REASONS GIVEN BY PREGNANT WOMEN FOR NOT RETURNING FOR THEIR RESULTS FOLLOWING VOLUNTARY COUNSELLING AND TESTING (VCT) FOR THE HUMAN IMMUNODEFICIENCY VIRUS AT EMBHULENI HOSPITAL

A qualitative study

By

Dr. DOUDOU KUNDA

NZAUMVILA

Submitted in partial fulfilment of the requirements for the Masters degree in Family Medicine (M. Med) in the Department of Family Medicine and Primary Health Care at Medical University of Southern Africa (MEDUNSA), University of Limpopo

Supervisor: Dr L H Mabuza

BTh (UNISA), MBChB, M Fam Med (Medunsa), FCFP (SA)

Co-supervisor: Mrs N H Malete

RN, RM, RCH (Psych)

Date submitted: 15.01.2010

DECLARATION

I, DK Nzaumvila hereby declare that the work on which this research is based is original (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being or is to submitted for another degree at this or any university.

Signed …… 

Date: 15.01.2010

DEDICATION

To my parents for your unconditional love which have shaped and guided me through life and supports me in everything that I embark on,

To my wife Rosy, I stand firm in the knowledge that your love and prayers will support me in all my ventures without any fear,

To Mrs Nomsa Malete for wisdom and scientific support thought the period of time I spent at Medunsa

ACKNOWLEDGEMENTS

I would like to thank my Supervisor Dr Mabuza who had made my success his concern, for his invaluable support and feed back.

My thanks go also the management staff of Embhuleni Hospital who made every asset easy for this study.

To the staff at the resource centre (Medunsa) who were of great assistance for providing me with literature.

Finally, my thanks go to the interviewees through their participation they made this study a reality.

ABSTRACT

Background

Some female patients consulting or bringing their children for HIV opportunistic infections have had a documented positive rapid HIV test done during pregnancy. Many of them did not go back for their CD4 result.

Aim of study

This study aimed to explore the reasons given by those women for not returning.

Objectives of study

The objectives of the study were to explore the reasons why women who had been tested for HIV by means of VCT failed to return for their CD4 results, to understand those reasons, to determine what information was given to the tested women before they were tested, to assess the availability of a personal support system (family, friends, etc), and finally to assess women's understanding of HIV, for which they were tested.

Study design: qualitative study.

Setting: Embhuleni Hospital, Mpumalanga Province.

Results and conclusion: lack of patient awareness to return for results, lack of ownership of the PMTCT programme by the health staff, poor quality of patient-healthcare provider communication, unpleasant experiences at health facilities

(such as workload and shortage), fear of stigma by patients, lack of personal support for patient and poor knowledge of the topic were the reasons why women failed to return for results.

Written dates to return for results during and after pregnancy should be issued and explained to each tested woman, HIV positive pregnant women should have a PMTCT supporter, staff trainings should emphasised to ensure that knowledge on the topic has been mastered by all involved healthcare providers. Programmes should be developed for patient psychological support.

ABBREVATIONS AND ACRONYMS

ANC	Antenatal Care
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
AZT	Zidovudine
CCMT	Comprehensive care Management and Treatment for HIV/AIDS
CTX	Cotrimoxazole
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
NVP	Nevirapine
PMTCT	Prevention of Mother-to- Child Transmission of HIV
RtHC	Road to Health Card
SdNVP	Single-Dose Nevirapine
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

TABLE OF CONTENTS

DECLARATION ii
DEDICATION iii
ACKNOWLEDGEMENTS iv
ABSTRACT v
ABBREVATIONS AND ACRONYMS vii
TABLE OF CONTENTS viii
CHAPTER ONE 1
INTRODUCTION 1
1.1 INTRODUCTION 1
1.2 MOTIVATION FOR THE STUDY 1
1.3 RESEARCH SETTING 6
1.4 AIM OF THE STUDY 7
CHAPTER TWO 8
LITERATURE REVIEW 8
2.1 INTRODUCTION 8
2.2 STATISTICS ON PMTCT 8
2.3 HISTORY OF PMTCTC 10
2.4 THE PMTCT AND SOUTH AFRICAN DEPARTMENT OF HEALTH GUIDELINES 14
2.4.1 Introduction 14
2.4.2 Enrolment of pregnant women in the PMTCT programme 15
2.4.3 Voluntary Counselling and Testing 17
2.4.4 Pre-test Group Information Session 18
2.4.5 Individual Information Session 19
2.4.6 Testing Algorithm for Pregnant Women 19
2.4.7 Post-testing for HIV Positive Pregnant Women 21
2.4.8 Clinical Care for HIV Positive Pregnant Women 22
2.5 LITERATURE PERTAINING TO THIS STUDY 25
2.6 Conclusion 32
CHAPTER THREE 35
METHODS 35
3.1 INTRODUCTION 35
3.2 RESEARCH DESIGN 35
3.3 AIM OF THE STUDY 36
3.4 OBJECTIVES OF THE STUDY 36
3.5 STUDY POPULATION 37
3.6 STUDY SAMPLE 37
3.6.1 Inclusion criteria 38
3.6.2 Exclusion criteria 38
3.7 DATA COLLECTION 38

3.8 DATA ANALYSIS 40
3.9 RELIABILITY 41
3.10 VALIDITY 42
3.10.1 Internal Validity 42
3.10.2 External Validity 42
3.11 TRIANGULATION 43
3.12 BIAS 43
3.13 ETHICAL CONSIDERATIONS 44
CHAPTER FOUR 46
RESULTS 46
INTERVIEW 1 46
INTERVIEW 2 53
INTERVIEW 3 58
INTERVIEW 4 61
INTERVIEW 5 64
INTERVIEW 6 67
INTERVIEW 7 70
INTERVIEW 8 73
INTERVIEW 9 76
CHAPTER FIVE 86
DISCUSSION 86
5.1 INTRODUCTION 86
5.2 ANC and PMTC process 86
5.2.1 Lack of awareness to return for the result 87
5.2.2 Lack of ownership of the PMTCT programme by the health staff 88
5.2.3 Poor quality patient-health care provider communication 89
5.3 Unpleasant experiences at Health Facilities 89
5.3.1 Lack of privacy and confidentiality 89
5.3.2 Blaming the health facility and health worker 90
5.3.3 Workload and shortage 92
5.4 Fear of stigma 92
5.5 Knowledge of HIV/AIDS and PMTCT 92
5.6 Support 93
CHAPTER SIX 94
CONCLUSION and RECOMMANDATIONS 94
REFERENCES 100
APPENDIX 110
APPENDIX 1: Approved Research Protocol 110
APPENDIX 2: Clearance certificate 125
APPENDIX 3: Permission letter from Embhuleni Hospital 126

TABLE OF FIGURES AND TABLE

FIGURE PAGE

1 Antenatal care stage……...2
2 Labour and delivery stage ……3
3 Postnatal care for mothers, check up by 6 weeks ……4
4 Integrated schema ……82
5 Interactions between themes……....84

Table PAGE

1 Highlighted themes and sub themes……81

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

Prevention of mother-to-child transmission (PMTCT) is a key global HIV prevention strategy. As the availability of PMTCT services is increasing, issues associated with the quality of PMTCT services have emerged that need to be addressed as these services are expanding. Moreover, many women make repeated visits for antenatal, postpartum and infant care, thus increasing their potential access to vital HIV/AIDS services that focus on primary prevention, vertical transmission, and care and support of those infected with HIV.

1.2 MOTIVATION FOR THE STUDY

Routine voluntary counselling and testing for HIV is offered to pregnant women attending the antenatal clinic at the Embhuleni Hospital and its satellite clinics.

The PMTCT guideline recommends that interventions be done at four stages.

- **Stage 1: Primary prevention of HIV and Mother to Child Transmission**

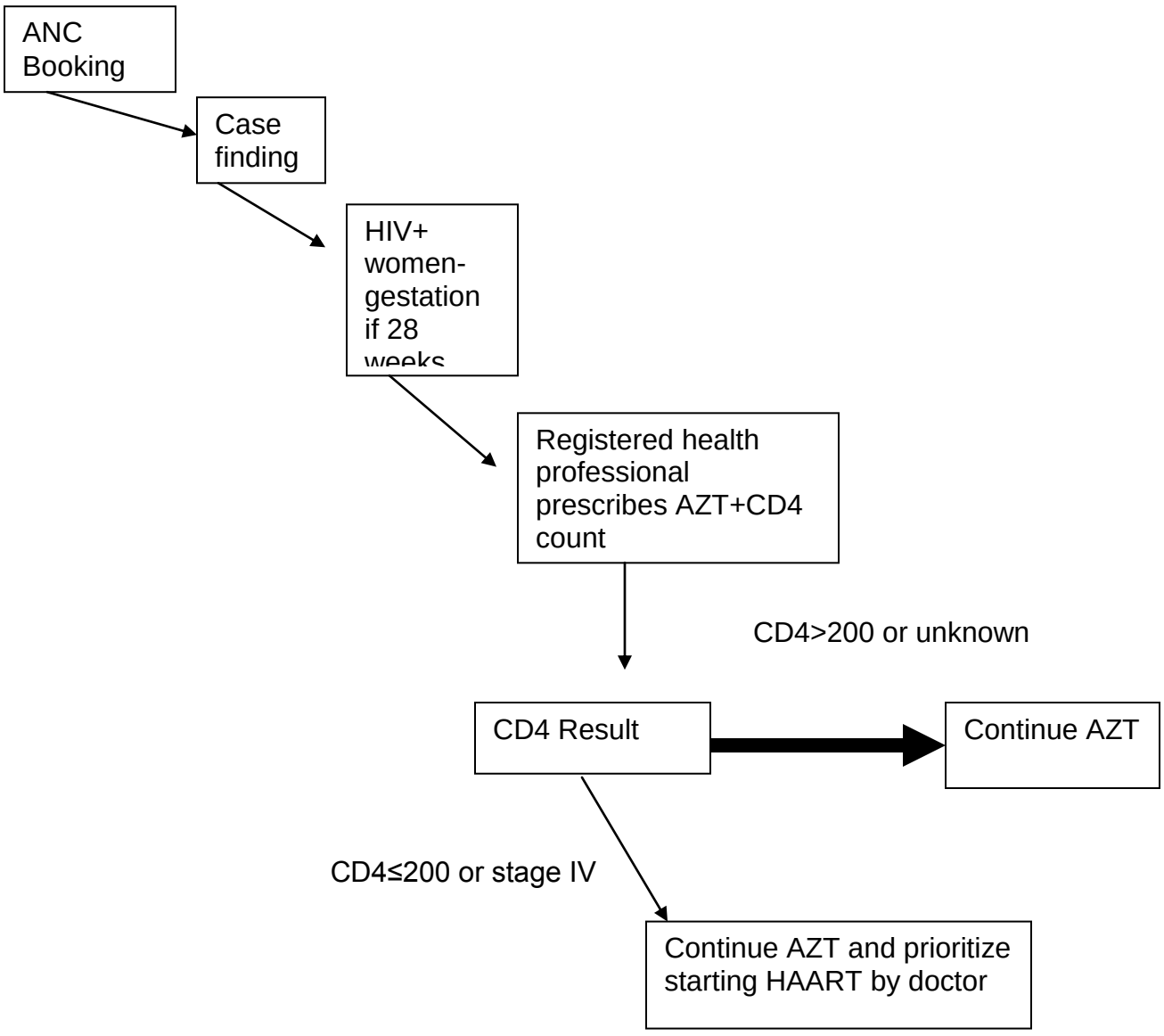
At this stage the goal is to reduce prevalence of HIV among women of child bearing age. The objectives as stated in the guideline are to implement targeted HIV prevention programmes for women of child bearing age, to strengthen

