also felt the need to lie so that their diagnosis might not be revealed.

➤ **Self-blame about the causes of HIV**

One participant explained how she blamed herself for delaying to bring her baby for follow-up.

".... Thinking that, what if he is positive, because we were not condomising with his father during pregnancy. Eish, you find that he has contracted it, such things. To come to test, I was afraid because after I did mixed feeding, I already knew that from the education, after mixed feeding, he was going to be positive. Every time when I look at him, my baby being sick, and the mistake is mine, all the time I would blame myself. ... Those who see him will think that it is babies' illnesses, whereas I will be knowing what the problem is" (IP1/1).

"I felt so guilty that I had brought this on myself and I couldn't deal with it". This was verbalized by a woman in the study on medication adherence for HIV-positive women caring for children by Wood et al.(2004:911) and supports this finding of self blame about the causes of HIV.

This was also found in the study by Painter *et al.* (2004:545), where one woman stated that she was ashamed of herself when realizing that she was infected by 'AIDS'.

- **Internal conflicts**

Participants verbalized the war raging inside them about doing or not doing – i.e. taking the baby to the clinic for follow-up or not.

- **Should versus should not:**

Participants expressed their internal conflicts in the following excerpts:

“I realized that at the end still I am going to make my baby suffer. He is going to be ill, and I am the one who knows. Those who see him will think that it is babies illnesses, whereas I will be knowing what the problem is.(IP1/1).

“I was telling myself that it is the same, still if you are afraid, you kill the baby you kill the baby and that fear will result in regret. I saw that it is best to take him, and he get treatment and he be right” (IP1/3).

In the study conducted by Woods *et al.*(2004:911), a woman who was afraid to take the medication stated, “I got sick so I knew if I didn't do something I was going to die. What would happen to them (her children) if I died? I got more scared of dying that I did of having the HIV so I took them (pills)”. She also expressed the fear and doubt of not taking pills, but seeing that she was sick and about to die, decided to take pills.

- **Traditional belief**

Though the issue of traditional beliefs was never mentioned by the individual participants (HIV-positive mothers), it was mentioned in almost all focus groups (nurses and HIV-counsellors) in the following terms:

“ There are some people of certain religions who come to the clinic to deliver only. And they believe in anything that is given to them at according to their religion and their beliefs”. (FG1/5/5).

“ You see these people who wear white clothes and cover their heads like this (demonstrating),.... They have got a problem these people because they say they don't take tablets. So there are people who are responsible for them. They say if they have a problem, those people must come and pray for them and they must be healed. So if a person from them come and she is positive, she is not going to take AZT correctly if you give her tablets, especially if the partner is also of that religion, and not only the mother in law because she must not take any medication. So, the delivery must be at home” (FG2/1/6).

In the study conducted by Braitstein *et al.* (2011:e43), their finding confirmed that the belief that the child was healed by faith or traditional medicine usage led to no follow-up of babies born to HIV-positive mothers.

“And the belief of black people on the traditional healers and prophets. The other day I was delivering a woman And she was positive. The mother ran to Hammanskraal to collect a robe because it was said she was not to deliver before the robe was here” (FG3/5/7).

Miller *et al.* (2010:53) support this finding that some of the patients in their study substituted antiretroviral treatment with traditional medication while others took it in addition to treatment and that kept them from attending their follow-ups. A similar finding was observed in a study in Northern KwaZulu-Natal, South Africa, namely that the decision to stop ART in HIV patients and being replaced by traditional medicine might be due to local health beliefs (Mepham *et al.* 2011:745). In the study of women from Africa living with HIV in London by Anderson and Doyal (2004:101), religious beliefs were important determinants of their decision and 16% of them used traditional African remedies.

3.3.1.2. External reasons

The participants in this research expressed external reasons for not bringing their babies for follow-up, like: relationship with life partner, own family, community and disclosure of status to external system.

Table 3.5 External reasons

3.3.1.2 External reasons	• Relationship with life partner • Own family • Community • Consequences of disclosure of status • Language barriers between health workers and patients that are immigrants
--------------------------	--

- **Relationship with life partner**

The sub-categories under this category include focus on maintaining the status quo, accusations about who is the actual ‘giver’ of HIV, which rank higher than the baby’s health and power of the in-laws.

The participants expressed that they did not bring the baby for follow-up due to fear that their relationship would be hampered.

- **Focus on maintaining status quo**

Participants, especially those who live with their partners, preferred to keep silent about the baby’s status and not wanting the baby seen taking medication in order to keep the relationship with the partner intact. These are verbalized in the following excerpts:

“She is scarred that if she discloses to her husband there will be fights in their relationship. Yes, you find that you fight and divorce. Yes he is the one she is afraid of” (PI2/2);

“ Isn’t it some when they realize that the mother and the baby are sick then conflicts will begin which will never end” (PI2/1);

“Being afraid that she will start to fight with the husband You will start in the home and will not live happily anymore” (PI3/1).

In order to avoid tension, women in the study by Chinkonde *et al.* (2009:149), succumbed to unprotected sex which may lead to re-infection.

According to these statements, mothers preferred to protect their relationships with their partners above ensuring that their infants received help as soon as possible. This was also found in Braitstein *et al.* (2011:e43) where mothers refused care because of family conflict. Participants in their study stated that as a result of disclosing the child’s diagnosis to the family members, the mother-child pair might experience intra-family discrimination or even violence or expulsion from the home. In contrast, Braitstein *et al.* (2011:e44) point out that not disclosing the child’s HIV status is a tremendous threat to the health of the child because of the need of care, treatment and support.

Jones *et al.* (2005:469) claim that in the cases where disclosure to the fathers still living with the mother did not occur, regular attendance at the clinics might be more difficult. To curb this problem, Torpey *et al.* (2010:4) suggested the integration of male partners in PMTCT. Bajunirwe and Muzooru (2005:6) in conclusion of their study also suggested the involvement of male partners, especially in the rural areas. In order to assist women to cope with the HIV- status, it is important that male partners should be involved in HIV testing as part of PMTCT programmes (Mirkuzie *et al.* 2010:8).

➤ **Accusations about who is the actual “giver” of HIV**

Most participants living with their partners had difficulty to disclose their status to them because of fear that the blame of the giver would be on them. These were expressed in the following statements:

“.... Will start fighting with the husband as the husband will say that she is the one who brought the disease because I do not sleep around and you do” (PI3/1);

“I know men can say that women are the ones who bring the sickness as they do not sleep around” (PI3/2);

“No, I have seen some women who say that if you disclose to your husband you will start fighting and will start saying that you came with the disease I do not know. Yes, I think Isn't it I sometimes hear people saying that if I find that my partner is HIV-positive she will be the one who will have contracted the disease as I do not sleep around” (PI2/2).

To be free from accusations, the baby was either taken to the clinic secretly as one participant said: “I think it is better to bring the baby for treatment even though you do not tell him” (IP2/3), or others did not bring their babies at all or only brought them when it was already too late.

This finding is confirmed by Dahl *et al.* (2007:70) in their study where it was found that if the woman was the one who tested HIV-positive first, she was blamed as the one who brought the disease in the family.

In their review of the rates of disclosure, Medley *et al.* (2004:304) found that a large proportion of HIV-positive women did not disclose their status to their partners. This may lead to both the mother and the baby not receiving the care they should receive because it will not be accessed freely. This is supported by the results found in the study conducted by Tejiokem *et al.* (2011:6) that failure of mothers to disclose their HIV status to partners was one of the causes of incomplete early infant diagnosis.

➤ **Relationship ranks higher than the baby's health**

The following statements were heard from the participants:

“ Looking to the relationship with their husbands more than the health of the baby” (IP3/1);

“ They are scared of what people will say That means that they do not care of the lives of their babies” (IP3/1);

“ She left with the baby. So when they asked her why do you leave with the baby because they are going to help you in there she said, who said my child is ill. This person knows her baby’s status and her status. She gave the reason that at her house her husband did not have flour There is no flour, I am going to buy flour for my house” (FG3/6/4).

➤ **Powers of the family in-law**

Participants verbalised the main reason for not bringing their babies was not only their relationship with their partners, but also that their family in-law were not supporting them, but instead fought against them. The following excerpts are from them:

“ It will be known that both her and the baby are sick and then they will start fighting in the house and the husband’s family will start to saying ‘chase this woman away, chase her away she is sick with her baby’ (IP3/2);

“It is not pleasant but if you tell them they (husband’s family) will start talking in other ways and they will talk in your absence. They will be saying ‘sickness this and that’ and they will start to cause conflicts between you. They will be saying ‘send her away because she having affairs’ and they will be forgetting that their own child can be infected by the disease” (IP2/2-3);

“ They say if they have a problem, those people must come and pray for them and they must be healed. So if a person from them come and she is positive, she is not going to take AZT correctly if you give her tablets, especially if the partner is also of that religion. And not only the mother-in-law I had told her to dodge and come and deliver in the clinic But the mother-in-law was watching her” (FG2/1/6-7).

This finding is confirmed in Varga *et al.* (2005:956) study, describing where a woman was moved out of the house by the husband after she had confirmed involuntary disclosure by using Pelargon formula milk. Health workers raised the fact that most mothers who had not disclosed, gave mixed feeding in fear of partners and family members’ questioning formula feeding.

- **Own family**

The family also has a role to play to individual members. In this research it was found that the family could be an obstacle for the mother to bring her baby for follow-up at the clinic. The sub-categories under own family include: status disclosure causes conflict and grandparents' reaction to HIV-status of grandchild.

- **Status disclosure causes conflict**

The participants mentioned the following expressions regarding the family's awareness of the child status:

*"Like at home they know I am positive. That is I was afraid that if ***** (the baby) could being positive, they would blame. ' You knew, why did you not protect the baby?' When they tested the baby (other), he was positive. I was afraid to tell at home because they were saying many things. To ask them that I money to go to Jubilee At first I lied. I told them that they say the baby has this and that. ... they like to move.. As they were moving to another house they got the baby's results, they were positive. When my father phoned me he said 'you killer'. So when it came back again with the form of this one, I told myself that they were going to say that I did it purposely, I knew already." (IPI1/2);*

This finding is supported by Mellins et al. (2003:414) that if the mother had not disclosed her serostatus attending health care appointments would be difficult and make her lie about her movements.

" My family talk a lot through the phone My sister knew and told those who live in Mamelodi and those living in Mamelodi told that one and she phoned me and said isn't it I told you that your baby is going to die because he is sick" (IP1/3);

"At the time she is afraid that you will find out that the baby is ill and the family will think differently on her. Yes, you find that the family does not know and they will see the baby taking medication and will want to know what is wrong with the baby.

.... Isn't it some when they realize that the mother and the baby are sick then conflicts will begin which will never end.” (IP2/1);

This finding is similar with that of Anderson and Doyal (2004:102) in their study of women from Africa living with HIV in London where they stated that keeping the HIV-status to themselves was to protect themselves from losing their partner and from verbal abuse.

➤ **Grandparents' reaction to HIV-status of grandchild**

One participant responded that she had a serious problem with her father who loved the child, as exemplified in this excerpt:

*“As they were shifting they got the baby's results, they were saying positive. When my father phoned me he said ‘you killer’ (PI1/2) The elder one. He is at home. So found out that he is positive. So my father did not accept it. He is the child he loved. He is the grandfather's child When he phoned he said ‘you are killer’, why did you all the time You did not this and that Even from home because I was living with my aunt at zone 5. **** (the baby) had a lump in the armpit. She told that your baby is sick. Then he developed sores on the body. ‘I tell you your baby is sick, truly he won't reach 6 months, he is going to die’. So after I found out that this one is positive they told that one and she phoned me and said isn't it I told you that your baby is going to die because he is sick. You see?”(IP1/3).*

No similar findings with regard to the reaction of grandparents could be found.

• **Community**

According to the participants, the community also played a role in the delaying of babies to be taken for follow-up due to the community gossiping, a hurtful action, and uncomfortable responses from community.

➤ **Gossiping a hurtful action**

Participants expressed hurtful action as follows:

“He is going to tell people”

“ When they see me they are going to talk about me”

“ They will start talking in other ways and they will talk in your absence” (IP2/2);

“ Then the other patients are around, they already know that such a person is suffering of such a thing. When you come out of the clinic they will be gossiping saying this and that about you. So she then went around telling those who did not see me and that hurt me very badly. So that is the reason I did not want to no longer show my face at the clinic anymore because I knew that everybody knew about my condition” (IP4/1).

According to the study by Anderson and Doyal (2004:102) on women from Africa living with HIV in London, women did not join support groups and those who did, left after one or two attendances in avoidance of gossip and HIV status being revealed.

➤ **Uncomfortable responses from the community**

Uncomfortable responses from the community were expressed by the participants as follows:

“ is the shame of what people are going to say. You fear that if my neighbour see me, what is he going to say. Caus my neighbour knows why we have come here for. I am just afraid that when he see me what is he going to say. He is going to tell people. How are they going to take me, when they see me they are going to talk about me” (IP1/1);

“ They fear what people are going to say” (IP4/1)

This finding is in agreement with what Varga and Brooks (2008:795) reported about the participant who started attending an antenatal clinic from a different clinic in to avoid being seen going to test and what people would think of her. In their study, Torpey *et al.*(2010) suggested mobilization of communities by traditional leaders/opinion leaders to access HIV/AIDS services and specifically increase male involvement in PMTCT services and this would reduce stigmatization of HIV and increase easily disclosure to partners. Chinkonde *et al.* (2009:149) also found in their study that women concealed their HIV-positive status due to fear of community interrogation.

- ***Consequences of disclosure of status***

In this category, the following subcategories emerged: leads to unwanted stress and reality of stigma .

- ***Leads to unwanted stress***

The participant verbalized the unwanted stress in this way:

“ When they realize that the mother and the baby are sick then conflicts will begin which will never end” (IP2/1);

“ Start to fight in the house and life becomes strained” (IP3/1).

Mothers may want to avoid additional stress and tension because of their status becoming known and therefore avoid taking their babies for follow-up.

- ***Reality of stigma***

“.... The community have stigma they themselves. even when she comes to collect Pelargon, she does not want to say I have come to collect Pelargon. She can stand there the whole day waiting for all the people to be helped They talk themselves outside that if you see someone collecting milk And some collect and

change the milk from that tin to nan because they themselves have stigmatized themselves” (FG1/3/15)

“ The problem is stigmatization. People diagnosed with HIV/AIDS are stigmatized among community members But we have a support group, ... So they know, they talk about it and they know that those are those that are So you see that the stigma is right in the clinic” (FG2/2/1);

“ The main thing that gives us problem is that HIV is still a stigma in many people. Even if I myself can be diagnosed HIV, even my colleagues will be looking at me It is not the community only. We still stigmatize it. If only this stigma could end up” (FG3/7/4).

This finding is comparative to the one found by Miller *et al.* (2010:51) where one of the subjects reported stigma at the workplace which prevented her to request time off to collect her treatment, due to fear of her colleagues.

“before we had a very high number. Now the number is low. They do not come any more. This time for the month we have seen Yes, it is 18 and you know it used be 60, 70 to an extend that they did not have sits” (FG3(b)/2/7)

“ That stigma, even when she enters the hall, she thinks that people are watching me as I collect the milk” (FG3/7/10).

In the study conducted by Kizito *et al.* (2011:56) on failure to follow-up tuberculosis treatment in an urban informal settlement in Nairobi, Kenya, they also found that stigma associated with TB contributed to failure to follow-up by their patients.

- **Language barriers between health workers and patients that are immigrants**

The language barrier was expressed in focus groups as follows:

“ Some of them the problem is language. You will find that the person did not understand what I said to her, moreover here we have foreigners a lot” (FG2/3/2)

“ here at our place in Winterveldt, the problem is that it is full of foreigners, more than our people who know the Setswana language we are talking. So most of them do not understand and this condition is much in them. They are so many at the support group” (FG2/5/4);

“ We have a problem of language here in Winterveldt. Language is a problem. Isn't it we have people from Mozambique, Maputo and Zimbabwe” (FG2/4/2);

“ And we have one interpreter who helps as the we test them and from here onwards I don't know how the sisters communicate with them Because most of them do not even understand English” (FG2/3/2);

“ The other one, we have many immigrants. Sometimes it is lack of communication or lack of understanding. You will find that she does not understand you you will find that they are afraid of the sister and so on. She is afraid to talk and come here only when the baby is ill. Sometimes even her status, she does not understand that she is HIV-positive. She does not know the language this side, but when you say you understand, she says she understand, but she does not know anything” (FG3/2/1);

This finding concurs with that of Lemly *et al.* (2007:349) in their study about factors related to medical appointment attendance after childbirth among HIV infected women in the Paris region, who found, in their study in connection with immigrant women, that two-thirds of their study population consisted of sub-Saharan women. In addition, the women in their study were found to be poor, with limited education, with language difficulties and faced social stigmatization, which was also found in this study.

3.3.1.3 Classical indicators of HIV

Table 3.6 Classical indicators

3.3.1.3 Classical indicators of HIV	● A HIV-positive baby implies HIV-positive mother ● The clue when you regularly visit the same clinic ● The use of milk formula
-------------------------------------	---

HIV-positive mothers managed to live with their status unknown to their partners, but feared that as soon as the baby's status is revealed by her taking the baby to the clinic regularly and giving medications at definite times and using specific feeding methods, it would indicate an HIV-positive mother.

- **An HIV-positive baby implies an HIV-positive mother**

The HIV-positive mothers feared to take their babies to the clinic for testing because they knew that the HIV-positive status of the baby would reveal their status too. This was verbalized as follows:

“ You find that the baby is ill and she is also ill” (IP2/1);

“ Not bringing the baby to the clinic on time yet knowing that both you and the baby are sick” (IP3/2);

“.... It is not simple to accept that I am positive and even my baby I am living with is also positive” (IP4/1).

Similar findings were observed in the study conducted by Varga and Brooks (2008:795). The woman in their study would not bring her baby to the clinic for testing, assuming that the baby was already positive like her and that the baby's HIV-positive results would involuntarily disclose her status. In contrast to this finding, where mothers feared to test their babies which may reveal the mother's status if found HIV-positive, the study conducted by Varga *et al.* (2005:955) found that testing the baby was used by mothers as a means of getting to know their own status by proxy as an HIV-positive baby did imply a HIV-positive mother.

- **The clue when you regularly visit the same clinic**

“ When you come out of the clinic they will be gossiping saying this and that about you” (IP4/1);

“ So that is the reason I did not want to no longer show my face at the clinic anymore because I knew that everybody knew about my condition” (IP4/2);

“ No, I did not come back here again due to past experiences. I instead went to another clinic” (IP4/4);

“As they do not disclose, they stay like that. Even when you tell them and get the interpreter, to explain, they do not want to be seen frequenting the clinic because they will know what that mean” (FG2/5/4).

The same results were confirmed in the study on women from Africa living with HIV in London by Anderson and Doyal (2004:100), where women reported that repeated visits to hospital depressed them as it reminded them of their diagnosis. According to the study by Painter *et al.* (2004:544), mothers were bothered by the location where they would be seen by people knowing them, which would disclose their seropositive status.

- **The use of formula milk**

The use of formula milk was seen as the motivating factor that made mothers bring their babies for follow-up, and the termination of supply led to failure to bring babies for follow-up. This is how it was verbalized:

“Some do come due to the issue of milk. The person will come for milk. After that we test them for PCR after that they do not make a follow-up for the results and they come only when the baby is ill” FG3/3/3);

“And when they complete collecting milk at six months and are cut, when you tell her to bring the child at one year six months, ...She does not come back” (FG3/3/9).

The provision of free milk as motivating factor to bring babies for follow-up is confirmed by the research conducted by Ukpe *et al.* (2009:339), which showed that follow-up declined around 2007 due to the frequent unavailability of free formula milk.

3.3.1.4 Organizational reasons

The categories under this theme are the following: health facility staff and mistrust in the capability of the health facility.

Table 3.7 Organizational reasons

3.3.1.4 Organizational reasons	• Health facility staff • Mistrust in the capability of the health facility • Fragmented services
--------------------------------	---

- **Health facility staff**

The sub-category that emerged under this category include: nurses' incompetence and lack of knowledge with regard to the management of HIV in babies and lack of confidentiality.

➤ **Nurses' incompetence and lack of knowledge with regard to management of HIV in babies**

Some of the statements verbalized by participants are as follows:

".... There are some who do not treat HIV-positive patients properly" (IP4/1);

" I think some of the sisters are not well informed about HIV" (IP5/2);

" I see the problem being that some of the sisters are not well informed about HIV and babies" (IP5/3).

The health workers in the clinics work in all departments, especially during the weekends and on night duty. All of them will, in one way or another, work with the

PMTCT client, either the baby or the mother. The need for every nurse to learn about PMTCT was verbalized in the following excerpts:

“ If we were all attending PMTCT. Irrespective that the sister is working with PMTCT or is not working with PMTCT, along the way you would meet this person, even if you do not work with PMTCT, you would be able to to notice that thing, to see that no, no, this person seems to be lost and do something about that and send her to the relevant people who supposed to continue with her” (FG1/5/6);

This finding is supported by Chopra *et al.* (2005:362) where in their study they cautioned that mothers came in contact with a wide range of nursing staff instead of the dedicated PMTCT staff and therefore, these nursing staff needed to be orientated to the PMTCT program, including HIV and infant feeding.

“Why not everybody attend PMTCT? Why not everybody know that Why not everybody know the protocols that when it is said the baby has come for 6 weeks, isn't it we know about our shortage of staff in our clinic, we are aware that anybody work in maternity, anybody work in PNC at some point. We don't know who on that day will meet such case in PNC (post natal care), we will have all the needed information to handle a case like that. This is what the sister was saying that why everybody is not attending these courses whether she works that side or not” (FG1/1/8);

“It goes to who is trained to do what. I may be working there for 6 weeks without skills to, like counselling skills” (FG1/2/9).

In support of these findings, Sripipatana *et al.* (2007:S108) agree that PMTCT services should be provided by the regular maternal and child staff and not by a separate cadre of health providers so as to ensure integration, with all the staff being appropriately trained in PMTCT and involved in service delivery, and that the mothers would have access to services from any provider seen at the facility.

“The other thing, if there could be more workshops or in-services right in the institutions. Because we can take for granted that there is no sister who at this stage does not know PMTCT... and only to find that the person only knows the basics or the general PMTCT, not information right as it is” (FG1/4/16)

Chopra *et al.* (2005:361) concluded that from the three sites of their study, counselling was poor with lack of encouragement to disclose, adherence to antiretrovirals, and of subsequent support for the infant feeding. This finding is confirmed in the results of the study regarding missed opportunities for the prevention of mother-to-child HIV transmission in the Eastern Cape local service area, Rispel *et al.* (2009:178) where the need for additional training of professional nurses, and for a formal system to update staff on new or revised guidelines, were also identified. They added the importance of lay counsellors to receive comprehensive training, role clarification and supervisory support.

The health workers agreed that if mothers did not bring their babies it could be as a results of lack of knowledge by some of them, especially the sisters who work with these mothers and their babies when there was shortage of staff or the regular staff was not available.

“Why not everybody attend PMTCT? Why not everybody know the protocols that when it is said the baby has come for six weeks, isn’t it that we know about our shortage of staff in our clinic, we are aware that anybody work in the maternity, anybody work in PNC at some point.... will have all the needed information to handle such a case why everybody is not attending these courses whether she works that side or not“ (FG1 (A)/1/8).

The health workers showed the frustration of working with PMTCT clients without adequate knowledge. This quest for finding knowledge was mentioned by participants in the study conducted by Horwood *et al.*(2009: 315-316) by acknowledging lack of skills to implement HIV care and inadequate training and knowledge of HIV.

Many researchers, including Rispel *et al.*(2009: 178) agree that there is a need for health workers to be trained accordingly to be successful in PMTCT the program. Holmes and Savage (2007:1066), in their study of exclusive breastfeeding and HIV, concluded that for health workers to give mothers appropriate help, they also need to be adequately informed, which is currently not happening.

➤ **Incongruent health education on HIV and AIDS**

One HIV-positive mother verbalized the incorrect information received from the clinic, and this was supported by health workers who were also not happy about their knowledge regarding PMTCT and their quest for more knowledge to be able to give adequate information to their patients. The following was mentioned by a participant:

“.... She did not get the right information properly basically they did not tell her in detail about HIV and pregnancy and how it affects the baby” (IP5/2);

This finding is confirmed by Painter *et al.* (2004:544). According to their study, some women do not consider prophylaxis to be effective because they were taught that the contamination between the mother and her infant (fetus) had already happened at the time of HIV testing since they were told that the virus passes through the blood that they share. They took the medication given to them as an illusion since they were previously told that AIDS is not curable.

In the study conducted by Painter *et al.* (2004:544) women were not satisfied with what they were told during counselling where one was told that she was negative but her blood was ‘dirty’. Counsellors should learn to use understandable language during counselling though they may sometimes find it difficult to get some words in African languages.

Horwood *et al.* (2010:318) in support of this finding, found in their study that there was a lack of both communication and HIV management skills to implement the HIV component to IMCI by the IMCI-trained nurses where their support and knowledge were crucial to HIV-people to access care.

In the focus groups the nurses also gave the information that showed that the HIV-positive mothers could be getting insufficient information from them due to being overworked, for example:

“.... You find that yes here they came for PNC They came for 6 weeks plus those ones who are not 6 weeks. Plus you are assigned for labour ward also. The minute you start to explore whatever she came for, then you are called on the other side. You hang up that one and you go and listen to what she says Then

you go to this one. 'Dress the baby we are through'. You did not go deep to what you wanted to go" (FG1 (A)/2/10);

"There is no time. We see many people. This clinic has many people" (FG3 (A)/2/8);

"No, no. Due to the workload we have, we do not have time. The formal one, we nurses we do not have time" (FG3 (A)/5/8).

Health care workers complained about the extra workload brought about by the impact of PMTCT, with no extra staff hired in some areas. This was seen to be the reason for poor quality of care of babies and even insufficient time to educate the mothers. This is confirmed by several studies. Perpetuation of stigma, discrimination and reluctance to take ARV prophylaxis were found to be due to lack of information and misinformation in the study by Torpey *et al.*(2010). Horwood *et al.*(2010:318) added that nurses may avoid distressing situations to protect their own wellbeing during high prevalence of HIV due to the increasing stress and workload they faced. Bwirire *et al.*(2008:1199) found that there should be support for staff working with PMTCT to be able to cope with their workload.