prevention of unwanted pregnancies among women living with HIV and lastly to support the implementation of women empowerment programmes and fight against gender violence (National Department of Health, 2008).

- **Stage 2: Antenatal care**

The guideline goal at Antenatal care is to increase coverage of target1 population (HIV positive women).

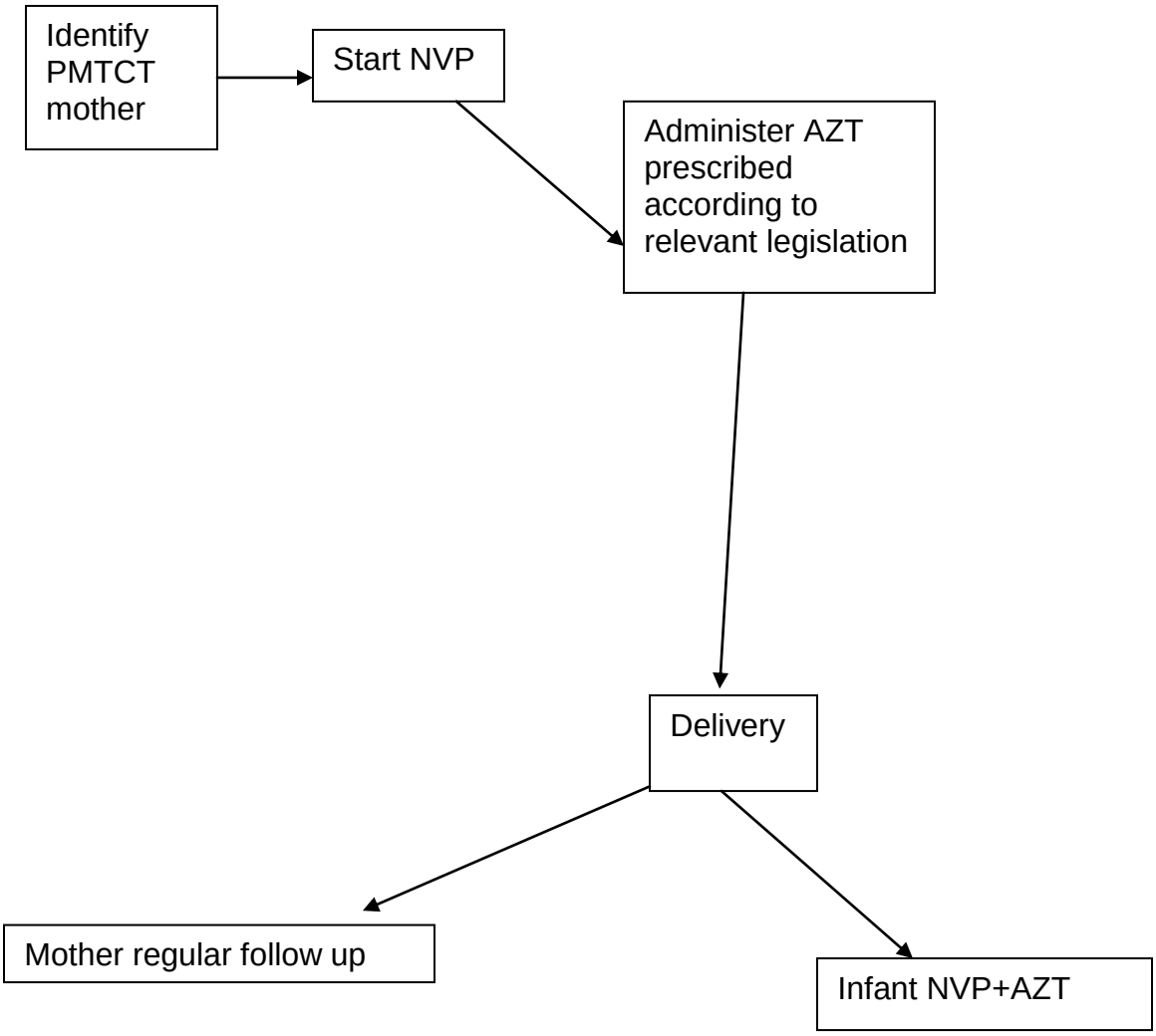
Figure 1. Antenatal care stage (National Department of Health, 2008)



- **Stage 3: labour and delivery**

During labour and delivery the goal is to minimize the risk of MTCT of HIV

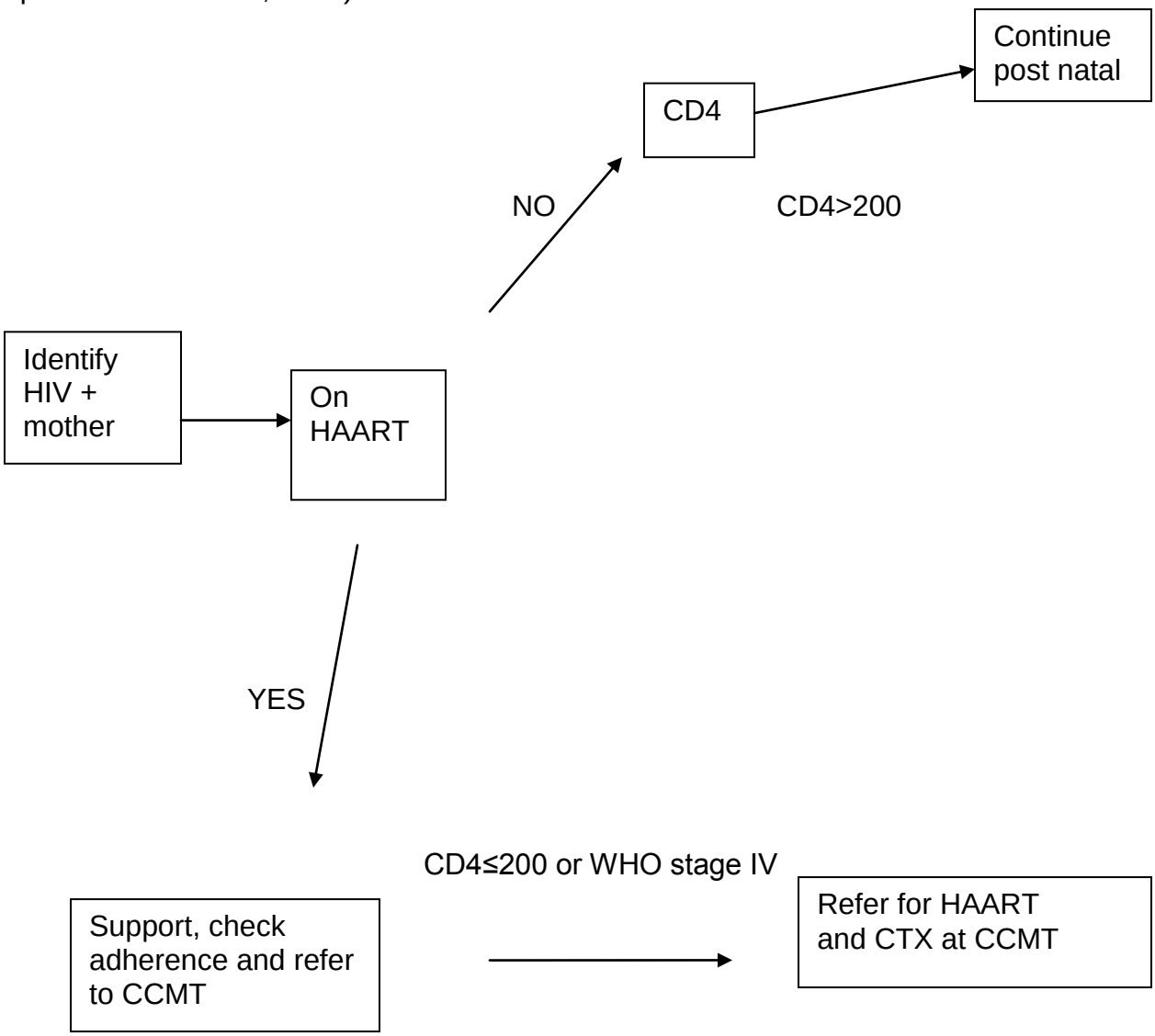
Figure 2 Labour and delivery stage (National Department of Health, 2008)



- **Postnatal follow up of mother and infant**

The goal in post natal is to reduce the risk of postnatal transmission of HIV

Figure 3 Postnatal care for mothers, check up by 6 weeks (National Department of Health, 2008)



A rapid test is offered to pregnant women at ANC or at labour. Should the test be positive, blood for CD4 is taken and results are available within 2 weeks.

An observation made at the Embhuleni Hospital and its satellite clinics was that of all the pregnant women, nearly 36% obtained a positive result in the HIV test. Only one quarter of these would attend the HIV wellness clinic and come back for their CD4 results, so that they could begin with Anti-Retrovirus Therapy (ART), if they qualified for this treatment. The rest would not attend the HIV wellness clinic, and would only present themselves to the hospital later with opportunistic infections or a subsequent pregnancy.

Women enrolled in PMTCT and/or HAART programmes need more frequent follow ups (**a two-week follow-up date must be given to women after their CD4 cell count has been taken**), and each health facility should have a mechanism in place to follow up on CD4 cell count results from the lab, discuss results with clients and trace women who do not return for their results (National Department of Health, 2008).

This apparent waste of resources needs to be explained- in other words, why do the majority of women who are tested not show any interest in their condition, despite having been counselled and informed of their status and the consequences thereof?

Prevention of mother-to-child transmission has one goal - to protect children from contracting HIV from their mothers by providing VCT and free treatment for HIV positive mothers during labour, as well as for the newborn baby (McIntyre, 2000; Dabis, 2002; Health Systems Trust,). Mothers are encouraged to be compliant

after being informed of their status, and that it is crucial for them to make use of the HIV care services for follow ups, treatment of opportunistic infections, infant feeding, counselling and group support. Prevention of mother-to-child transmission is key to reducing the transmission of HIV to the infant at birth. Family physicians have an obligation in every consultation with a patient, which is an opportunity for prevention and health promotion (Mash, 2000).

Therefore, after VCT, mothers are informed to come back after 2 weeks so as to be informed of their results: HIV and CD4 count.

1.3 RESEARCH SETTING

This study was conducted at the Embhuleni Hospital, which is located in the Albert Luthuli local municipality in the Mpumalanga province of South Africa.

- **Albert Luthuli Municipality**

The Albert Luthuli Municipality was established in 2000 and is part of the Gert Sibande District Municipality. The municipality consists of the following towns and villages: Nhlazatshe, Elukwatini, Mooiplaas, Tjakastad, Badplaas, Dun Donald, Glenmoore, Swallow'snest, Bett'sgoed Hartbeeskop, Mayfloer, Fernie1, Fernie2, Diepdale and Carolina.

It covers an area of 5.573 km^2 with an estimated population of 191 379 people, and is served by two hospitals, namely Embhuleni and Carolina. A total of 25 101 households are located in the area, with an average household size of 4.6 people. The dominant population group is African, followed by White. Most of the people in this area are between 5-19 years old, and a very low percentage of

them are above the age of 65. According to the population census (2007), the gender profile is 43 % males and 57% females, and the majority of them are unemployed.

- **Embhuleni Hospital**

The Embhuleni Hospital was built in 1982, and is situated in Elukwatini, a deep rural area that has no recreational facilities, with scenic surroundings, in the south-eastern part of the Mpumalanga Province. It is 30 km east of Badplaas and 25 km north-west of the border post of Swaziland. The hospital serves fifteen satellite clinics, three community health centres and two mobile clinics, with 117 points and one mobile dental clinic. There are five private practitioners and numerous traditional healers.

The Embhuleni Hospital serves a population of approximately 191 379, and has 220 approved beds. The services rendered consist of; promotive, preventive, diagnostic, curative and rehabilitative services delivered in a comprehensive and integrated manner, with the involvement of a wide range of professionals and support staff.

1.4 AIM OF THE STUDY

This study sought to explore the reasons given by pregnant women for not returning for their results following voluntary counselling and testing (VCT) for the human immunodeficiency virus at the Embhuleni Hospital.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The implementation of PMTCT has raised many issues, but it was difficult for the researcher to find articles dealing specifically with this topic. Most researchers have recognised the problem, but very few of them have conducted research in this regard.

The researcher reviewed literature from the Department of Health in order to gather all relevant information and data on PMCT in South Africa. The majority of the articles were retrieved from the Internet the author used PubMed, Google and Bink engines with “PMTC”, non-return for HIV results as key words. Other articles were obtained from Medunsa departmental resource centre. The researcher used the references to enquire more articles.

2.2 STATISTICS ON PMTCT

Globally, the rate of HIV infections is growing, and by 2006 in sub-Saharan Africa, nearly 25 million adults and children were living with HIV (Draper et al., 2008, UNAIDS/WHO AIDS, 2006). More than 4 million children are estimated to have died from AIDS, primarily as a result of mother-to-child transmission (MTCT) of HIV. The vast majority of these children are located in sub-Saharan Africa (Joint United Nations, 2005, Geddes, 2008).

Mother-to-child transmission of HIV remains the most common route of HIV infection for HIV positive children under the age of 5 years, and the virus is transmitted either during pregnancy, labour and delivery, or after birth via breastfeeding (McIntyre, 2000; Wilson, 2004).

Therefore, preventing mothers from transmitting HIV to their children implies that prevention of HIV infection among women of reproductive age should be promoted, by providing comprehensive voluntary counselling and testing (VCT) for HIV among pregnant women during antenatal care, and providing follow-up care for HIV positive women by forging ties with existing HIV care services or facilities, and referring women for group support and infant feeding counselling. (Joint United Nations Programme, 2005; Geddes, 2008). In South Africa in 2006, an estimated 38 000 children acquired HIV infection around the time of birth, and an additional 26 000 children were infected through breastfeeding (Global Expanded Inter-agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children, 2007), and the target for the South African National Strategic Plan (NSP) on HIV & AIDS and STI's for 2007 - 2011 is to reduce MTCT to less than 5% of infants born to HIV positive women by 2011(Department of Health, 2007).

The South African National Department of Health has established its goals in a comprehensive programme to prevent mother-to-child transmission, and these goals include high-quality antenatal, delivery and postpartum services; voluntary counselling and testing services; short-course ARV prophylaxis for HIV infected pregnant women; counselling and support for safe infant feeding practices; and

improved health, family planning and safe motherhood programmes (National Department of Health, 2008).

2.3 HISTORY OF PMTCTC

Mother-to-child transmission is the most important source of HIV infection in children, and in the absence of any interventions, the risk of MTCT of HIV is 15-30% in non-breastfeeding mothers and 20-40% in breastfeeding mothers (De Cock et al*.,* 2000). This risk of MTCT can be reduced to below 2% by interventions that include ARV prophylaxis given to women during pregnancy and labour, and to their infants during the first weeks of life. Obstetrical interventions including elective caesarean delivery and breast milk replacement (Dorenbaum et al., 2000; Thorne et al*.,* 2004). The feasibility of the above was evidently impossible in this study, since in resource-constrained settings, elective caesarean delivery is seldom available (Buekens et al*.,* 2003*)* and/or safe, and refraining from breastfeeding is often not acceptable, feasible or safe. Since one third to two thirds of overall transmission occurs around the time of labour and delivery, efforts to prevent MTCT in resource-constrained settings have mostly focused on this crucial period, as well as on breastfeeding.

ARV prophylaxis around the time of delivery alone can reduce the risk of MTCT in a breastfeeding population almost two-fold after a vaginal delivery (41–47% reduction in risk) (Gay et al, 1999; Jackson et al*.,* 2003). If ARV prophylaxis is extended to include the last month of pregnancy, efficacy at six weeks can be as high as 63% (Petra study team, 2002). However, even when peri-partum ARV

prophylaxis is used, infants remain at substantial risk of acquiring the infection during breastfeeding.

In 2001, the United Nations General Assembly committed countries to reducing the proportion of infants infected with HIV by 20% by 2005 and 50% by 2010 (United Nations, 2001, WHO, 2004).

In 2003, an estimated 700 000 children were newly infected with HIV, and about 90% of these infections occurred in Sub-Saharan Africa, while new HIV infections in children were becoming increasingly rare in many parts of the world (United Nations, 2001; UNAIDS, 2003).

On 5-6 February 2004, the WHO convened a technical meeting on ARV drugs and PMTCT of HIV infection in resource-limited settings in Geneva, Switzerland. Scientists, policy-makers, programme managers and community representatives reviewed the most recent experience with programmes and evidence on the safety and efficacy of various ARV regimens for preventing HIV infection in infants (United Nations, 2001; WHO, 2004), but the feasibility of PMTCT remained questionable at that time (Dabis et al*.,* 2002; HIV/AIDS, 2004).

Several studies have confirmed that in countries with limited resources, a short therapy regimen could be cost-effective - monotherapies such as Zodovudine (Shaffer et al, 1999; Lallemant et al*.,* 2000), or Nevirapine (Guay et al*.,* 1999; Moodley et al., 1999), and bi-therapies such as Zidovudine and lamuvidine (Moodley et al., 1999;Chaisilwttana et al., 2002).

In South Africa, a seroprevalence survey in 2005 showed that 30, 2% of pregnant women were HIV positive (Department of Heath, 2005; Draper et al*.,* 2008), and this was reduced to 29, 1% in 2006 (National Department of Health, 2008).