➤ **Lack of confidentiality**

".... They do not have a secret for the person who has come. They do it publicly so that everyone deserve to know what you are suffering from. And once one knows, they are not secretive...." (IP4/1)

".... Is not a sister but works from reception and said 'it is those (people with HIV-positive status) who are going there' And she then went around telling those who did not even see me and that hurt me very badly" (IP4/2).

In adding to this finding, Horwood *et al.* (2010:998) stated that to provide optimum care for the baby, respect for confidentiality must be considered. Varga and Brookes (2008:787) confirm that barriers to active participation to PMTCT are caused by fears of mothers concerning counsellors' ability to maintain confidentiality of their status. One participant stated that she would never disclose her status to the nurses who would sit with her file discussing her because there is no confidentiality in the clinic. The study by Anderson and Doyal (2004:100) reveals that HIV-positive women

travelled long distances for out-patient appointments, to preserve confidentiality in their local area.

Mothers whose seropositive status is exposed, may cause their babies to suffer because they are reluctant to take their babies for care, in order to keep their status confidential.

- **Mistrust in the capability of the health facility**

Under this category the following sub-categories emerged: Hospital a “better option” than the clinic and HIV-testing is faulty.

- **Hospital a “better option” than clinic**

The following are statements from participants:

“.... When I got to the hospital I met sisters who took their time to inform me. Even when I have problems they explained to me And I know that at 6 weeks at the hospital the way they have informed me She said to me that things have changed lately But I was not happy about that and there was no way in which I could go back to hospital” (IP5/2).

“Cause somewhere I thought that I understood the whole procedure but I was confused when I went back to the clinic” (IP5/3)

This perception may have grounds, as health professionals working in clinics have to rotate between duties and are involved for longer periods.

No similar findings with regard to the reaction of grandparents could be found.

- **HIV-testing procedure is faulty**

One HIV-positive mother verbalized this as follows:

“.... Some of them have questions that I tested and found that I am HIV and I tested again and found that I am negative. The testing was giving a problem. It was showing one stripe for a long time”(IP5/1).

It is understandable that patients do not trust the capabilities of the clinics if the tests do not give the same result consistently.

- **Fragmented services**

The health workers are overworked, with extra duties due to PMTCT, but are not happy with the fragmentation of services where a patient could be sent to different rooms to get service from each of them. They feel some clients are missed for that reason. The following are the quotes from them:

“We do not know whether the mother was told on that day to take the baby for PCR and where and whether the mother found the place being full or has not seen the queue and left. But if the PCR was done in the same room as, like we use to do We use to do it ourselves in the PNC room. We are not sure whether on that day the mother was referred to that room for PCR, or whether she reached it, we don't know” (FG1/1/9).

In support of this finding, Horwood *et al.* (2010: 997) argue that the first visit of babies for immunization was the best time to check babies for HIV exposure and PCR testing but because of fragmentation of services, babies are missed for PMTCT, and because of poor recording, babies can only be tested depending on the mother if she report the HIV-exposed baby. Ginsburg *et al.* (2007:2530) support the finding that if integration of services for mother and child is not appropriate and coordinated, information will be lost or not communicated due to navigation of separate healthcare facilities of the mother and her baby. Research by Scripipatana *et al.* (2007:S111) confirm that follow-up of HIV-exposed infants is well-performed in child wellness clinics where they routinely attend for their immunization as well as well child care.

3.3.1.5 *Baby related reasons*

The two categories under this theme are: Baby ultimately the main concern and baby is the burden.

Table 3.8 Baby-related reasons

3.3.1.5 Baby-related reasons	• Baby ultimately the main concern • Baby is a burden
------------------------------	---

The two categories under this theme are: Baby ultimately the main concern and baby is the burden.

- **Baby ultimately the main concern**

Participants showed the need for the baby's wellbeing by taking a decision to take the baby to the clinic to get help. These are some of their statements:

"Yes, I realized that at the end still I am going to make my baby suffer" (IP1/1);

"I saw that it is best to take him, and he get treatment and be right up until there will be cure" (IP1/3);

"I Think it is better to bring the baby for treatment even though you do not tell him (father of the child), even if you love him, but as long as you take the baby for treatment" (IP2/3).

In the study conducted by Wood *et al.* (2004:911) on medication adherence of HIV-positive women caring for children, a woman who had stopped taking her medication due to overwhelming guilt, when asked what made her to re-engage with care, gave the reason that it was for concern of children. During interviews, women verbalized their relationships with their children as the strongest motivators in their choice of

care for their health. This decision is confirmed by the results in the study done by Varga *et al.* (2005:958) where mothers took a decision to disclose their HIV-status looking to the welfare of their babies more than to what they will face from it.

- **Baby is a burden**

The following sub-category emerged under this category: the first consideration remains the relationship with life partner and thereafter the baby.

- **First consideration remains the relationship with life partner and thereafter the baby**

The participants expressed themselves in this way:

“.... She and the husband live well” (IP2/3);

“ O, I think mothers are looking to their relationship with their husbands more than the health of the baby.(IP3/1)

“Yes, that means they do not care about the lives of their babies” (IP4/1)

This finding is in contrast with the study done by Anderson and Doyal (2004:103) in which women described that their strength to carry on with treatment was for their children, to see that they were brought up healthy.

3.3.2 Strategies to encourage mothers to bring their babies for follow-up

During the focus group interviews, health workers were asked about the strategies they suggested to encourage mothers to bring their babies for follow-up. There were two main themes, namely organizational strategies and patient-focused strategies.

Table 3.8 Strategies by midwives and HIV-counsellors

3.3.3.1 Organisational strategies	• Trans-organisational coding system • A place of birth-to-clinic contingency plan • Congruent health education
3.3.3.2 Patient-focused strategies	• Perinatal VCT support as a process • Clinic policies and procedures should be from a person-centered approach

3.3.2.1 *Organisational strategies*

The following categories emerged from this theme as the participants verbalized what actions they took to encourage the women to bring back their babies to the clinic: Trans-organisational coding system, a place of birth-to-clinic contingency plan and congruent health education. From the different findings found in the three focus groups who work in the same sub-district, it shows that there are no strategies in place to curb the problem of low follow-up of babies born to HIV-positive mothers.

- **Trans-organisational coding system**

For the continuity of care, the baby's card must specify the status of the baby (coded) as it was the case during interviews, since some mothers do not communicate their status to health workers due to different reasons. That should be a coding system that can start at any hospital and be a source of communication between hospitals and clinics in order to ensure that babies are identified between clinics, even when the mother denies her status.

The participants verbalized their concern about mothers who come from outside their clinic and other institutions with no coding and/or different coding system, as follows:

“Coding, isn't it we code? But it is as if immediately after delivery when our babies come, they come with their cards not coded. So our babies are lost because when

they are not coded when they are brought for PNC or there you will find that he/she is lost and not knowing how he/she is, status not known” (FG2/4/3);

Ginsburg *et al.* (2007:2531) argue that the maternal HIV-positive status should be routinely available on the infant’s hand-held record for the identification of HIV-exposed in a child clinic as communication between health workers and facilities.

“If we were all using the uniform coding and whatever, even there we would have a way to all see” (FG1(A)/5/6).

In a study conducted by Haddow *et al.* (2003:350) on patient lost for follow-up the data showed that 29 of their cases were attending follow-ups in another clinic without any correspondence between the centres. Such cases call for the attention to have better ways or sources of communication between facilities.

Health workers were concerned because of their experiences where the mother would be asked about her status and would answer to say it is well, and after some weeks the baby is brought to the clinic in a very serious condition, where then health workers will then decide to test the baby and wait for the results which will be positive. If the baby’s card was coded or communicated the status of the baby, this situation would have been prevented.

“I still want to reinforce this that even if we work in different institutions, we should know and do one thing. Other people when they come from other institutions having booked there, coming to our institution doing this, as people who are sent to one place to learn about PMTCT/VCT whatever, we come having learned something that they have learnt in the other way, and not knowing how they do their coding. So there came several people Their cards were coded in the other way, their coding was hidden, being different up until you ask the mother who is ready to tell the truth and you only get the truth from her. But being in almost one area, but not having received the very same thing. When I say in the same area,.... I mean being all in Pretoria but not doing the same thing. ” (FG1(A)/5/11).

In support of this finding, Ginsburg *et al.* (2007:2531) state that infants do come for immunization but, not being identified as HIV-exposed and may be lost unless the mother’s ante-natal card is brought – which is not the case in our facilities because

the card is left where the mother has delivered. The only source is by asking the mother her status.

- **A place of birth-to-clinic contingency plan**

The follow-up process should start at the place of birth and increase the awareness of not only immunizations but follow-up HIV-screening. From the participants' comments, it was clear that there was no continuity of treatment. In addition to other reasons the patient was not aware that she was supposed to take the baby to the clinic at six weeks to be checked for HIV. Mothers know about the six weeks follow-up and immunization but not about the baby's HIV screening. This is exemplified by the following excerpt:

"We use the six weeks follow-up because they come for their immunization. Yes they start at six weeks. They come for follow-up and their immunization" (FG2(b)/1/1).

In their study of provision of care following PMTCT services in resource-limited settings, Ginsburg *et al.* (2007:2531) found that babies did come for immunizations but failed to be identified as HIV-exposed. They were in the system but their status was not known.

"And you find that they are from other clinics They will deliver from somewhere then they will come when the baby is sick. They will be coming from KZN, coming from Mpumalanga, they come from outside not around. They are many who delivered there, especially the Zimbabweans And they will land up here when the baby is sick" (FG1(B)/2/3).

This finding is supported by Ginsburg *et al.* (2007:2531) in that the recording and reporting of the infant HIV-exposed status enable the health workers to track the infants.

The follow-up process should start at the place of birth and increase the awareness of not only immunizations but follow-up HIV-screening. Horwood *et al.* (2010:997) contend that the first immunization visit (six weeks of age) provides an opportunity for PCR testing of HIV-exposed babies. However, because PMTCT is done separately, and the poor recording of PMTCT means that the baby's status will be

dependent on whether the mother reveals the status of the baby, which is not easy since that will be revealing her own HIV status.

- **Congruent health education**

Correct information on HIV and AIDS in the event of an HIV-positive mother and a newborn should be provided from the place of birth and all applicable health systems in order to have standardized information. The participants stressed the reinforcement of education even though what was to be educated was not mentioned. This is exemplified by the following excerpts:

“I think that you tell the person the importance of why she should come so the strategy that we should use is reinforce education every time so that she can see the importance of coming back” (FG1(B)/2/1);

“.... Education, that education must always be reinforced amongst the PMTCT clients, the importance of doing PCR, why they should do it and the benefits thereof. Unlike staying at home and not doing it and the baby will not get the help they were going to get” (FG1(B)/5/2)

“I think also reinforcement. Even if they have been explained to at VCT that side, counselled and everything done, we also this side as midwives we should reinforce that ‘lady, you should come back and bring the baby. If you don’t bring your baby back, this is what is going to happen to your baby. Do you want your baby to be like this?’” (FG3(b)/3/2);

“.... They should reinforce. Is that You give her the importance that if she will not come what will happen. That is, the importance of this treatment that she should attend. Otherwise if she does not know the importance thereof she won’t care that, I can just stay because here is the baby and the baby is fit.” (FG3(b)/4/2)

Lemly *et al.* (2007:353), in support of this finding, stated the importance of women being reminded of the health and wellbeing of their children being connected to their own throughout even after delivery.

3.3.2.2 *Patient-focused strategies*

The following categories emerged under this theme: Perinatal VCT support as a PROCESS and clinic policies and procedures should be from a person-centered approach.

- **Perinatal HIV testing support as a process**

HIV testing is not a once off event but should be seen as a continuous process where the mother's initial diagnosis and support are deliberately extended to a next phase, namely infant-testing where the mother is supported towards the testing of her baby. The following are the participants concerns in encouraging the mothers to bring their babies for follow-up:

“If there could be something like, at each and every time during ANC follow-up, make sure that they have accepted” (FG1/4/5).

In the study conducted by Anderson and Doyal (2004:100), women found the hospital and the clinic as the major source of information where the importance of continuity of care was emphasized.

There is a great need for pregnant women to be informed of all aspects of PMTCT throughout pregnancy, intra-partum and at post-natal visits. Mothers do not take information in the same way at the same time, therefore, each one should be counselled to eliminate fears and myths regarding HIV.

- **Clinic policies and procedures should be from a person-centered approach**

Policies and procedures should be from a “person within the system” approach. The focus should be more on the individual mother's unique coping with her HIV-status and her readiness to cope with the HIV-status of her child.

➤ **Follow-up**

The practical follows-up mentioned in the groups were phoning patients to visit the clinic and home visits by a volunteer.

➤ **Phoning patients to visit the clinic**

In one clinic the participants found the phoning of clients as effective. This is how they verbalized it.

“If they do not come we make follow-ups by calling them and have their contact numbers and call them and if they do not come again we then send.”(FG1(b)/1/1).

The method of phoning clients to return for follow-up was found to be effective in the study conducted by Tejiokem *et al.* (2011:4), where they experienced a higher rate of return through an active tracing method with multiple reminder calls. A study by Parekh and Brown (2003:349) also confirms this finding when out of 114 patients, they managed to contact 97 through mobile phones and home contact telephones and only 17 were unable to be contacted.

➤ **Home visit by a volunteer and/or DOT supporter**

In one focus group they mentioned the use of a volunteer to do home visits for the mothers who did not bring their babies on due appointment.

“Normally we we encourage them at the post natal clinic. And then of which failure, we had a volun ... we’ve got a volunteer who usually follows them up if they stay locally” (FG2(b)/6/3);

“She do home visits. It is functioning very well. And then most She stays in Winterveldt and so they trust her most. She is a volunteer” (FG2(B)/6/4);

In this clinic, though they had a volunteer to make home visits for follow-up of babies not brought for follow-up, there were challenges with residents’ addresses. The following excerpts were verbalized by the participants to that regard:

“And another problem, these people are not staying in the same place, they change addresses. Even if you can trace her, if you were fortunate maybe you manage to trace her with the very same address, they will say that, that person has last left on such and such a day. She does stay here any longer. She lives at such and such a place. So that is the problem we have” (FG3/8/5);

“Isn’t it may be at post delivery you find that she has been taken six weeks and she became lost and when you need to trace her there is no communication, she does not have cell phone. She cannot be found from the stand given. Sometimes they give wrong addresses. You will find that they give you a stand for example Maluleka stand. When you go there, there is no that number given” (FG2/4/6).

This finding concurs with what Tejiokem *et al.* (2011:3) found in their study, namely that 149 infants in their study were lost for follow-up due to the inability to trace them, as the contact information was missing or incorrect, and the vital status information could therefore not be obtained.

3.4 SUMMARY

Chapter 3 discussed the findings of this study with direct quotations from participants and confirmation from other studies. Literature was incorporated from other published articles, journals and an electronic data base to refute or confirm the findings and highlight new insights gained.

The next chapter will deal with conclusions, limitations and recommendations to improve the follow-up rate of babies born to HIV-positive mothers.

CHAPTER 4

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter is about the conclusions deducted from the previous chapter about research findings, the limitations of the study and recommendations that will help towards the improvement of the follow-up rate of babies born to HIV-positive mothers.

Five individual interviews with HIV-positive mothers and three focus group interviews involving 24 participants, consisting of 20 nurses and 4 HIV-counsellors were conducted to answer the research question of exploring and describing factors contributing to the low follow-up of babies born to HIV-positive mothers. Focus groups were interviewed in the second round to explore and describe strategies that can be used to encourage HIV-positive mothers to bring their babies for follow-up.

4.2 CONCLUSIONS

The reasons for low follow-up of babies born to HIV-positive mothers as described by HIV-positive mothers and nurses and HIV-counsellors were classified as internal reasons, external reasons, classical indicators of HIV, organizational reasons and baby-related reasons. The strategies that can be used to encourage HIV-positive mothers to bring their babies for follow-up, according to nurses and HIV-counsellors, were classified as organizational strategies and patient-related strategies.

The following are the researcher's conclusions with regard to reasons for low follow-up of babies born to HIV-positive mothers and strategies that can be used to encourage HIV-positive mothers to bring their babies for follow-up:

- Fear about disclosure remains a huge obstacle for mothers and this contributes to the babies' loss for follow-up. Though mothers' HIV-status could be hidden, the fear that the baby could be positive was a problem to mothers because their status would also be revealed due to the positive baby's status. The fear included the fear that, if the baby would test positive, the mother had to explain that to the family, and she and her baby would be judged accordingly. When the baby should get treatment the mother would have to explain the reason and that would lead to indirect disclosure. When a mother decided to feed the baby with formula milk, it could also cause her own status to become known. In her choice to take the baby for testing the mother would become confronted with the reality that her status could be revealed, even if she had not disclosed her status to her family before. Couple counselling, involvement of partners in PMTCT and use of community leaders to talk about the reality of HIV and AIDS could minimize the fear for disclosure and eventually lead to more mothers bringing their babies for follow-up.
- Traditional beliefs could also pose a delay in a mother bringing her baby for follow-up. Some mothers believe in not taking medicine. Even if a mother understands the importance of taking AZT as prophylaxis, her partner or mother in law may prohibit her bringing her baby if they are also of the same belief. Some mothers prefer to deliver at home and will only come out of the house after 14 days, which means that the HIV-positive mother and the baby will not receive the Nevirapine as they should. The use of radios and television for health education in different languages concerning PMTCT will be of great importance to the community at large.
- Stigma remains real and causes a delay for babies to receive health care and thus to prevent unnecessary illnesses and infant mortality. There is stigma in the community, self-stigma and even among health workers. Mothers avoid the collection of formula milk because the community knows that Pelargon is mainly for HIV-exposed infants. They also avoid joining support groups because they know that the mothers who meet in the support groups are known as 'those ones'. The fear for stigma leads to a reduction in the number of women participating in support groups which are beneficial to both the mother and her baby, as well as the health workers. More awareness activities are important in the community to curb stigma.

- The language barrier between the health workers and immigrant patients at the facilities cannot be overlooked. The high influx of immigrants is an important reason for the failure of babies to follow-up due to language barriers. Counselling is not effective because of language barriers. Health workers experience problems of communicating a woman's HIV status. Babies are lost for follow-up because the mothers do not know they are positive and the babies will only be brought to the health facility when they are ill. An urgent solution to curb this problem is necessary to prevent infant mortality and increase the uptake in PCR testing at six weeks of age.
- The clue provided by the regular visit to the same clinic, was seen by HIV-positive mothers as involuntary disclosure of their status. Being seen frequenting the clinic causes others to make conclusive statements. To avoid the gossip and knowing what frequenting means to others, mothers change clinics, and this brings about low follow-up of babies of whom track is lost. To curb this, health workers should prevent fragmentation of services where different dates for different services such as immunization or HIV-testing are given to patients. Immunisations and baby health services should be incorporated in the follow-up of HIV-exposed babies, unless more frequent visits are made.
- Nurses' incompetence and lack of knowledge with regard to management of HIV in babies were seen as obstacles by both mothers and nurses themselves. Due to shortage of staff, nurses work in all the departments of the clinics. When a nurse has to attend to a baby brought for PMTCT follow-up and she does not have knowledge about it, it causes stress – both to the mother and the health worker. There is a need for all health workers to be trained in PMTCT, in-services training should be conducted, mentoring and support should be given to health workers and staff should be increased so as to be able to cope with the workload that has increased with regard to PMTCT.
- Coding remains an obstacle when trying to trace babies who need to be followed up. Some babies come with no written code, while others have codes based on coding systems from other facilities, regions or provinces that cannot be understood without a code key. At the time of data collection a coding system was used, but trans-organisation communication was poor. Nurses depended on the

mother to tell the truth about her HIV-status for optimal care to be given to both mother and her baby. Some mothers did not tell the truth, since some still feared to disclose their status, even to health workers. This caused HIV-exposed babies to be tested later than required. Improvement on the side of health workers to write on the baby's road-to-health card is of paramount importance to enable effective follow-up of these babies.

Most findings of this study were similar to other studies, except for the following: confusing information, being undisciplined, relationship ranks higher than the baby, grandparents' reaction to HIV-status of grandchild and hospital "better" option than clinic, appeared to be unique findings in this study.

4.3 LIMITATIONS

This study was contextual and therefore cannot be generalised. The reader should consider the context in which the study was done to decide if it can apply to other settings. One focus group had a member who did not participate in the group and the researcher as a facilitator, tried to engage every one, and was cautious not to embarrass or intimidate her. Inclusion of immigrant participants would have added value to this study, but it was not easy to trace them.

4.4 RECOMMENDATIONS

The results of this study of exploring and describing reasons for low follow-up of babies born to HIV-positive mothers identified issues that can be valuable for nursing practice, nursing education and for nursing research. These are included as recommendations hereunder.

4.4.1 Nursing practice

4.4.1.1 Community involvement

- Health care providers should be able educate the community in the language (terms) understandable to them. There must be strategy to ensure that each HIV positive mother understood the importance to bring the baby for follow-up.
- Partners should be included during the antenatal period, in counselling and testing for HIV and all aspects of PMTCT to assist those with language problems.
- More campaigns should be arranged and organised to raise community PMTCT awareness.

4.4.1.2 Resources

- Health care providers should make use of educational materials to explain matters such as statistics.
- Health care providers could use cell phone messages to remind clients of their return dates.
- In order to alleviate the staff shortage and provide better service, more staff should be appointed and allowance should be made for part-time.
- More staff should be appointed to enable people to attend the clinics during weekends and nights.
- Support and mentoring to health workers working with HIV and AIDS (PMTCT) clients should be provided to prevent and help health workers suffering from burn-out.

4.4.2 Nursing education

- Inclusion of HIV and AIDS and PMTCT in the curriculum of both basic and advanced courses.
- All health workers in Primary Health Care should be trained in HIV and AIDS with PMTCT included and record should be kept to ensure compliance.

- All workers must receive training in client centred care – treating people with respect and being courteous.
- Relevant short courses should be developed in readiness to be accredited as soon as a ‘Continuous Professional Development’ system for nurses and midwives is implemented.

4.4.3 Policy making

- Changes in policy should be disseminated to different areas simultaneously to prevent confusion among health workers.

4.4.4 Nursing research

The results of this study have brought to the fore issues that need further scientific investigation:

- Exploring the use of cell phones as a way to deliver health care messages.
- Exploring the experience of immigrants regarding communication with health workers.
- Exploring the health workers’ feelings about working with PMTCT.

4.5 CLOSING REMARKS

This study aimed at exploring and describing reasons for low follow-up of babies born to HIV-positive mothers by HIV-positive mothers and nurses and HIV-counsellors and to find out from the nurses and HIV-counsellors what strategies can be used to encourage the mothers to bring their babies for follow-up.

The emic perspective of HIV-positive mothers regarding the reasons why they do not bring their babies for HIV testing at the recommended time, together with the etic

perspective of the health workers enabled the researcher to answer the first research question. The findings are valuable in understanding the challenges faced by women in the context of the current study, and how they can be supported, for example in case of fear of disclosure. The second research question was answered by the nurses and counsellors working with HIV-positive mothers who provided suggestions regarding strategies to encourage mothers to bring their babies for follow-up. These findings can contribute to guidelines to improve service delivery and higher intake of babies born to HIV-positive mothers.

REFERENCES

ADVERTING HIV AND AIDS (AVERT). 2010a. Worldwide HIV & AIDS statistics. <http://www.avert.org/worldstats.htm>. Date of access: 12 July 2011.

ADVERTING HIV AND AIDS (AVERT). 2010b. Sub-Saharan Africa HIV & AIDS statistics. <http://www.avert.org/africa-hiv-aids-statistics.htm>. Date of access: 12 July 2011.

ADVERTING HIV AND AIDS (AVERT). 2010c. South Africa HIV & AIDS statistics. <http://www.avert.org/safricastats.htm>. Date of access: 12 July 2011,

ANDERSON, J. & DOYAL, L. 2004. Women from Africa living with HIV in London: a descriptive study. *AIDS care*, 16(1):95-105, January.

AVERT see ADVERTING HIV AND AIDS

BABBIE, E. 2007. The practice of social research. 11th ed. Belmont, Calif.: Thompson Wadsworth Publishers. 511 p.

BABBIE, E.& MOUTON, J. 2001. The practice of social research. South African edition. Cape Town: Oxford University Press. 674 p.

BAJUNIRWE, F. & MUZOORA, M. 2005. Barriers to the implementation of programs for the prevention of mother-to-child transmission of HIV: a cross-sectional survey in rural and urban Uganda. *AIDS research and therapy*, 2(10).<http://www.aidsrestherapy.com/content2/1/10>. Date of access: 6 December 2011.

BRAITSTEIN P., SONGOK J., VREEMAN R.C., WOOLS-KALOUSTIAN K.K., KOSKEI P., WALUSUNA L., AYAYA S., NYANDIKO W. & YIANNIOUSTSOS C. 2011. "Wamepotea" (They Have Become Lost): Outcomes of HIV-Exposed Children Lost to Follow-Up From a Large HIV Treatment Program in Western Kenya. *Journal of Acquired Deficiency Syndrome*, 57(3):e40-e46.

BRINK, H. 2006. Fundamentals of research methodology for health care professionals. 2nd ed. (Revised by Van Der Walt, C. and Van Rensburg, G.) Cape Town: Juta Co.226p.

BURNS, N.& GROVE, S.K. 2005. The practices of nursing research. 5th ed. Philadelphia, Pa.: Saunders. 780 p.

BURNS, N.& GROVE, S.K. 2007. Understanding nursing research: building an evidence-based practice. 4th ed. St. Louis, Mo.: Saunders/Elsevier. 586 p.

BWIRIRE, L.D., FITZGERALD, M., ZACHARIA, R., CHIKAVA, V., MASSAQUOI, M., MOENS, M., KAMOTO, K. & SCHOUTEN, E.J. 2008. Reasons for loss-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 102:1195-1200.

CHIKONDE, J.R., SUNDBY, J. & MARTINSON, F. 2009. The prevention of mother-to-child HIV transmission programme in Lilongwe, Malawi: why do so many women drop-out. *Reproductive health matters*, 17(33):143-151.