The Western Cape Province was the first to launch a PMTCT programme in South Africa. In January 1999, the sub-district of Khayelitsha was selected as a site for implementing a pilot PMTCT programme (Draper B.et al., 2008).

In 2001, a national comprehensive package for a Prevention of Mother-To-Child Transmission programme was introduced, and policy guidelines for the standards of care were developed.

The national PMCT programme is available in about 3000 primary health care facilities countrywide. The package includes:

- Primary HIV prevention programmes for women of child-bearing age,
- Routine provision of voluntary HIV counselling and testing to pregnant women,
- Safe infant feeding counselling and support,
- Safe obstetric practices,
- Single dose nevirapine to the mother and infant, as well as the provision of infant formula to women who choose this route and who will be able to do it safely and in an acceptable, feasible, affordable and sustainable manner (National Department of Health, 2008).

The goal of the PMTCT programme is to increase coverage of the target population (HIV positive pregnant women), with the following as objectives:

Prenatal phase:

- Identify pregnant women who are HIV positive
- Ensure that HIV positive pregnant women enrol in the PMTCT programme
- Do a CD4 count on all HIV positive pregnant women
- Assess the results according to the WHO clinical staging guidelines
- Encourage repeat HIV testing at not later than 34 weeks of pregnancy
- Provide primary prevention counselling and support for HIV negative pregnant women
- Provide positive prevention counselling
- Encourage the involvement of the family
- Provide individualised psychosocial support
- Screen HIV positive women for TB
- Provide AZT prescribed by a registered health professional (in line with the relevant legislation and regulations) from 28 weeks of gestation
- Provide HAART for pregnant women, with indications for such treatment
- Offer other relevant non-HIV services
- Provide safe infant feeding counselling
- Provide nutrition support according to the South African National Guidelines on Nutrition for People Living with HIV, AIDS, TB and other chronic debilitating conditions of 2007.

Postnatal follow- up for mother and infant:

- HIV diagnosis – PCR at six weeks
- Identify all HIV infected infants who are eligible for HAART and initiate such therapy according to available guidelines
- Ensure safe infant feeding practices for all infants, and monitor weight gain and growth
- Provide cotrimoxazole for HIV exposed babies and HIV positive babies
- Clinically test all mothers for anaemia and send blood specimens for haemoglobin assessment if anaemic
- Treat anaemia in consultation with a doctor trained in HIV & AIDS care
- Assess and treat symptoms and signs of postnatal infection
- Keep mothers healthy.

2.4 THE PMTCT AND SOUTH AFRICAN DEPARTMENT OF HEALTH GUIDELINES

2.4.1 Introduction

In February 2009, the National Department of Health released the new policy and guidelines for the implementation of the PMTCT programme (National Department of Health, 2008). This is an update of the National PMTCT policy and guidelines. The South African PMTCT programme, conceptualised in 2000, has been implemented at pilot sites since 2001, and nationally since 2002. This

policy document seeks to provide continued guidance towards successful reduction of mother-to-child transmission of HIV, building on work done over the past decade.

The researcher found it important to report in this study on the relevant aspects of the new guidelines for PMCT, as discussed below.

2.4.2 Enrolment of pregnant women in the PMTCT programme

This means that these women will then:

- Receive routine antenatal care, including micronutrient supplementation.
- Be provided with information on the availability of PMTCT interventions during any healthcare consultation.
- Be counselled on safer sex and provided with condoms
- Be counselled on safe infant feeding options and assisted in making an appropriate feeding choice
- All pregnant women who are HIV positive should:
- Have a CD4 cell count taken on the same day that their HIV positive status is established, and preferably at the first ANC visit (or at the earliest opportunity), and this should be assessed in terms of clinical stages according to the WHO staging.
- Be screened for TB, in line with Basic Antenatal Care (BANC).
- Receive ARV regimens prescribed by a registered health professional (in line with relevant legislation and regulations) for a PMTCT short course or HAART.

- Women who start HAART during their pregnancy should be monitored and managed, where possible, by the same provider and in the same setting, and should be followed up on by the antenatal healthcare worker until at least 6 weeks postpartum, before being referred to a CCMT service point.
- Women who test HIV negative should receive post-test counselling and counselling on risk reduction interventions, focusing mainly on how to maintain their HIV negative status, and should continue to receive routine antenatal care.
- Women who test HIV negative should be offered a repeat HIV test at or around 34 weeks to detect late sero-conversion.
- Women who choose not to be tested should be offered voluntary HIV testing at every subsequent visit during the antenatal period, or shortly after childbirth if testing at onset of labour is not possible.
- Unscheduled women in labour should be offered voluntary counselling and testing for HIV during the first stage of labour, and then offered a PMTCT intervention if they test positive.
- For continuity of care and management, information on HIV status, infant feeding choice, PMTCT/HAART regimens and CD4 cell counts should (with patient consent), when necessary, be shared between health care personnel at all levels of the health service sector.

2.4.3 Voluntary Counselling and Testing

- All women receiving antenatal care (first attendees and women attending follow-up visits) should be given routine information about voluntary HIV testing and the PMTCT programme.
- The initial information on HIV and its transmission should be provided in a 'Group Information Session'.
- Thereafter, all women who have not previously been tested or those who require repeat testing should go to a counsellor for a one-on-one 'Individual Information session'.
- At the individual information session, each woman should be informed of the routine voluntary HIV testing procedure and the option of not agreeing to this for whatever reason. She should be given the opportunity to ask further questions, and should then be offered an HIV test and asked to provide verbal and written consent to this testing. A woman may refuse this test.
- Women who refuse to have an HIV test should be offered routine voluntary HIV testing on every subsequent clinic visit
- All women who test HIV positive on the screening rapid test should have their HIV status confirmed using a second rapid finger prick with a different kit.
- Post-test counselling should be offered to both HIV positive and negative women – HIV positive women should only be counselled after the second rapid HIV test has been performed and if this confirms a positive HIV

status. Details of what information to provide during pre-test information sessions and post-test counselling are provided below.

2.4.4 Pre-test Group Information Session

- Staff should conduct a general group information session on HIV and PMTCT-related issues for all women coming for first or repeat antenatal visits.
- A group information session should include the following key components: information about HIV transmission and how to prevent it, information about the HIV testing process, the importance of early access to treatment, information about choices for infant feeding, information about mother-to-child transmission of HIV, and possibly, measures to reduce this, In addition, information about interventions that can keep HIV-exposed infants healthy, such as Cotrimoxazole prophylaxis and antiretroviral therapy, should be provided, together with an assurance of confidentiality and discussion of shared confidentiality, as well as couples counselling and the option to not take the test.
- The group information session should provide further information on the programme and include the fact that an HIV test is a necessary step for enrolment in the PMTCT programme, unless a woman's HIV status is already known to be positive. Furthermore, CD4 cell counts and clinical staging are important for clinical decision-making.

2.4.5 Individual Information Session

- Individual information should be made available to all pregnant women following the group information session.
- The components of the individual information session include: assessing whether or not the information provided in the group session has been absorbed, answering any remaining questions and seeking to clarify any misunderstandings, discussing the way forward and the treatment options for enrolment in the PMTCT intervention, and obtaining consent (written and verbal) for HIV testing.

2.4.6 Testing Algorithm for Pregnant Women

- Testing must be seen as a key entry point for reinforcing HIV primary prevention and accessing HIV care and PMTCT services.
- HIV testing of women should occur as part of the first antenatal encounter. Blood collected for routine antenatal screening, including haemoglobin, HepBs Ag, Rhesus factor and syphilis screening should include a big enough sample to perform a rapid HIV test and CD4 cell count if required (‘tube specimen’). The sample taken for HIV testing will not be processed if the pregnant woman objects to being tested for HIV.
- At the time that this routine blood is drawn, and where there is written and verbal consent, a rapid HIV test should be done, with either a drop of blood from the venepuncture site or a finger prick.

- If the rapid HIV test is positive, a confirmatory HIV test should be done utilising blood from a finger prick and another rapid HIV test kit (different test kit). The woman should be present when this confirmatory test is done. She should be considered to be HIV positive if the second rapid test is also positive. She should then be given her results and receive post-test counselling.
- If the test is negative and the woman is asymptomatic, she is considered to be HIV negative. Women who test HIV negative should be offered a repeat HIV test at or around 34 weeks in order to detect late sero-converters.
- If the results are discordant, i.e. the first rapid HIV test is positive and the second rapid HIV test is negative, a specimen of blood should be collected and a laboratory ELISA test should be conducted. In this case, the woman should be asked to return for the HIV test results following the completion of the ELISA test or at a subsequent antenatal visit. The implications of and need for the laboratory test should be explained to her.
- For women who have missed the opportunity of being tested during the first antenatal visit, the testing algorithm should follow the above protocol whenever they are tested.
- Following testing, all HIV positive women should have a CD4 cell count done, be screened for TB and assessed according to the WHO clinical staging guidelines.

- Professional nursing staff at the facility should be trained in performing rapid HIV tests and on the importance of confidentiality.
- The following algorithm should be applied for HIV testing.

2.4.7 Post-testing for HIV Positive Pregnant Women

- All HIV positive women should be assessed according to the WHO clinical staging guidelines, and have their CD4 count checked, preferably on the same day as the confirmation of their HIV positive status.
- The post-test counselling session for women who are HIV positive should include the following key components over a number of counselling sessions, which may not all occur on the same day (information on and referral to support services and positive living, information about therapy, the side effects of the medication and where to report these, the transmission risks associated with STI infection, dealing with stigma, and information about safer sexual practices during pregnancy and in the long-term.
- Women who are in WHO clinical stage 4 should be considered for commencement of HAART as soon as possible. HIV positive women should be offered counselling at every subsequent antenatal care visit or earlier, if the woman or counsellor deems this necessary in order to assist her in coping with and thinking about the implications of her diagnosis. Women requiring additional psychosocial support should be referred to a social worker or psychologist. Counsellors identifying complex issues

which they are not comfortable handling should similarly make a referral to a social worker or psychologist.

2.4.8 Clinical Care for HIV Positive Pregnant Women

The key elements of care for the HIV positive pregnant woman include: routine Antenatal care, prevention and management of opportunistic infections, especially TB, prevention and management of sexually transmitted infections (STIs), infant feeding, counselling, psychosocial support, positive prevention, use of micronutrient supplementation and, where necessary, nutritional support, use of antiretroviral drugs, safe obstetric practices, with an emphasis on early detection and treatment of postnatal infections and anaemia.

Women enrolled in PMTCT and/or HAART programmes need more frequent follow ups (a two-week follow-up date must be given to women after their CD4 cell count has been taken), and each health facility should have a mechanism in place to follow up on CD4 cell count results from the lab, discuss results with clients and trace women who do not return for their results.

- **Managing opportunistic infections**

Women with CD4 ≤200 cell counts are particularly vulnerable to opportunistic infections. Some opportunistic Infections that HIV positive pregnant women experience, particularly with a CD4 ≤200 cell count, include tuberculosis, urinary tract infections, pneumocystis jiroveci pneumonia (PCP), cervicitis and other STIs, vaginal candidiasis, human papilloma virus infection, vulvovaginal candidiasis and diarrhoea. Cotrimoxazole prophylaxis should be provided to

women with either WHO stage IV disease or those who have a CD4 cell count below ≤200 cells/ml. This should be done in accordance with the Adult ARV Guidelines.

All opportunistic infections should be managed according to the DOH National Guidelines on the Management of Opportunistic Infections in HIV Positive Adults. Care must be taken with drug choices in the first trimester of pregnancy. Combination of cotrimoxazole, AZT and anaemia of pregnancy requires careful monitoring, with the support of a doctor. AZT for the PMTCT regimen must be prescribed according to existing regulatory frameworks.

- **Nutritional support**

Micronutrient supplementation for HIV positive women is the same as that routinely provided during pregnancy for all women. Supplementation includes multivitamins, iron and folate. However, in the case of advanced HIV diseases where malnutrition, wasting or poor weight gain is evident, nutritional support in the form of vitamin- and mineral-fortified porridge should be provided. These women should also have an opportunistic infection such as tuberculosis excluded and be monitored closely.

- **Antiretroviral (ARV) Therapy**

Antiretroviral therapy provides the opportunity to significantly reduce maternal HIV viral load and MTCT. A reduction in the HIV transmission rate is achievable using regimens containing single, dual- or triple-drug combinations.

Decisions concerning the support of women’s choices of infant feeding to avoid mixed feedings and reduce MTCT need to be made during pregnancy.

Indications for ARVs during pregnancy are as follows:

1) To treat women with advanced HIV who meet the criteria to start treatment with Highly Active Antiretroviral Therapy (HAART), in order to delay the progression of the disease. While being used for maternal health, it is expected that this regimen will also reduce the risk of mother-to-child transmission of HIV. This regimen will be referred to in this study as HAART. HAART describes the use of a triple-combination of antiretroviral therapy to treat advanced HIV.
2) To reduce the viral load in a pregnant woman so as to decrease the risk of HIV transmission to her child. This regimen will be referred to as the PMTCT regimen. Here, the PMTCT regimen refers to the combination of ARVs used at various stages of the antenatal, intrapartum and/or postnatal period that aim to reduce transmission, as well as any resistance to these drugs. Women with a CD4 cell ≤200 cells/mm3 and/or women who are at WHO stage IV of the disease should be prioritised for HAART at any stage of pregnancy. For pregnant women not requiring HAART, a PMTCT regimen is the main strategy to reduce MTCT. Women presenting at 28 weeks or later should be started on AZT prescribed by a registered health professional (in line with relevant legislation and regulations) at that visit, unless clinically anaemic (pale) or laboratory findings indicate that they are severely anaemic (i.e. Hb<7g/dl). HIV positive women with anaemia should be managed by a doctor prior to initiation of any antiretrovirals, including AZT. Toxicity monitoring for pregnant women on

AZT is essential. ARVs given soon after birth to infants born to women who are HIV positive have been found to be an effective strategy for reducing MTCT, whether or not maternal ARVs are received, and forms the basis of a post-exposure prophylaxis strategy. The administration of sdNVP and a 7-day course of AZT prescribed by a registered health professional (in line with relevant legislation and regulations) to the infant have been shown to be effective in reducing MTCT. In instances where there has been only sdNVP given to the mother or she has had less than 4 weeks on an AZT or HAART regimen, the infant will require sdNVP and 28 days of AZT.

2.5 LITERATURE PERTAINING TO THIS STUDY

The implementation of PMTCT has raised many issues. Some authors have mostly focused on socio-economic constraints (such as poor roads and telecommunications, and an under-developed transport system) as obstacles to PMTCT (Skinner et al., 2005; Peltzer et al., 2007). Other authors have pointed out the fear of discrimination or domestic violence afterwards (Termman et al, 1995; Pool et al., 2001), missed opportunities for PMTCT (Sherman et al., 2004; Rispel et al, 2009). The issue of following up on HIV positive women after VCT during ANC for breastfeeding (Jones et al, 2005; Fadnes et al, 2009) and disclosure to partners (Antleman et al, 2001; Verga et al, 2008) and several researchers in Sub-Saharan African countries have advocated that solutions should be found with the couple (Hollos , 2004; Desgrées du Loû, 2005).

To date, insufficient studies have focused on the failure of women to return for their own results.

Catania et al. have identified that failure to return for posttest counselling was associated with low educational level, anxiety about HIV infection, poor understanding of what the HIV test result meant, young age and looking for testing because of a blood transfusion

Ladner et al. conducted a cohort study to identify factors associated with failure to return for HIV post-test counselling in pregnant women in Kigali (Rwanda). The only variable significantly associated with failure to return was a positive HIV test result (odds ratio, 0.7; 95% CI, 0.5-0.9; P = 0.009), independently of obstetrical history and socioeconomic status. The authors suggested that innovative approaches to HIV testing and counselling programmes are needed, and that the importance of psychosocial and cultural factors associated with HIV testing should be emphasised in African populations.

Painter et al. conducted a qualitative cross-sectional study from October 1998 to the end of May 1999 in Abidjan (Côte d'Ivoire), with the objective of finding out why pregnant women who obtained HIV-1 positive test results and were offered short course antiretroviral prophylaxis to prevent transmission of HIV from mother to child did not participate in follow-up visits before starting prophylaxis. The authors had a purposive sample of 27 women who had received HIV-1 positive test results and were invited to return for monthly follow-up visits before starting prophylaxis with zidovudine at 36 weeks' gestation, but they had either refused to do so or had discontinued the visits. Among these participants, none of the

women had started prophylaxis. The authors noted difficulties experienced by women during their contacts with staff working with the prevention programme, and that the negative views that they had about the programme could have contributed to their non-participation in prophylaxis. They suggested that on the one hand, training and supervision of programme staff may increase the likelihood of positive interactions between staff and clients, thereby facilitating women's participation in preventing transmission of HIV from mother to child, and that on the other hand, outreach and mobilisation in communities that are served by prevention programmes may complement these measures at programme level by contributing to increased social support for women's efforts to prevent transmission of HIV from mother to child.

A study conducted to demonstrate the feasibility, from the public health perspective, of preventing mother-to-child transmission of human immunodeficiency virus type 1 (HIV-1) in Abidjan (Côte d'Ivoire) for six months in 1998-99. VCT was routinely provided in four health centres with zidovudine, and alternatives to breastfeeding were provided free of charge to HIV-infected women. Of the 4309 pregnant women in the study who attended their first antenatal care visit, 3756 benefited from individual counselling (87.2%), and 3452 (80.1%) agreed to undergo an HIV test. Among the 2998 HIV negative women, 71% returned for their test results, whereas only 60% of the 445 HIV positive women did so. The authors concluded that an insufficient proportion of women returned to obtain their test results. This was especially so among HIV positive women, the target group for preventing mother-to-child transmission of

HIV. Additional staff were required in order to offer voluntary counselling and HIV testing to the study women, and the close supervision and strong commitment of health workers were essential (Msellati et al.,2004).

The Zvitambo study in Zimbabwe, reported on at the 3rd Conference on Global Strategies for Prevention of HIV Transmission from Mother to Infant in September 2001, showed that many women were willing to be tested, but only 20% chose to receive their results (Piwoz, 2001).

Collection of test results has been considered as the most challenging activities of PMTCT (Perez, 2004). It was admitted that there were inevitable dropouts at each step of the VCT process, and noted that not all women agreed to be tested, and not all those who were tested returned for their results, but this study did not provide the proportion of women who did not come back for their results or the reasons for their failure to return Bassetts, 2002).

Bassetts proposed universal testing, with the option to opt out from receiving the results. In this approach, women would be tested, but they would be allowed to opt out of being informed of the results.

Paoli et al., in their study conducted in 2004, recognised that not all of those who were tested came back for their results, but this study did not focus on them.

In 2007, Nuwagaba-Biribonwoha et al. made the observation that women who accepted HIV testing did sometimes not wait for their results, although these were normally available later the same day. The problem occurred mostly among those women who were tested late in their pregnancy, without time to cope with their HIV status. Some women attended the antenatal clinic once and then

vanished without a trace. Others did not deliver in the PMTCT hospitals and so missed antiviral prophylaxis and modified intrapartum obstetric care. This difficulty was more common in rural areas and when women depended on spouses for transport to the hospital. The follow-up of women and their babies after delivery was even more difficult. Those who had normal vaginal deliveries sometimes did not see the need to return to the PMTCT hospitals for postnatal services. They were concerned that women who had not disclosed their HIV status to their partners would be more likely to not receive follow-up care, as they preferred not to be traced to their communities.