CHOPRA, M., DOHERTY, T., JACKSON, D. & ASHWORTH, A. 2005. Preventing HIV to children: quality of counselling of mothers in South Africa. *Acta Paediatrica*, 94:357-363.

DAHL, V., MELLHAMMAR, L., BANJURIWE, F. & BJORKMAN, P. 2007. Acceptance of HIV testing among women attending antenatal care in south-western Uganda: risk factors and reasons for test refusal. *AIDS care*, 20(6):746-752, July.

DE VOS, A.S. 2005. Qualitative data analysis and interpretation. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. *Research at grass roots*. 3rd ed. Pretoria: Van Schaik. p. 333-349.)

DOH 2010 (See SOUTH AFRICA)

EVIAN, C. 2000. Primary AIDS care. 3rd ed. Houghton: Jacana Education. 332 p.

GAUTENG DEPARTMENT OF HEALTH. 2009. HIV statistics for January-June 2009 of the Tshwane-Metsweding District, ODI sub-district. Pretoria: Gauteng Department of Health. 2 p.

GINSBURG, A.S., HOBLITZELLE, C.W., SCRIPATANA, T.L. & WILFRED, M.D. 2007. Provision of care following prevention of mother-to-child transmission services in resource-limited settings. *AIDS care*, 21(18):2529-2532.

GREEFF, M. 2005. Information collection: interviewing. (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. *Research at grass roots*. 3rd ed. Pretoria: Van Schaik. p. 286-313.)

HADDOW, L.J., EDWARDS, S.G., SINKA, K. & MERCEY, D.E. 2003. Patients lost to follow-up: experience of an HIV clinic. *Sexually transmitted infections*, 79:349-350.

HENNING, E., VAN RENSBURG, W. & SMIT, B. 2004. Finding your way in qualitative research. Pretoria: Van Schaik Publishers. 179 p.

HOLLOWAY, I. 2005. Qualitative research in health care. Maidenhead, Eng.: Open University Press. 300 p.

HOLMES, W.R. & SAVAGE, F. 2007. Exclusive breastfeeding and HIV. <http://www.thelancet.com> Date of access: 9 March 2009.

HORWOOD, C., HASKINS, L., VERMAAK, K., PHAKATHI, S., SUBBAYE, R. & DOHERTY, T. 2010. Prevention of mother-to-child transmission of HIV (PMTCT) program in KwaZulu-Natal, South Africa: an evaluation of PMTCT evaluation and integration into routine maternal, child and women's health services. *Tropical medicine and international health*, 15(9):992-999, September.

HORWOOD, C., VOSE, A., VERMAAK, K., ROLLINS, N. & QAZI, S. 2009. Routine checks for HIV in children attending primary health facilities in South Africa: attitudes of nurses and child caregivers. *Social sciences & medicine*, 70(2010):313-320.

IOANNIDIS, J.P.A., TAHA, T.E., KUMWENDA, N., BROADHEAD, R., MTIMAVALLYE, L., MIOTTI, P., YELLIN, F., CONTOPOULOUS-IOANNIDIS, D.G. & BIGGER, R.J. 1999. Predictors and impact of losses to follow-up in an HIV-1 perinatal transmission cohort in Malawi. *International journal of epidemiology*, 28:769-775.

JONES, S.A., SHERMAN, G.G. & VARGA, C.A. 2005. Exploring the socio-economic conditions and poor follow-up rates of HIV-exposed infants in Johannesburg, South Africa. *AIDS care*, 17(4):466-470, May.

KIZITO, K.W., DUNKLEY, S., KINGORI, M. & REID, T. 2011. Lost to follow-up from tuberculosis treatment in an urban informal settlement (Kibera), Nairobi, Kenya: what are the rates and determinants? *Transactional of the Royal Society of Tropical Medicine and Hygiene*, 105:52-57.

LANGFORD, R.W. 2001. Navigating the maze of nursing research: an interactive learning adventure. St. Louis, Mo.: Mosby. 336 p.

LEMLY, D., MANDELROT, L., MEIER, F., FIRTION, G., MATHERON, S., JEANTILS, V. & SCOTT, T.A. 2007. Factors related to medical appointment after childbirth among HIV-infected women in the Paris region. *AIDS care*, 19(3):346-354.

LINCOLN, Y. & GUBA, E. 1985. Naturalistic inquiry. Beverly Hills, Calif.: Sage. 416 p.

MANZI, M., ZACHARIAH, R., TECK, R., BUHENDWA, L., KAZIMA, J., BAKALI, E., FIRMENICH, P. & HUMBLET, P. 2005. High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling-up requires a different way of acting. *Tropical medicine and international health*, 10(12):1242-1250.

McCOY, D., BESSER, M., VISSER, R. & DOHERTY, T. 2002. Interim findings on the National PMTCT pilot sites: summary of lessons and recommendations. Durban: Health Systems Trust. <http://www.hst.org.za/uploads/files/pmtctsummary.pdf> Date of access: 6 May 2007.

McKEE, N., BERTRAND, J.T., BECKER-BENTEN, A. & LEE BECKER, B. 2004. Strategic communication in the HIV/AIDS epidemic. Thousand Oaks, Calif.: Sage. 351 p.

MEDLEY, A., GARCIA-MORENO, C., MCGILL, S. & MAMAN, S. 2004. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programs. *Bulletin of the World Organisation*, 82(4):299-307.

MELLINS, C.A., KANG, E., LEU, C., HAVENS, J.A. & CHESNEY, M.A. 2003. Longitudinal study of mental health and psychosocial predictors of medical treatment

adherence in mothers living with HIV disease. *AIDS patient care and STDs*, 17(8):407-416.

MEPHAM, S.O., BLAND, R.M. & NEWELL, M-L. 2010. Prevention of mother to child transmission of HIV in resource -rich and -poor setting. *BJOG, an international journal of obstetrics and gynaecology*, 118(2):202-218.

MEPHAM, S., ZONDI, Z., MBUYAZI, A., MKHWANAZI, N. & NEWELL, M.L. 2011. Challenges in PMTCT antiretroviral adherence in northern KwaZulu-Natal, South Africa. *AIDS care*, 23(6):741-747.

MILLER, C.M., KETLHAPILE, M., RYBASACK-SMITH, H. & ROSEN, S. 2010. Why are antiretroviral patients lost to follow-up? A qualitative study from South Africa. *Tropical medicine and international health*, 15(suppl.1):48-54.

MIRKUZIE, A.H., HINDERAKER, S.G. & MORKVE, O. 2010. Promising outcomes of a national programme for the prevention of mother-to-child HIV transmission in Addis Ababa: a retrospective study. *BMC health service research*, 10(267).
[http://www.biomedcentral.com/ 1472-6963.10/267](http://www.biomedcentral.com/1472-6963.10/267) Date of access: 5 November 2011.

MOUTON, J.& MARAIS, H.C. 1994. Basic concepts in the methodology of the social sciences. Pretoria: Human Sciences Research Council. 276 p.

NEWELL, M. 2005. Current issues in the prevention of mother-to-child transmission of HIV-1 infection. *Transactions of the Royal Society of Tropical Medicines and Hygiene*, 100(1):1-5.

NURSING ACT 2005 (See South Africa)

Oxford Advanced Learner's Dictionary of current English. 1993. New York: Oxford University Press. 1580p.

PAINTER, T.M., DIABY, K.L., MATIA, D.M., LIN, L.S., SIBAILLY, T.S., KOUASSI, M.K., EKPINI, E.R., ROELS, T.H.&WIKTOR, S.Z. 2004. Women's reasons for not participating in follow-up visits before starting short course antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV: qualitative interview study. *British medical journal*, 329:543-546.

- PAREKH V. & BROWN C.B. 2003. Follow up of patients who have been recently sexually assaulted. *Sexually Transmitted Infections*, 79:349.
- PATTINSON, B. 2009. Perinatal Care Survey of Tshwane/Metsweding:2009. City of Tshwane. 59p.
- PELTZER, K., MOSALA, H.T., DANA, P. & FOMUNDAM, H. 2008. Follow-up survey of women who have undergone a Prevention of Mother-to-Child Transmission Program in a resource-poor setting in South Africa. *Journal of the Association of Nurses in AIDS care*, 19(6):450-460.
- POLIT, D.F. & BECK, C.T. 2008. Nursing research: generating and assessing evidence for nursing practice. 8th ed. Philadelphia, Pa.: Lippincott Williams & Wilkins. 796 p.
- POLIT, D. F., BECK, C. T. & HUNGLEY B. P. 2001. Essentials of Nursing Research – methods, appraisal and utilization. 5th ed. Philadelphia: Lippincott
- RISPEL, L.C., PELTZER, K., PHASWANA-MAFUYA, N., METCALF, C.A. & TREGER, L. 2009. Assessing missed opportunities for the prevention of mother-to-child HIV transmission in an Eastern Cape local area. *South African medical journal*, 99(3):174-179.
- RUBIN, H.J. & RUBIN, I.S. 1995. Qualitative interviewing: the art of hearing data. Thousand Oaks, Calif.: SAGE Press. 302 p.
- SEIDMAN, I. 1998. Interviewing a qualitative research: a guide for researcher in education and the social sciences. 2nd ed. New York: Teachers College Press. 143 p.
- SHAPIRO, R. L., HUGHES, M.D., OGWU, A. KITCH, D. LOCKMAN, S. et.al. Antiretroviral Regimen in Pregnancy and Breast-feeding in Botswana. 2010. *The New England Journal of Medicine*, 364(24): 2282-2294.
- SHERMAN, G.G., JONES, S.A., COOVADIA, A.H., URBAN, M.F. & BOLTON, K.D. 2004. PMTCT from research to reality: results from a routine service. *South African medical journal*, 94(4):289-363.

SOUTH AFRICA. Department of Health. 2008. Policy and guidelines for the implementation of the PMTCT programme. [sfmtct-f.html](#) Date of access: 9 March 2009.

SOUTH AFRICA. Department of Health. 2010. Clinical guidelines: PMTCT (Prevention of Mother-to-Child Transmission).
http://www.fidssa.co.za/images/PMTCT_Guidelines.pdf Date of access: 15 December 2011

SOUTH AFRICA. Nursing Act, No. 33, 2005. Pretoria: Government Printer.

SRIIPATANA, T., SPENSLY, A., MILLER, A., MCINTIRE, J., SANGIWA, G., SAWE, F., JONES, D. & WILFRED, C.M. 2007. Site-specific interventions to improve prevention of mother-to-child transmission of human immunodeficiency virus programme in less developed settings. *American journal of obstetrics & gynaecology*, 197(3 Suppl):S107-112.

STEVENS, W., SHERMAN, G., DOWNING, R., PARSONS, L.M., OU, C.-Y., CROWLEY, S., GERSHY-DAMET, G.M., FRANSEN, K., BULTERYS, M., HOMSEY, J., LU, T., FINKBEINER, T. & NKENGASONG, J.N. 2008. Role of the Laboratory in Ensuring Global Access to ARV Treatment for HIV-Infected Children: Consensus Statement on the Performance of Laboratory Assays for early Infant Diagnosis. *The open AIDS Journal*, 2:17-25.

STREUBERT-SPEZIALE, H.J. & CARPENTER, D.R. 2003. Qualitative research in nursing: advancing the humanistic imperative. 3rd ed. Philadelphia, Pa.: Lippincott Williams & Williams. 374 p.

STRINGER, E. 2004. Focus groups. (In Bassett, C. Qualitative research in health care. London: Whurr Publishers. p. 6-29.)

STRUWIG, F.W. & STEAD, G.B. 2001. Planning, designing and reporting research. Cape Town: Pearson Education South Africa. 279 p.

STRYDOM, H. & DELPORT, C.S.L. 2005. Sampling and pilot study in qualitative research (In De Vos, A.S., Strydom, H., Fouché, C.B. & Delport, C.S.L., eds. Research at grass roots. 3rd ed. Pretoria: Van Schaik. p. 327-332.)

TEJIOKEM, M.C., FAYE, A., PENDA, I.C., GUEMKAM, G., NDONGO, F.A., CHEWA, G., REKACEWICZ, C., ROUSSET, D., KFUTWAH, A., BOISIER, P. & WARSZAWSKI, J. 2011. Feasibility of early infant diagnosis of HIV in resource-limited settings: The ANRS 12140-PEDIACAM Study in Cameroon. *PLoS one*, 6(7):1-7 N

TERRE BLANCHE, M., DURRHEIM, K. & PAINTER, D. 2006. Research in practice: applied methods for the social sciences. 2nd ed. Cape Town: University of Cape Town Press. 594 p.

TORPEY, K., KABASO, M., KASONDE, P., DIRKS, R., BWEUPE, M., THOMPSON, C. & MUKADI, D. 2010. Increasing the uptake of prevention of mother-to-child transmission of HIV services in a resource limited setting. *BMC Health Research*, 10(29). <http://www.biomedcentral.com/1472-6963/10/29> Date of access: 05 December 2011.

UKPE, I.S., BLITZ, J., HUGO, J. & THELEDI, M. 2009. The infant feeding practices of mothers enrolled in the prevention of mother-to-child transmission of HIV program at a primary health care clinic in the Mpumalanga province, South Africa. *South African family practice*, 51(4): 337-339.