Karchel et al. conducted a prospective observational cohort study between April 2004 and September 2005. They evaluated the risk factors for treatment denial and loss to follow-up in an antiretroviral treatment (ART) cohort in a rural African setting in western Kenya. Appointments for clinical and laboratory investigations were scheduled at baseline and 0.5, 1, 2, 4, 6, 9, 12, 15 and 18 months after start of treatment. The clinical examination comprised staging of HIV infection and screening for concurrent diseases. Laboratory investigations consisted of blood tests - CD4 counts were evaluated at baseline and every six months thereafter. ART, supportive drugs, laboratory tests and counselling were provided free of charge to patients. Adherence to ART was assessed by patient self-reports, a visual analogue scale, and pill counts. They found that a total of 35 (22%) of the 159 enrolled participants failed to begin ART, of whom 20 were pregnant women, four died, and one had a severe psychiatric disorder resulting in treatment denial. The reasons for treatment denial were not identified for the

remaining patients. The authors concluded that pregnancy and a lower level of education were risk factors for treatment denial (follow up), and the same observations were made by other studies (Stringer et al*.,* 2003; Karcher et al., 2006)

A cohort study conducted in Malawi by Manzi et al*.* showed that a total of 3136 mothers (average age of 22 years) was registered at the antenatal clinic of the Thyolo district hospital between March 2002 and February 2003. Of these, 2996 were pre-counselled, and 140 refused pre-test counselling (wanted to receive consent from husband and did not come back). Six hundred and forty six (22%) were found to be HIV positive and included in the PMCTC programme. Two hundred and eighty eight (45%) returned at 36 weeks of pregnancy, two hundred and six (32%) returned for hospital delivery, two hundred and two babies (34%) received Nevirapine at the hospital, one hundred and ninety six (30%) babies were brought to the postnatal clinic, and one hundred and twenty two (19%) returned for their six months' postnatal visit. The authors concluded that the progressive loss to follow-up of over three quarters of the HIV positive cohort by the 6 month postnatal visit challenged the possible impact and credibility of their current programme, which is almost the same as in South Africa, and they suggested that a new way of thinking is needed in order to improve the effectiveness of the PMTCT programme (Manzi et al, 2005).

In 2004, A Cape Town study found that health policy, health services and health-seeking behavior accounted for the problems experienced in PMTCT programme (Delva, 2004).

A review of the prevention of mother-to-child transmission programme of the Western Cape Province from 2003-2004 highlighted referrals from the PMCT programme to ARV clinics. Once women were identified as having low CD4 counts by routine CD4 testing early in pregnancy, it was important to identify what steps were required for the appropriate management of these patients. HIV positive women with CD4 counts less than 200 were considered to be patients at risk, both obstetrically and for increased vertical HIV transmission.

Protocols were developed during 2004 to facilitate the referral of PMCT patients with low CD4 counts to ARV sites. Two weekly satellite ARV clinics were set up in midwife obstetric units in one urban sub-district with an HIV prevalence of 27%. Between December 2004 and November 2005, 130 patients had been seen at one of the midwife obstetric unit's RV clinic - 93% of these had been referred before 29 weeks' gestation and were able to be started on ART inb sufficient time before delivery (Draper et al., 2008).

The proportion of women on whom a CD4 count was performed was not recorded as routine data, and laboratory data for the first half of 2004 were specifically examined to assess the progress of CD4 testing. Operationally speaking, CD4 testing was successfully introduced in the Western Cape PMTCT programme and proved to be especially useful in areas of HIV prevalence in order to identify high-risk individuals. Routine recording of the proportion of HIV positive women who undergo CD4 testing should be recommended as a useful indicator for a PMTCT programme. In addition, recording of CD4 count results and the successful referral of women requiring HAART can supply valuable

evidence for service delivery. This would allow the necessary expansion of access to HAART that is demanded for women accessing PMTCT services (McIntyre et al, 2008). Efficient management of patients through early identification, referral and appropriate management with HAART should ensure a further decline in the transmission rate (WHO, 2006; Draper et al., 2008).

Geddes et al. reported in 2008 that although HIV positive women tested during pregnancy were referred to an adult HIV clinic, it is unclear how many mothers who need HAART continue with these services. The incentive for HIV positive mothers to obtain care and treatment is great during pregnancy, but possibly declines once the baby is born and found to be HIV negative. More should be done to monitor this and keep these women using these services. Women who received a short-course of HAART during pregnancy for PMTCT prophylaxis should be monitored in order to start them on ARV therapy when their CD4 counts reach the treatment threshold (Geddes, 2008).

A study showed that only 6% of HIV positive women reported participating in a support group (Rispel et al., 2009), although it is known that it can assist HIV positive women to deal with stigma and isolation, and also provide emotional support, improve HIV knowledge and promote positive living (Miller et al*.,* 1998; Summers et al., 2000).

2.6 Conclusion

Mother-to-child transmission (MTCT) is the most important source of HIV infection in children (United Nations, 2001, WHO, 2004). Antiretroviral drugs

have offered a good opportunity for PMTCT, which has been implemented in many countries. Several studies have dealt with problems raised by the PMTCT implementation programme all around the world in different ways, but few of them have highlighted the issue of HIV positive women dropping out (not coming back for results) as the main focus of their research.

It was clearly showed that failure to go for follow-up care after an HIV rapid test was higher among HIV positive patients than their negative counterparts. (Ladner et al., 1996; Msellati et al, 2004)

Other authors suggested that training and supervision of programme staff may increase the likelihood of positive interactions between staff and clients and increase the number of pregnant women coming back for their results after VCT (Painter et al., 2004).

Some authors reported some difficulties with regard to VCT programmes, and recognised that not all of those who were tested came back for their results (Paoli t al., 2004), while others admitted that there were inevitable dropouts at each step of the VCT process and noted that not all women agreed to be tested, and not all those who were tested returned for their results. However, these studies did not give the proportion of women who did not return for their results, and did also not give the reasons for their failure to return. It was then suggested the universal testing with the option to opt out from receiving results. In this approach, women would be tested, but they would be allowed to opt out of being informed of their results (Bassetts, 2002).The Zvitambo study in Zimbabwe

showed that many women were willing to be tested, but only 20% chose to receive their results (Piwoz, 2001).

A progressive loss to follow-up of more than three quarters of the cohort by the six months' postnatal period was reported in Malawi (Manzi et al., 2005).

CHAPTER THREE

METHODS

3.1 INTRODUCTION

The researcher has committed himself to understanding and finding out why so many HIV positive pregnant women did not show any interest in continuing with the PMTCT programme. The opportunity was given to these women during this study to express their feelings and experiences with regard to this issue, since this study aims at discovering the meaning of social phenomena as experienced by the actors themselves (Shapiro, 1992).

3.2 RESEARCH DESIGN

This study was a qualitative one. Qualitative research has been defined as multi-method in focus, and involving an interpretive, naturalistic approach to its subject matter. This means that qualitative research studies things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meaning that people bring to them (Britten et al., 1995).

Strauss and Corbin have provided another interesting definition: qualitative research means any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification.

Qualitative research aims at discovering the meanings of social phenomena as experienced by the actors (interviewees) themselves (Shapiro, 1992), and its

methods are particularly appropriate for researching a previously unexplored topic or one that is poorly understood (Britten et al., 1995).

The qualitative research method used in this study helped in understanding each respondent's feelings and gave an overview of the phenomena observed among HIV positive pregnant women at Embhuleni Hospital.

The trusting relationship formed during the interview phase of qualitative research enables the researcher to get access to data that would not be accessible with quantitative methods, and qualitative research allows for the investigation of beliefs and attitudes concerning a sensitive topic.

3.3 AIM OF THE STUDY

This study sought to explore the reasons given by pregnant women for not coming for follow-ups after they had been informed of their HIV status.

3.4 OBJECTIVES OF THE STUDY

The objectives of the study were as follows:

- To explore the reasons why women who had been tested for HIV by means of VCT at the antenatal clinic at Embhuleni Hospital failed to return for their results.
- To understand the reasons given by women for not returning for their results following voluntary testing and counselling for the human immunodeficiency virus.

- To determine what information was given to the tested women before they were tested.
- To assess the availability of a personal support system (family, friends, etc).
- To assess women's understanding of HIV, for which they were tested.

3.5 STUDY POPULATION

The study population was all the pregnant women attending the antenatal clinic at Embhuleni Hospital or its satellite clinics, and who had accepted HIV VCT, but did not come back for their results or for follow-up after 6 months.

3.6 STUDY SAMPLE

The sampling method used for this inquiry was purposive sampling. In qualitative studies, sampling is determined by the purpose of the researcher (Field & Morse, 1989).

Purposive sampling is the most dominant sampling method in qualitative studies According to Patton, it seeks information-rich cases which can be studied in depth (Patton, 1990). Among those HIV positive women who met the inclusion criteria for the study, 10 were selected.

The researcher collected data of all the female patients who had undertaken the rapid HIV test during pregnancy at the Outpatients and Accidents and Emergency Departments, but had not reported back for results at least two weeks after testing. These patients were visited at their places of residence by

the research to request them to participate in the study. The nature of the study was explained to each respondent. On consenting to participate, each was requested to sign the informed consent form

3.6.1 Inclusion criteria

- Pregnant women enrolled for antenatal care at Embhuleni Hospital or its clinics, or any other clinic;
- Pregnant women who had had a positive HIV rapid test after VCT and who did not come back for their CD4 results at least after 2 weeks;
- Pregnant women at least 16 years of age;
- Women fluent in SiSwati or SiZulu.

3.6.2 Exclusion criteria

- Pregnant women who had refused HIV VCT;
- Pregnant women who had been counselled and tested and came back for their CD4 results.

3.7 DATA COLLECTION

An interview should be a conversation piece, not an inquisition (Simon, 1981). The data collection for this study was done using a free attitude interview technique. The free attitude interview was first reported in 1980, and is described as a non-directive, controlled depth interview (Vroslijk et al., 1980).

The data collection process began by obtaining interviewee details, followed by an exploratory question. The free attitude interview was conducted by a nurse trained in the use of this technique.

The researcher is not fluent in IsiSwati or IsiZulu and could not therefore conduct the interviews. Mrs N H Malete (RN, RM, RCH) (Psych) conducted them. The venue was the matron's office in the paediatric ward, and the spoken volume of the interviews varied from one participant to another.

The main exploratory question was in SiSwati: *Ngicela ungichazele kutsi yinindzaba ungeti kutohlola imiphumela yakho yengati* nekulandzelela kutsi kugula kuhamba njani*?* (English translation: *Can you tell me in as much detail as possible why you did not come back for your HIV results?).*

All the interviews were tape-recorded and field notes were taken. The interviewees were not stopped while talking, except for clarification. The interviewees were given reflective summaries at the conclusion of each idea under discussion.

The interviews were allowed to carry on until there was no further information to be gained from respondents. This is known as the saturation point.

Each tape-recorded interview was transformed into a verbatim transcription. The services of a qualified linguist were enlisted to translate the transcribed scripts from SiSwati into English. Reverse translation from English into SiSwati was also done to ensure the accuracy of the translation, and that the original meaning of the statements in the transcripts was preserved.

3.8 DATA ANALYSIS

Data analysis in qualitative research is particular in itself, since it does not use any statistical procedures. Bogdan and Biklen have defined it as " working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned and deciding what to tell others".

Data used in qualitative research are presented in a form called an interview, and interview products are presented in words through speech.

To analyse the interviews the researcher has used conversation analysis which is a method for studying interactive talk. It investigates the structure and process of linguistic interaction, whereby inter-subjective understanding is created and maintained. Conversation analysis examines the minute details of talk-in-interaction, something which became generally accessible with the advent of tape recorders. The centre of attention is not the speakers' intentions in their statements, but what specific speech segment accomplishes (Steiner et al, 2007).

The researcher has deductively analysed the data collected by identifying the emerging themes and then grouping them into conceptual categories, and finally integrating them into common phenomena. This analysis has used the following steps:

- Immersion and crystallisation of raw data

  The researcher reviewed the transcripts several times in order to make sense of the data obtained from the interviewees.

- Structured transcripts

  The researcher then developed an analytic structure based on the general sense resulting from the transcripts, based on the logical deduction of cause and effect. The structure of the transcripts generated categories, themes and their relatedness.

- Cutting and pasting

  The researcher then cut out themes from different parts of the transcript and pasted them into their categories – with the aid of a computer (Microsoft Word-programme).

- Integration

  The researcher then looked for connections between the generated categories in order to clarify and explain them, and then integrated the different themes.

3.9 RELIABILITY

Reliability is when independent researchers discover the same phenomena and there is agreement on the description of the phenomena between the researcher and participants (MacMillan et al., 1993). It is the extent to which a test achieves repeatability of results every time it is used. Reliability of data in this study has been ensured by adhering to the exploratory question and allowing interviewees to discuss it in detail.

The interviewees were only prompted with further questions contained in the interview form with regard to relevant issues not covered in the exploratory

question. This ensured the consistency and repeatability of discussions for each interviewee.

Reliability relates to the consistency and trustworthy of research findings, and is often evaluated in terms of whether or not a finding is reproducible at other times and by other researchers (Steiner et al, 2007).

3.10 VALIDITY

3.10.1 Internal Validity

Hoepfl has defined this as the extent to which the findings accurately describe the reality in a conventional inquiry. Internal validity in a qualitative study can refer to the degree to which the explanation of phenomena matches the reality of the world, and the degree to which the interpretation and concepts have shared meanings between the participants and the researcher (MacMillan et al, 1993).

3.10.2 External Validity

External validity refers to the ability to generalise findings across different settings in conventional research (Hoepfl, 1997). It is defined in terms of detailed descriptions that enable others to understand similar situations and extend this understanding to subsequent research (MacMlilan et al., 1993).

To ensure content validity, the transcribed and translated records, as well as the analysed data have been made available to interviewees for their comments with regard to the credibility of the information. Each and every interviewee received a copy of her interview in SiSwati, so that she could verify whether or not the

transcript was really what she had said during the interview. Furthermore, translations and transcriptions are verified by a second, independent person. This ensured the objectivity of the information that was gathered.

To ensure face validity (which deals with the relevance of the research tool as evaluated by interviewees), the research team explained the tools being used for the study to each interviewee (audiotapes and material for note-taking), and the process that was followed during the gathering of information. Furthermore, it has been explained to each interviewee that she was free to seek clarity at any time during or after the study on anything pertaining to the study.

3.11 TRIANGULATION

Triangulation is defined as the use of different sources of data for the same phenomena (Dowell et al., 1995). A detailed record of all original tape recordings, field notes, notebooks, transcripts and other data collection tools was kept in this study. This allowed the research team to look at information from various perspectives, thereby triangulating the results of information obtained.

3.12 BIAS

Bias can be defined as any effect at any stage of the research process, or any inference that tends to produce results that depart systematically from the true values. Hence, in order for one to appreciate the importance of bias in research, it must be differentiated from the conventional use of the term, which refers to a partisan point of view on an issue, or a one-sided inclination of mind (Ogubanbanjo, 2001).

- **Selection bias** was introduced through the purposive selection of interviewees. However, since this study aimed to focus on the depth of information, the bias thus introduced should not have played a significant role.
- **Interviewer bias** can occur during the research interview, whereby the interviewer subconsciously or even consciously gathers selective data (Ogunbanjo, 2001). This was minimised in this study by adhering to the exploratory question, and by using a standardised data collection form for each interviewee.
- **Bias in interpretation of data**. This is the result of errors arising from inferences and speculations. Some sources of this type of bias include failure of the researcher to consider every interpretation that is consistent with the fact and to assess the credentials of each respondent, and the mishandling of participants, which all constitute exceptions to some general conclusions (Ogunbanjo, 2001). The researcher has minimised this bias by feeding the data back to interviewees for their validation.

3.13 ETHICAL CONSIDERATIONS

Permission to conduct the study was sought from the Family Medicine Department Research Committee (DRC). Approval to conduct the study was obtained from the Medunsa Research and Ethics Committee (MREC) of the University of Limpopo (Medunsa Campus), and the project number was MREC/M/130/2008; PG. The researcher was granted permission to conduct the study from the Medical Manager of Embhuleni Hospital. All the interviewees who

had agreed to participate in the study signed a consent form, and they were all assured of confidentiality and anonymity.

CHAPTER FOUR

RESULTS

In this chapter, each interview will be preceded by a short demographic summary of the participant, with a comment on the interview procedure. In each interview, the interviewee's speech is highlighted in bold. A summary of highlighted themes will follow the interviews.

INTERVIEW 1

Interviewee Profile

Ms NN, 30 years old, single and unemployed, was in cohabitation with the father of her second child, but they have since separated due to his unfaithfulness. She had an elder child who had psycho-sexual problems arising from alleged sexual abuse by her aunt (mother's younger sister), and it is also alleged that this child was sexually abused by her uncle.

She was well groomed and articulate, but very emotional when reflecting about what had happened to her. However, she detailed her woes and discussed at length as to reasons for her not returning for her follow-up after receiving an HIV positive result.

She was recruited while she consulted for an opportunistic infection.

4.1.1. ANC and the VCT process

She explained how she found out about her status**: "After I had my pregnancy test (second child), even though I didn't want this baby, I just thanked God that I was pregnant (I love kids and I love my baby) - it was just the situation at home you know".**

Being unemployed, it caused her more stress when she found out that she was pregnant: **"I'm unemployed - how I am going to take care of this baby?"** She relied on God for everything: **"For all the things I prayed for, I wanted my baby to be healthy".** She watched some health education programmes on pregnant women and HIV on TV and decided to go and get tested: **"I watched on TV, they said what to do when you are pregnant, then something came to my mind... You know I decided to go and test, that's how I found out I was positive, then I got started with my ANC".**

4.1.1.2 Lack of ownership of PMTCT by the health staff

According to one can get from her she was still attending the health facility after birth: **"…my baby was 2 weeks and 2 months, she experienced some breathing problems, I came to the hospital…"** but still she did get her CD4 result.

4.1.2. Unpleasant experiences at health facilities

4.1.2.1 Blaming the health facilities or health workers

The researcher would like to bring to the reader's mind at that time dual therapy was not implemented. She delivered by C-section and she explained that her newborn baby was not given Nevirapine: **"when I had my baby I was so discouraged that he wasn't given ARV's by this other nurse…"** and it is one of the reason why she failed to go back for her CD4 result: **"… so I think that's the reason why I never came back… I gave birth on Monday, and on Friday, when the doctor discharged me, that's when they realised that he didn't get ARV's".** She has reported the matter: **"…because if I don't do anything it will keep on happening to other mothers"**.

- **Lack of courtesy**

When her baby was admitted at the hospital, she took the opportunity to find out why her baby wasn't given ARV's. She went to see the sister who received her baby. In spite of her anger, she cooled down and avoided making a scene: **"…told her there was something bothering me, that my baby didn't get ARV's when she was born and you are the first person who received her. I just had this fear that my baby was positive.** The nurse said to her: **"*Why are you worried that your baby might be positive, why? She will live, so why should you worry that your baby didn't get ARV's, she might be positive; it's not a problem she'll live.*** This wickedness made her sad***: "…That is what she said…you know it made me so sad".*** The sister told again to keep quiet:

"shut up, you don't know anything". She was so hurt that she decided to report this sister to her supervisor in the labour ward.