UNAIDS. 2006. 2006 Report of the global AIDS epidemic. (A UNAIDS 10th anniversary special edition.) Genève: WHO. 629 p.

VARGA, C. & BROOKES, H. 2008. Factors influencing teen mothers' enrolment and participation of mother-to-child HIV transmission services in Limpopo Province, South Africa. *Qualitative health research*, 18:786-802.

VARGA, C.A., SHERMAN, G.G. & JONES, S.A. 2005. HIV-disclosure in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa. *AIDS care*, 18(8):952-960

WOOD, S.A., TOBIAS, C. & MCCREE J. 2004. Medication adherence for HIV-positive women caring for children: in their own words. *AIDS care*, 16(7):909-913.

Appendix A Ethics approval from North-West University



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Karin Minnie

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: <http://www.nwu.ac.za>

Ethics Committee

Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za

2009-08-04

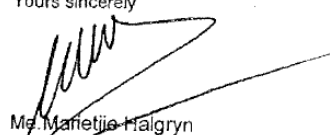
ETHICS APPROVAL OF PROJECT

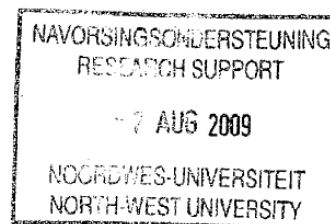
This is to certify that the next project was approved by the NWU Ethics Committee:

Project title		Factors contributing to low follow-up of babies born to HIV positive mothers																									
Student		A Mogomotsi																									
Ethics number	<table border="1"><tr><td>N</td><td>W</td><td>U</td><td>-</td><td>0</td><td>0</td><td>0</td><td>3</td><td>0</td><td>-</td><td>0</td><td>9</td><td>-</td><td>A</td><td>1</td></tr></table>												N	W	U	-	0	0	0	3	0	-	0	9	-	A	1
	N	W	U	-	0	0	0	3	0	-	0	9	-	A	1												
Institution Project Number Year Status																											
Status: S = Submission R = Re-Submission P = Provisional Authorisation A = Authorisation																											
Approval date: 3 August 2009							Expiry date: 2 August 2014																				

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance. The formal certificates are in process and will follow shortly.

Yours sincerely


Ms. Mafetjo Halgryn
NWU Ethics Secretariate



Appendix B Letter to request permission from Department of Health

1

Mrs A.M. Mogomotsi
P. O. Box 87
MORULA
0196
09.11.2009

To: Dr Ndimande
Karel Schoeman Building
179 Skinner Street
PRETORIA
0001.

Dear Sir,

Re- Permission to conduct research at your institutions as part of the requirements for my M. Cur Degree studies at NWU

I am a M. Cur Degree (Midwifery and Neonatal Nursing Science) student registered with the North-West University (NWU), Potchefstroom Campus. As part of the degree, I must conduct a research project and my topic is "Factors contributing to the low follow-up of babies born to HIV-Positive mothers". Ethical approval has been granted by the NWU Ethical Committee.

The purpose of the research is to:

- explore and describe the factors contributing to the low follow-up of babies born to HIV-Positive mothers;
- explore and describe the deficiencies in the existing follow-up strategies;
- make recommendations that will improve the follow-up rate and care of babies born to HIV-Positive babies.

In order to achieve the above, HIV-Positive mothers who did not return their babies for follow-up will be interviewed followed by a focus group interviews with midwives and HIV-Counsellors.

I therefore, hereby request permission to conduct the research in the 24HR clinics, Kgabo, Boekenhout and Phedisong 4 CHC. Herein, I have enclosed a research proposal, a copy of the Ethics committee approval letter and an example of the consent forms to be completed by the volunteering participants.

After the research report has been compiled, the results will be made available to your office as well as to the clinics.

Thank you in anticipation,
Mrs A.M. Mogomotsi

Name and contact details of student researcher:
Mrs A.M. Mogomotsi
W 012-703-2993
Cell 076-273 1389

Name and contact details of study supervisor
Dr. Karin Minnie
School of Nursing Science
Potchefstroom Campus
North-West University
Tel 018-299-1836.

Signature of student *A. Moganotsi* Date *08/12/09*
Signature of supervisor *KS Minnie* Date *8/12/09*

Appendix C Permission from Gauteng Department of Health and Social Development



Lefapha la Maphelo le Tshebeletso le Ntshetsopele ya Sechaba
Department of Health and Social Development
Umnyango wezeMpilo no kuthuthukiswa komphakathi
Department van Gesondheid en Maatskaplike Ontwikkeling
ODI DISTRICT HOSPITAL

Enquiries: Dr J.V. Ndimande

Maureen Moleleki

Tel: (012) 701 3125

Fax: (012) 702 0469

Email: maureen.moleleki@gmail.com

05/03/2010

THE CHIEF DIRECTOR
DR P.H. MADUNA

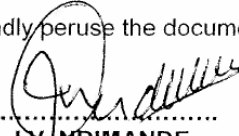
RE: REQUEST BY MRS A.M. MOGOMOTSI TO CONDUCT RESEARCH

Mrs. A.M. Mogomotsi is employed in our district at Phedisong 4. She has an approved protocol for her research and is seeking permission from the Chief Director's office.

TITLE: FACTORS CONTRIBUTING TO LOW FOLLOW-UP OF BABIES BORN TO HIV
POSSITIVE MOTHERS

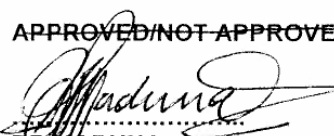
I have looked at the relevant documents and wish that she be allocated to do her research.

Kindly peruse the documents.


.....
DR J.V. NDIMANDE
DISTRICT FAMILY PHYSICIAN
TSHWANE METSWEDING

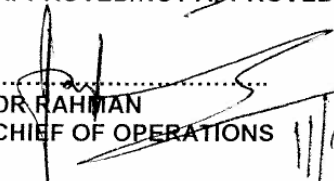
APPROVED/NOT APPROVED

RECOMMENDED.


.....
DR MADUNA
CHIEF DIRECTOR
REGION C

5/3/2010

APPROVED/NOT APPROVED


.....
DR RAHMAN
CHIEF OF OPERATIONS

11/03/2010

Appendix D Ethical approval from Tshwane/Metsweding Research Ethics Committee



Umnyango wezempilo no Kuthuthukiswa Komphakathi
Lefapha la Maphelo le Tshebetso le Ntshetsopele ya Sechaba
Department of Health and Social Development
Departement van Gesondheid en Maatskaplike Ontwikkeling

TSHWANE/METSWEDING REGION
Enquiries: Dr F Senkubuge
+27834024493
Email: fsenkubuge@gmail.com

TSHWANE/METSWEDING REGION RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

Meeting: 01/2010

PROJECT NUMBER: TMREC 2010/05

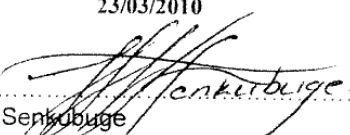
PROJECT:

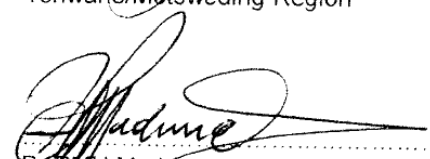
Title: Factors contributing to the low follow-up of babies born to HIV- Positive mothers
Researcher: AM Mogomotsi
Supervisor: Dr CS Minnie
Department: North-West University Potchefstroom Campus
Degree: M.Cur (Midwifery and Neonatal Nursing Science)

DECISION OF THE COMMITTEE

Approved

Date: 23/03/2010


Dr F Senkubuge
Chairperson Tshwane/Metsweding Research Ethics Committee
Tshwane/Metsweding Region


Dr PMH Maduna
Chief Director: District Health Services
Tshwane/Metsweding Region

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedure as approved by the committee.
ALL CORRESPONDANCE TO INCLUDE PROTOCOL NUMBER

Appendix E Request for permission from the clinic

P.O. BOX 87
MORULA
0196
04 MAY 2010

THE BBS
MABOPANE

Dear madam

RE: REQUEST TO CONDUCT A RESEARCH AT YOUR CLINIC

I, A Mogomotsi an Mcur student at Potchefstroom University, and hereby request to conduct a ~~research at your clinic~~. My topic is 'Factors contributing to low follow-up of babe born to HIV positive mothers'. Approval has been granted from the district and ethic committee of Potchefstroom University. Enclosed with this letter are the following:

- Approval from the district
- Ethics approval letter
- Participation information letter and consent form for mothers
- Research proposal
- Participation of information letter and consent for nurses and HIV-counselors

I will be glad if my request can be granted.

Yours faithfully
A.MOGOMOTSI

Appendix F. Informed consent form for individual participants

PARTICIPATION INFORMATION LETTER AND CONSENT FORM FOR MOTHERS

Dear participant

I am a M. Cur student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding factors influencing follow-up of babies born to HIV positive mothers. My intension is to understand the factors that contribute to the low follow-up of these babies and formulate recommendations that will increase the follow-up to enable the health service to deliver optimal care to the mothers and their babies. In order to do so, it is necessary to obtain your views on the contributing factors.

You were selected to participate as you will be able to contribute valuable information. As you know, all babies' cards are routinely checked as part of the 'Integrated management of childhood illnesses (IMCI) program. You were identified through the code on your baby's 'Road to health' card that indicates if he/she was exposed to HIV.

The nature of you expected participation

You are asked to participate in the phase of the study where individual interviews will be held with mothers.

The interview will be set up by appointment at a time and venue of your preference. The interview will last 20-60 minutes Your permission is also asked to record the interview to be transcribed and analysed afterwards. The recording will be locked away in a safe place and the final reports will not be traccable back to individual participants. Field notes will also be taken to keep the records of your responses.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has

been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

I acknowledge that it may be difficult to share your opinions and will try by all means to limit your discomfort as much as possible. An experienced interviewer will conduct the interview and if you experience any psychological discomfort professional counselling will be available after the interview.

Right to withdraw

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. There will not be discriminated against you if you prefer not to participate.

Confidentiality

Any information that you provide will be kept strictly confidential. The tapes and transcriptions will be kept under lock and key. The results will be published or presented in such a fashion that all participants will remain unidentifiable.

Possible benefits of this research

Although you may not directly benefit from the study, your contribution will add to the knowledge of and insight into the factors influencing follow-up of babies of HIV positive mothers. This will contribute to the formulation of recommendations to increase the follow-up to enable the health service to deliver optimal care to mothers and their babies.

Information

If you have any question about the research you are welcome to contact the researcher,

Mrs. A. M Mogomotsi: 012-7032993 (w), 076 273 1389 (c)

Email: anneline.mogomotsi@webmail.co.za

A copy of the results will be made available to your clinic and/or to you at your request.

I hereby request your permission to participate in the study by completing the attached consent form.

Sincerely

A. Mogomotsi

Anneline M. Mogomotsi

M. Cur student

Dr Karin Minnie

Dr Karin Minnie

Supervisor

Appendix G. Informed consent form for focus group participants

PARTICIPATION INFORMATION LETTER FOR FOCUS GROUP PARTICIPANTS

Dear participant

I am a M. Cur student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding factors influencing follow-up of babies born to HIV positive mothers. My intension is to understand the factors that contribute to the low follow-up of these babies and formulate recommendations that will increase the follow-up to enable the health service to deliver optimal care to the babies. In order to do so, it is necessary to obtain your views on the contributing factors.

The nature of your expected participation

You are asked to participate in the phase of the study where focus group interviews will be held with health workers delivering services to mothers and babies.

The focus group will consist of about 5-10 members and will last for about 45-60 minutes. The appointment for the interview will be arranged at a time and venue at your convenience. You will be asked regarding the factors that contribute to the low follow-up rate of babies born to HIV-positive mothers and the deficiencies in the existing follow-up strategies.

Your permission is also asked to record the interview to be transcribed and analysed afterwards. The recording will be locked away in a safe place and the final reports will not be traceable back to individual participants. Field notes will be taken to keep the records of your responses.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

An experienced interviewer will conduct the interview and it is not foreseen that you will experience any discomfort although the sensitivity of the topic is acknowledged.

Possible benefits of this research

Your contribution will add to the knowledge of and insight into the factors influencing follow-up of babies of HIV positive mothers. This will contribute to the formulation of recommendations to increase the follow-up to enable the health service to deliver optimal care to the babies.

Right to withdraw

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. There will not be discriminated against you if you prefer not to participate.

Confidentiality

Any information that you supply will be kept strictly confidential. The results will be published or presented in such a fashion that all participants will remain unidentifiable.

Information

If you have any question about the research you are welcome to contact the researcher, Mrs. A. M Mogomotsi: 012-7032993 (w), 076 273 1389 (c)

Email: anneline.mogomotsi@webmail.co.za

A copy of the results will be made available to your clinic and/or to you at your request.

I therefore, hereby request your permission to participate in the study by completing the attached consent form.

Sincerely

Anneline M. Mogomotsi.

Dr Karin Minnie

CONSENT TO PARTICIPATE IN THE STUDY

I have read the above information before signing this consent form. The content and meaning of the information is clear to me. I have been given opportunity to ask questions. I understand that if I do not participate it will not be to my disadvantage. I hereby volunteer to take part in this study.

Participant's signature

Date

Appendix H Demographic information for individual participants

Please tick and fill in where appropriate

Age:

Parity:

Religion:

Standard of education:

Marital status:

Employment:

Appendix I. Demographic information for focus group participants

Please tick where appropriate

1. Age:

<20yrs. 21yrs – 39yrs. 31yrs – 40yrs. 41yrs – 50yrs.
51yrs – 60yrs. >60yrs

2. GENDER : Male Female

3. RELIGION:

4. Have you been trained in any of the following? Please tick.

VCT.PMTCT.BREASTFEEDING.NONE OF THE ABOVE.

5. Any other, please specify.

Appendix J Field notes for individual interviews

Observational notes

37 years old, parity 3, unemployed, attended high school and speaking Setswana.

Participant looked bright and ready on arrival. Interview took place in the car, at her choice and privacy was confirmed without any interruptions or noise. Written consent was given. Was anxious at first but very free later during the interview.

Personal notes

I felt very comfortable with this participant. She expressed herself and showed great knowledge of the subject. She spoke freely and with gestures.

Methodological notes

The interview was initiated by an open-ended question, followed by probing. Used reflections and clarifications.

Appendix K Example of field notes for focus group participants

Observational notes

Show excitement and readiness, looking forward to the interview. Group of nurses and HIV-counsellor. Trained on VCT with some on PMTCT.

Personal notes

Interaction free amongst the group. All participating. Rich information given. Some showing gestures of being furious because of not having trained but working with these mothers.

Methodological notes

Main question was asked. From the answers, probing questions followed until the questions were exhausted.

Appendix L Transcript of individual interview

EXAMPLE OF FIELD NOTES OF AN INDIVIDUAL PARTICIPANT

I: Ok, thank you mama for agreeing to come here that I may ask you some questions related to the topic that I have explained to you, that there are babies that come to the clinic when they are already ill and some already going to hospital because they never came to the clinic at the time they were told to come and their mothers being HIV positive. So I would like to hear from you, what do you think is the reason behind mothers not bringing their babies to the clinic on time.

R: Eish, I think it is because of fear and not being able to accept that you are HIV, that is why most mothers do not bring them. Some of them are just ignorant.

I: Ok , I hear you. When you say fear, how does the fear affect the baby?

R: Isn't it now when you are HIV, you think that maybe the baby is also HIV and some have not disclosed in the family that she is HIV. It is unlikely that when you are HIV to tell people of your status. So I think that is the reason behind not bringing the babies on time.

I: I understand but is that the only reason why they do not bring them on time?

R: I think that is the reason.

I: And then what will be the reason for them not to tell their family about their status?

R: Eish. Isn't it when you are HIV you do not accept immediately. You have doubts and some of them have questions that I tested and found that I am HIV and I tested again and found that I am negative. Things like that of not having the knowledge that when you have tested you are HIV. You understand?

I: I hear you, but I want to clearly understand. A pregnant women who has come to the clinic, when she has tested been tested and was told that she is HIV positive, I want to understand if it is possible for her to be told that she is not positive?

R: Hai, it is not possible. But what I heard from others when we gather, isn't it we meet and talk? Like the other one sometime she said the testing was giving a

problem. It was showing one stripe for a long time so she does not know where she stands and has not mentioned it to her family. And now she is 6 months pregnant.

I: But what was she told?

R: She is positive.

I: She was told she is positive.

R: What I think is that she hasn't accepted that she is positive and then even the pills that they give us before, when I listen to her she is not taking them the way they said we should take them.

I: Because she hasn't accepted.

R: Yes because she hasn't accepted and that puts the baby at risk when she does not take the correct dose because you have to take them twice a day. Sometimes she tells me that she forgets.

I: I understand you .

R: Or it is sometimes I think that it is at times I think she did not get the right information properly basically they did not tell her in detail about HIV and pregnancy and how it affects the baby.

I: What HIV does when you are pregnant on the baby. I understand .So do you believe that if people were to be well informed that would also make them bring the babies on time to the clinic?

R: I was thinking that way. Like when you are at the clinic for pregnancy care there should be lessons that focus only on HIV that inform. Even though the others are not HIV positive but that lesson should focus strictly on HIV and inform people. I also didn't know it in the beginning but what helped me is that when I began going to the clinic they straight away sent me to the hospital and when I got to the hospital I meet sisters who took their time to inform me. Even when I have problems they explain to me. That is why I managed to go through and reach a stage where the baby is negative.

I: I understand. So you are basically saying that at the time you left the clinic and go the hospital the level of information was not.... ?

R: It was not like at the hospital.

I: So you are saying the level of education should be increased here at the clinic?

R: Yes

I: I thank you very much for assisting us because we will take it from there. But there is one thing that I do understand clearly. As the mother is told that she has tested positive and has not accepted, I think they should bring her baby and come and see how he/she is.

R: That's how it is, that one should bring the baby. I brought mine at 6 weeks because at the hospital after giving birth they then transfer you to the clinic.

I: Mmm (yes)

R: I went to the clinic at 6 weeks. When I reach at the clinic on the other side, the babies' side I found one sister .I told her that I have brought the baby for 6 weeks. Isn't it that the baby has to be brought to the clinic at 6 weeks? She told me and I know that at 6 weeks at the hospital the way they have informed me I must bring the baby to get tested .So she told me I think some of the sisters are not well informed about HIV. She said to me that things have changed lately, the baby should be tested at 9 months. But I was not happy about that and there was no way in which I could go back to hospital. I have to go there again. And on top of that she did not even give me a specific medication in which the baby should take after birth. I then went again the following day. When I came there again I found another sister and she explained to me saying, 'have you come here for the 6 weeks?' I explained to her that I came for 6 weeks and this and that happened and she was also surprised. I also explained that I am also amazed because I knew that the procedure should be like that. You understand ?

I: Mmm (yes)

R: She then told me 'you should bring the baby'. I carried the baby again the following week and that was when they conducted those tests. They then explained

to me there where I go for treatment the other side that you should bring the child at 9 months because I only knew the 6 months only which they did and got the results and then was told to be back after 9 months. They also gave me medication that should be taken every day which is white in colour.

I: When did they give it to you ?was it when they tested for the first time

R: They gave it to me when I tested her for the 1st time and I also take milk for her so they gave me again because they give you in 4 4s

I: Mm

R: Mm

I: I understand. So you think the problem is with

R: I see the problem being that some of the sisters are not well informed about HIV and babies

I: What should be done with them?

R: EeEe (yes, yes)

I: But.....

R: Cause somewhere I thought that I understood the whole procedure but I was confused when I went back to the clinic.

I: Because it was not the one you know?

R: You understand, because I was convinced that at the hospital I was given all the information.

I: I understand, so at the end, if I want to clearly understand you. the mothers also have a problem?

R: Yes, the mothers also have got a problem. I see it is on both sides of the mothers and at the clinic some of the sisters.

I: I understand.

R: It is not all of them because, you hear I say some of them. The first one gave me the information that I did not know and there was no way that I was going to force her because of she is a sister and I cannot push her and tell her that I was told to come here. But the second one gave the information which I am familiar with and that was like I was not telling the truth and of which I was honest because my main concern was the baby.

I: Mmm (yes)

R: Mmm (yes).

I: Mm m (yes). Because I have noticed that at the time you came according to my knowledge I found out that you brought the baby at 2 months and I asked myself why did you bring your baby late. But as you say that you were being turned away all this time I then see why you delayed.

R: Mmm (yes)

I: And that from your side you were more concerned about the baby.

R: Mm. Rightfully my main concern was the baby.

I: To see the baby being helped? And you had a problem at the clinic?

R: At the clinic. Mmm (yes).

I: I understand. But since you say that you meet as women and talk about these things, isn't there anything you know that may be the reason that causes the mothers not to bring their babies to the clinic on time. Because we have a lot of babies that go to the hospital when they are very ill.

R: I you know, we do meet as women and talk like when we go there for treatment. Even there at the treatment I think that these pregnant women should make a day just to come and talk about that when you are pregnant you should protect your baby. It is as if they take it some take it they take it those who do not know it take it for granted , the way I see it.

I: Those who do what ?

R: Those who are not those who are pregnant, and were told that they are positive and then are told that treatment this and that, it seems they don't take it they take it lightly. They don't take it seriously. Like you heard I say I came across a lady who is pregnant and is not taking her medication properly. You see what I mean? But at the end the baby will come being positive, Isn't it? where as she should have protected the baby to come being negative, you understand how it is? I see that most of the babies come being positive because they do not take their treatment when they are pregnancy seriously.

I: I understand and also am thankful because you help us to see how we should do. I am thankful for the information that you have given me. Is there any other thing you want to say related to this topic?

R: I, the other thing that I want to say is that even after that 6 weeks they should tell us what the next step is because I am giving him that medication and do not know when she should stop drinking it. All that I know is that after 9 months I should take her back.

I: Ok, that we can discuss after we are done here because that is not part of the topic. But I would like to thank you a lot for giving me your time that I should ask you these questions and all the information you have given me, and maybe, one day I may ask you that I come and talk with you about what we have discussed.

R: Ok, I am also thankful.

I: Thanks a lot.

Appendix M Transcript of focus group interview

I: Thank you sisters and the counsellor to come so that we can continue with this research that I was telling you about that there is a low follow up of babies who are born to HIV positive mothers. So the last time I got the reasons from you, but today I just came and I thank you for coming. I came to ask this question that which strategies do you use to encourage these mothers to bring their babies back at the scheduled time to the clinic. Who can start?

I: I think we are working with them and we know what we say to them. Yes, you are welcome.

R1: Ok I think that we have been educating them telling them the importance of bringing the babies and to educate the family so that the family can give them support and to also remind them that they should come to the clinic and if they do not come, or maybe I am talking too much?

I: No, you can continue

R1: If they do not come we make follow ups by calling them and have their contact numbers and call them and if they do not come again we then send.... just because we do not do home visits, they are no longer done I do not know. But also to do home visits to find out why they are not coming, maybe they have problems of money or maybe the mother herself is sick and cannot bring the baby and there is no one assisting her.

I: Yes, if we come back to the topic, I said last time you gave me reasons and thank you and those are some of the reasons they gave last time. But now my question was only, what strategies do we use, not what makes them not to come. What strategies do you use to encourage them to come. So I want to make a follow up to what you said that we talk to the families. Is this something that we practice?

All: Mhhmhh (no, no)

I: Because what I want, I'm not asking what do you think is the best that we should do, but I want to know what do we use, what strategies do you use in this clinic to make sure that your people come back?

R2: I think that you tell the person the importance of why she should come.

I: Education, Ok

R2: With the family, it becomes difficult why because the person will be having confidentiality and when you tell the family that this person should come you must tell the reasons. So the strategy that we should use is reinforce education every time so that she can see the importance of coming back.

I: Thank you. Who else can say something?

R3: Also another point that is important, the client should be actively involved in choosing a date that is suitable to her. Because you as the nurse might give her a date and four weeks to come and on that specific day she has commitments or she will be having financial problem. Let her be involved by her telling you that sister I can come on this date because it is suitable for me, then it is fine.

I: Can I make a follow up sister on that?. Are you saying that you make clients to choose a date or are you suggesting that to be done? Is that what you practice?

R3: I personally, I come up with a date. If that client cannot come on that date then I ask which date is suitable for you. Then she will give me a date and we will agree on it

I: O.K, and we still find low follow up of babies still not being brought back irrespective.

R3: It's very few of them, because it is a clinic. The next time she come she can meet a different sister who will tell her that I can only see you on such and such a date. Maybe she does not try to be like me by asking her which one is suitable for you. Then the client will obviously be unable to come. So, that can also be a suggestion that here at the clinic how about we practice this strategy of letting the client choose first the date that she sees suitable provided it falls within the given time frame, if it is a month's time frame it should not elapse more than that month.

I: Thank you guys. Maybe I should find out from you guys that, this thing of a person being given a date that suits her, have you all been practicing it?

All: No.

I: O.K. So it is not practice thoroughly. Any other strategy that we use?

R4: Yes, I personally, when the client comes being on PMTCT, in fact when the client come, I find out first about the program whether she are on PMTCT or not. And then I have seen that it works when you ask the client if there are any problems that she is encountering, ask questions before dismissing her and talk to her that she may know where she is going especially instilling the education on PMTCT. Because if she comes and you just say it is 6 weeks and you do the PCR and she leaves. When she comes back you do not ask her how the baby sleeps and other things and next time you give her results which are negative and she goes there is nothing that you are doing. She will not see the importance of coming back.

I: So asking questions from every client....?

R4: Yes especially the PMTCT client involve her you see. If she decided that she has been going to the clinic for a while, only for medication and now I'm tired she will see that it is important that she go.

I: I know that you work scarcely this side but do you have something to say ?

R5: No, I was thinking of the one of.... of....

I: Sister

R5: education that education must always be reinforced amongst the PMTCT clients, the importance of doing PCR, why they should do it and the benefits thereof. Unlike staying at home and not doing it and the baby will not get the help they were going to get. So basically education is what I think is of more importance and also the one of sister xxxxxxxx is still a point, of finding out, ask questions and find out whether the mother is on the programme.

I: So irrespective of the two or as you been using these two main strategies of educating and involving the mother through questions. Do you see the improvement of these babies being increased, is the number increased even though they do not all come ?

ALL: Yes

I: Even though they still not all come. But these two strategies works for some?

R4: It is very few to find those who come at 18 months without having done any test, it is very few. Most of them do come and they comply.

R2: And you find that they are from other clinics, not around our clinic. Less number is those who come from other clinics not around our clinic. They will deliver from somewhere then they will come when the baby is sick. But otherwise those who are from the clinic, do.

I: That is why I am doing this research for all the clinics around. Because if you delivered in Boekenhout, or the hospital, Odi or Ga-Rankuwa or Kgabo, they are still our clients. That is why I said we have a problem in this district. So, whether it is here or other clinics, then we have to have strategies that we use.

R2: The thing when I said from other clinics, I don't mean the clinics around us. From outside, like people will be seeing not done, they will be coming from KZN, coming from Mpumalanga, they come from outside not around. They are many those who have delivered there, especially the Zimbabweans, they come like this, having delivered there, coming travelling like this and had no chance to take the baby and they will land up here when the baby is sick.

I: Thank you. I think that statement I would wonder if you have a statistics for those people who come from outside having not done PCR while the mothers are positive. You know there is something that I want to say, can we say it is true what we say and we even have a proof towards that. Isn't it even some of your clients you say they also do not come?

R1: There are some of ours who do not come. Very few.

R3: And then for this one what sister ... is saying, it is going to be a bit difficult to prove. Remember the time the client comes to the clinic already she has started to live here, and she is going to give the address from here in Ga-Rankuwa. But the history may say the child has been born somewhere, probably Mpumalanga or elsewhere. Well prove can be on the card if really there is a card. Some do not even have a card at that time and really when she has come to the clinic you cannot return the child back due to her not having a card, even the law does not agree.

I: Thank you. Any other thing? Have you exhausted them? That was that guys and thank you so much.

R5: Thank you.

I: Is there no any other thing? Do you want to say something?.

R1: Sister Mogomotsi, are we not saying concerning the family, are we ... as we educate these mothers, everybody who is positive, we encouraging them to disclose.

I: Are you telling me?

R1: I am asking.

I: Ask them.

All: Yes. We do.

R1: Isn't it? And then, now on that point again, I say, I am the one who say that, I say when we educate these mothers, we advise them to disclose to their families so that ,when she has gone to work, there should be someone who bring the baby on her behalf or if she is being held up by any other thing. Isn't it you won't be available all the time. Isn't it you need support. We say we need support, they should give her support. We involve the family, so that it can give this mother support, so that the baby does not default.

I: Who involve the family? Is it the client herself or do you involve the family?

R1: We educate the client to disclose to the family, she herself disclose so that the family can give her support. I am saying this because yesterday there was this client who came, a male, apparently he was the father who came to collect the medication for the baby, and he was denied and was told he won't be given. Later the mother came.

R2: You will find that this person, his communication.... a person will say I have come to collect the medication and when you ask him 'do you know how to give it?', he says I don't even know what it is for. You can't give the person the medication he does not even know how to give it to baby and having no information about it, do you understand?

I: O.K.

R1: And I asked the mother that did he know what that was and what is it given for? She said yes, it is the baby's father, he knows the baby takes treatment, since she is exposed.

I: That was a very good point

R4: To add on that, if there is a family involvement or she has disclosed, there is no breaking of defaulting, there is continuity. If the mother is ill and very sick, the granny come and explain that some things I understand some I do not, the mother is sick or she has gone to work just like that. But if there is no disclosure in the family, there is a problem. This mother may not be able to come every time and this baby is going to default

I: So seeing that you have encouraged disclosure, do you find it to be happening, is it easy for these mothers to disclose?

R1: Because at the end of the day neh, this mother passed away, and the children are left with the granny. What is going to happen?

R2: You know there are so many cases that... you will find that the person has passed away, her mother brings the baby to the clinic, she does not even know what is happening. She will discover when it is said let us do this and that on the baby, it is only that she discovers that the baby is positive, you understand? And it started that far. You will find that the mother did not attend did not take the AZT at 14 weeks, she did not she did not want to disclose. There was no one who knew what is happening. There are so many, who do not want to disclose. Few do disclose. There are many who few who I have seen, the granny having brought the baby, 'no her mother is sick of that condition'. You see that she understands something. It shows that she did disclose it is just that this mother does not want to put it straight. You understand? But few, few, few are disclosing. The majority don't.

I: If we go back to the previous interview it was said that the problem is disclosure. Therefore this is what we wish should happen but it is not yet happening. And therefore even when a person has died, don't you find problems with people who died and the family not knowing the cause?

R2:And when you ask a person that 'do they know? She will say, 'yes'. And I, for one, it is difficult for me to go to a person and ask them if she has told them, because we don't know if that person has really told them. It is not going to be simple to ask them, did she tell you that she is positive or did she tell you that she has a disease, you understand? So it becomes difficult. She will tell you that she has told them. To make a follow-up from the family it is difficult. Because you can say, did she tell you? 'What? 'and they raise ears, what are you going to say? When you ask them if she told them that she is positive, you break the confidentiality.

I:Thank you guys because the main thing was which strategies do you use and I got two of them, and thank you, thank you very much. I may still come back next time with follow up of something.

Appendix N Confidentiality agreement

Herewith I.....ID number.....

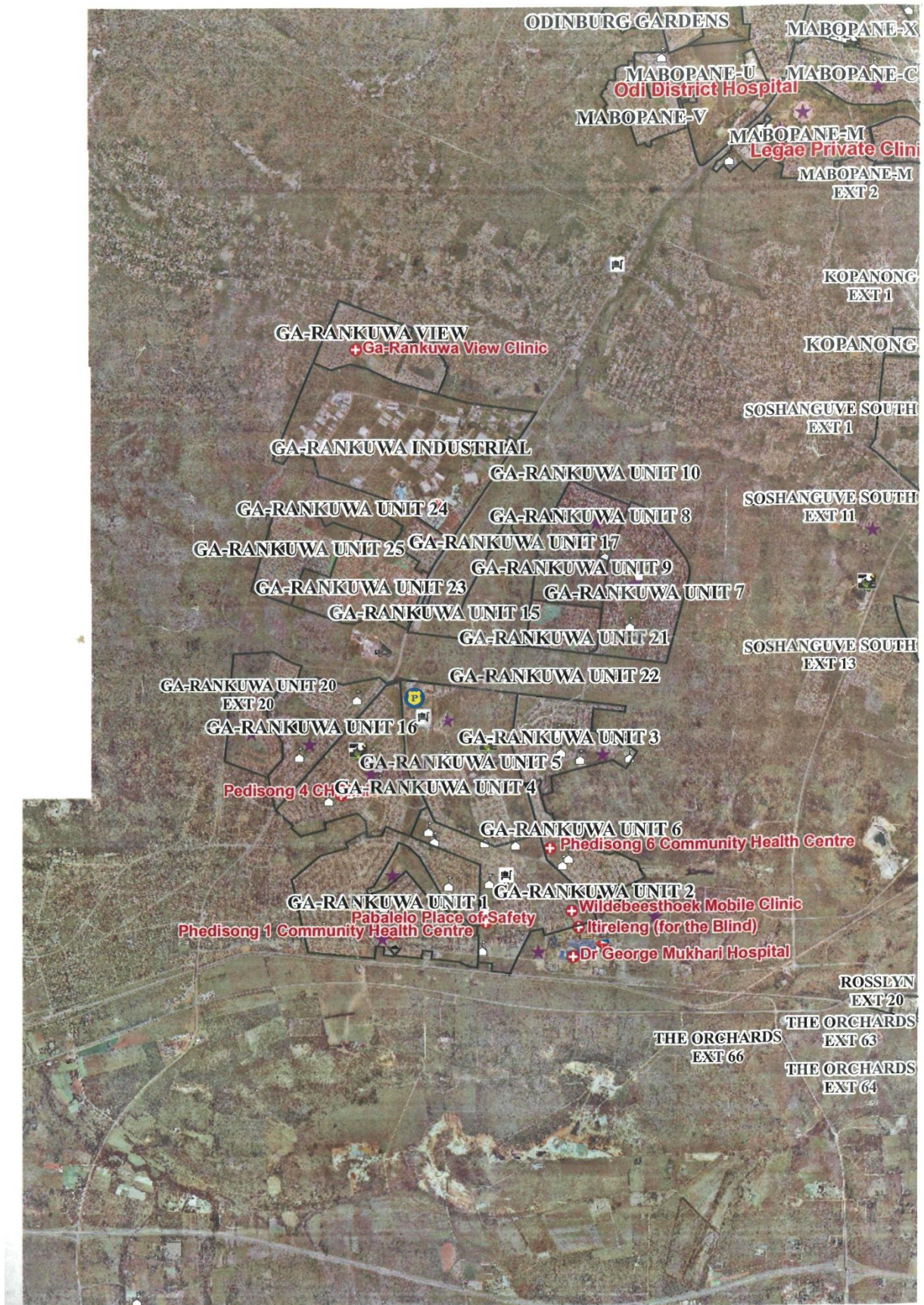
declare that I understand that the data I am exposed to are to be kept safe and confidential at all times. I will not share the content of what came to my attention with anyone other than the co-coder and the supervisor, Mrs AM Mogomotsi.

Researcher.....Date.....

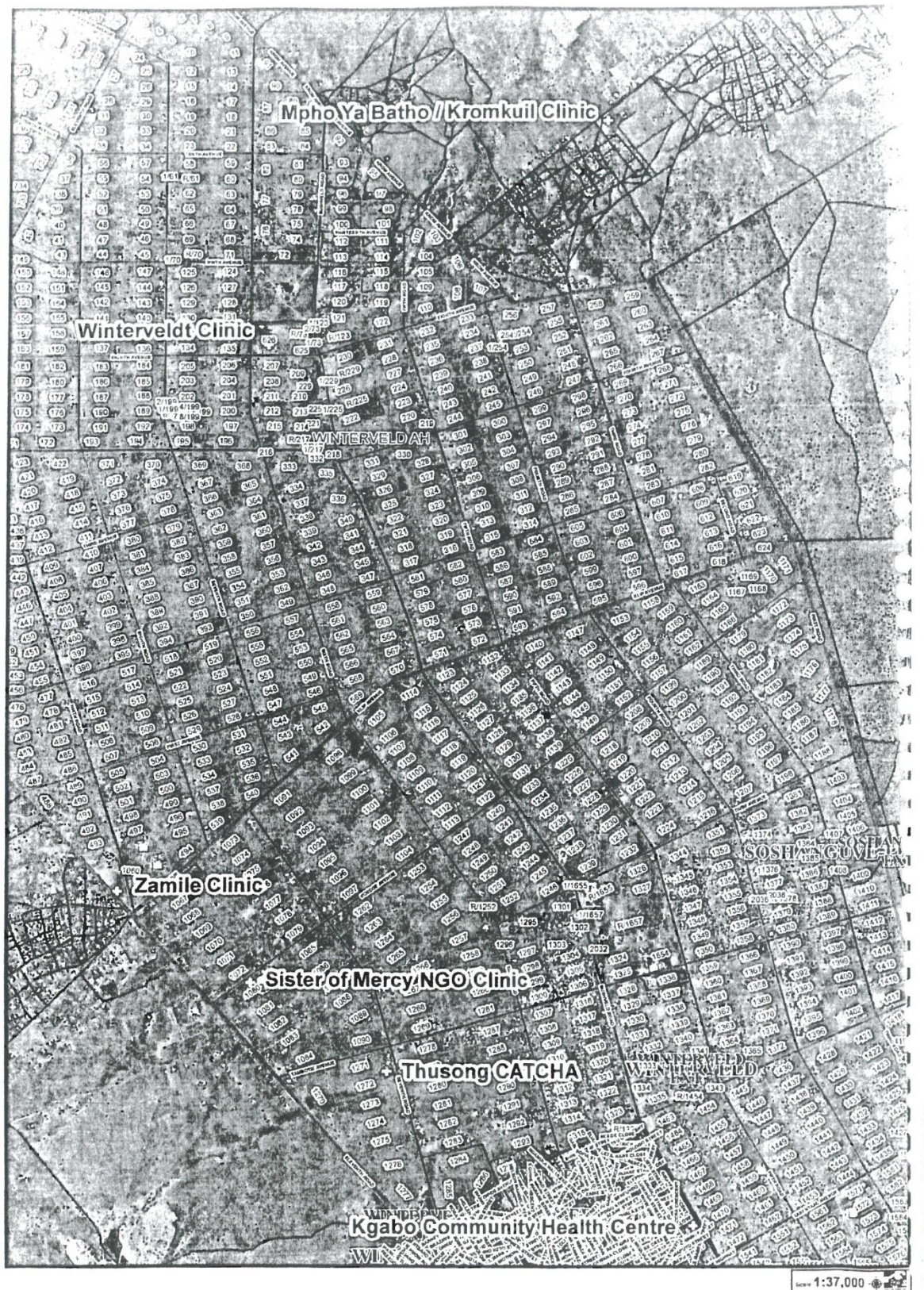
.....Date.....

Facilitator/ Co-coder/supervisor

Appendix O: Area served by Phedisong 4 Community Health Centre



Appendix P: Area served by Kgabo Community Health Centre



Appendix Q: Area served by Boekenhout Clinic