She continued by saying that she wouldn't advise anyone to consult at the hospital and gave her reason as follows: **"…you get harassed, they speak to you as if you are a child".**

And she shared the fact that she knew that she had to come back for the result: **"My baby is 1 year and 10 months, so I found out when I was 2 months pregnant. I was supposed to go back when my baby was 6 months…"**she was scared knowing that ARV clinic is in the Hospital where that nurse is working: **"…but I was scared that I'll see the nurse who did this to my baby because I reported her..."**

4.1.2.2 Lack of confidentiality and privacy

The interviewee highlighted the lack of confidentiality at the clinic discouraged her to pursue the PMTCT: **"…Like I come here and talk with one of the nurses, but after that you'll hear the very same person talking with other patients about your status…"**

She continued later on with a personal experience she has to face while she brought her son to the clinic. She reported how one of the patients was embarrassed and humiliated by one the nurse in front of everyone: **"…then she start shouting at this girl, telling her to go and get condoms so that she can show her how to put one, you know you are smelling like a rotten fish…"**

The interviewee was so offended in a such way that she left the clinic: **"…After that I just decided to go home, cause I couldn't stand someone treating another human being like that".** She explained if she was infected she will not go to the clinic: **"…I will also be afraid to come here if I have STI's…I'm going to be afraid to go to the clinic or hospital, because I know how they are going to treat me as if I'm worthless, that's why you get people…"**

As consequences of such humiliating experiences at the clinic people in the comminute prefer to borrow money and consult private doctors when have STI's for more privacy: **"…they don't even bother to go to clinic, you can just ask someone to lend you money so that you can go to a private doctor (you know you are going to be safe there)…"**

4.1.3 Fear of stigma

The interviewee made it clear and said: **"My understanding has to do with being afraid…"** She explained that counsellors are not what she expected them to be: **"…you expect the person who gives you the results to be more understanding, to tell you or explain what ever you need to know about this disease… But you find that, that's not the case…** She continued and stated that beside that she is afraid that people will know her status: **"another thing is that we are afraid to talk about HIV, because I'm afraid people will know I'm HIV positive".**

4.1.4 Knowledge of HIV/AIDS and PMTCT

The respondent seemed to be well informed. Her knowledge about HIV/AIDS and PMTCT came from health education programmes on TV and ANC clinic attendance.

4.1.5 Support

The interviewee explained that she was a single parent: **“I’m a single parent with 2 children to look after - my family is not around**”. Responding to the question regarding whether or not she had any support, she said: **“No, I don’t have - maybe it’s because I’m sick** …**I don’t have that.”** She shared the fact that she did not have a good relationship with her family: **“we don’t get along”.** She explained that her mother was sleeping with her husband and her son is sexually abused by her younger sister.

4.1.5.1 Non existing support system

Her son and herself needed a psychologist consultation but it never happen since there is no medical psychologist at the hospital and the social worker failed to transfer them: **“…they don’t take people from around here, and we must organise our own psychologist, so I couldn’t do anything about that… since then I have been having problems with my son”.**

4.1.5.2 Limited individual financial resources

The interviewee shared her concern about not having enough food: **"…I wish to go and that I know the stage where I am so that I can start with ARV's, but my other problem is that I don't have enough food at home, thinking of not having enough food, at the same time I must drink my pills it frustrates me."**

4.1.6 Conclusion

This was a very prolific interview. The interviewee was tested for HIV when she was 2 months pregnant, and at the time of the interview, the baby was 2 years and 10 months old. Her reasons for not coming back for her results were as the fear of stigma, experience at health facilities and non existing support system with the community, limited individual financial resources.

Besides the abovementioned reasons, she also did not have adequate support from her family, and she was experiencing a great deal of stress.

INTERVIEW 2

Interviewee Profile

Ms KS, 26 years old, was single and unemployed, and had three children. She revealed that she was already aware of her HIV status when she had her second child. She was not well groomed, and looked ill, wasted and pale. The baby looked chubby but not well cared for. She did not communicate well, and needed a lot of prompting during the interview.

She was recruited while she brought her baby for opportunistic infection.

4.2.1 ANC and PMTCT process

The interviewee looked shy at the beginning of the interview.

She explained that she found out her HIV status when she was pregnant with the previous baby, while she was staying in Piet Retief: **“It started with my second baby. They told me that my blood was dirty at Piet Retief clinic, they told me I was HIV positive”.** Some education was given and she was advised to disclose her status to her husband: **“They said we must take care of ourselves, and you must use condoms and you have to tell your partner, that you went to the clinic and they told you that you are positive”.** She reported that after she had the second baby, she developed some chest pain, which was diagnosed as pulmonary tuberculosis:” **I had my second baby, and I**

started to experience some pain under the right breast. I coughed a lot, and they even gave me cough mixture, they told me it's TB". She was still getting treatment for Pulmonary Tuberculosis when she fell pregnant for the third baby: **"While still going for treatment, I got pregnant with my third child".** At Piet Retief clinic, they wanted to know why she didn't use a condom, and she explained that her husband fought with her and accused her of cheating on him. He preferred for them to die together rather than to use condoms: **"…He told me that I'm having an affair, when I told him at the clinic they gave me condoms, and that I have this disease, and he said if we die, we will die together…Then I fell pregnant".** She was physically tired, and she preferred to leave her partner and return to her home in Arrheimburg (location around Embhuleni Hospital): **"You know being there was going to complicate my life, I can't even do things, and I get tired. That's when I left him, to live here with my father and continue the treatment here at the hospital, while I was still pregnant".** At the ANC clinic at Embhuleni Hospital, she was tested again: **"They did test me. They told me to start from the beginning".** She was introduced to the doctor who started dual therapy: **"They told me to see the doctor first and the doctor gave me the treatment that I must drink these pills, until I give birth".** She knew the purpose of the treatment: **"it is to protect the baby not to be infected by this disease".**

4.2.1.1 Lack of awareness to return for the result

She claimed that she was not aware that she was supposed to come back since the baby was born: **“I didn’t know I had to come…”** and she explained that this was the reason why she did not come back: **“that the reason I ended staying at home”.** The interviewee was not informed about her result, she emphasised after she had given birth, and she didn’t come back because she didn’t know that she had to: **“After giving birth I didn’t come back, after I had my baby I just stayed at home. I didn’t know I had to come back…”**

4.2.1.2 Poor quality patient-health care provider communication

The interviewee was on AZT as soon as she restarts ANC at Embhuleni Hospital and said that the only appointment she had was her last ANC appointment, and that was in December - she had delivered in November. She never went back - she thought that when they said that she should come back in December, she would still be pregnant: **“They told me I must come back in December, since I already had the baby in November then I stayed at home”.**

4.2.1.3 Lack of ownership of the PMTCT programme by the health staff

The interviewee was still ignorant of her CD4 result although she kept on attending the clinic after her second baby, and she was diagnosed with pulmonary tuberculosis: **I coughed a lot… they told me it’s TB”.**

4.2.2 Unpleasant experiences at the health facility

She reported that she was not given Nevirapine to be taken at onset of labour: **"…they didn't give it to me…"**

4.2.3 Knowledge about HIV/AIDS and PMTCT

Her previous pregnancy gave her some experience with regard to PMTCT. She knew that she was supposed to receive Nevirapine at the onset of labour, but her general knowledge in this regard was inadequate.

4.2.4 Support

The interviewee did not have support from her partner to whom she has disclosed her status, he refused to use a condom and preferred to die rather than to do so: **"when I told him at the clinic they gave me condoms, and that I have this disease, and he said if we die, we will die together…"**

She reported that after she failed pregnant she was weak that she has to move to her parent place for more support:**"…You know being there, was going to complicate my life, I can't even do things (I get tired)".**

4.2.5 Conclusion

The interviewee knew that she was HIV positive while she was pregnant with her second baby, and she never went back for CD4 even when she was going to the

clinic for pulmonary tuberculosis. While she was still on treatment for tuberculosis, she fell pregnant.

She then moved from Piet Retief to Arrheimburg. At Embhuleni Hospital, the rapid test was done again and she started on dual therapy. After she had given birth, she did not come back because she was not told that she had to come back for. Her family is supportive

INTERVIEW 3

Respondent Profile

Ms NM, 18 years old, was single and unemployed. She was accompanied by her mother, whom she allowed to be with her during the interview. At the time that the researcher selected her, she said that she was not knowledgeable about HIV/AIDS. She agreed to participate in the study and requested to be accompanied by her mother, since she was currently on treatment for TB and was weak. She was not a great communicator, and as a result it was difficult to obtain information from her relating to the topic. She said that she was not told that she was positive, but in her file it is documented that she tested positive to rapid test and she benefited from dual therapy.

4.3.1 ANC and VCT process

The interviewee explained how she started with ANC: **"I first went to the clinic… I went the time I had my scale appointment, I was 5 months I went there until I was 9 months and I gave birth on the 13th December, 2008".** She share what happened on the first day at the clinic and then she added that: "**We were told what to eat when you are pregnant and how to raise our children and not give birth at home but we must give birth at the hospital. They gave us 2 pills to drink (white and yellow), once they are finish you must tell**

them so that they can give us more, and must not forget to eat right food, so that the baby can be healthy".

4.3.1.1 Lack of awareness to return for result

Beside the health education on how to raise their children and to give birth at the Hospital and iron supplementation she said that nothing else was said to her: **"That's the only thing they told us".** When asked about whether or not they withdrew blood, she answered that: **"They told us nothing, they just filled our blood in some containers that look purple and red and they…"** She was given an appointment: **"… told me next time I come back, they will give me the white pills",** she admitted that the test was for HIV screening: **"…it was to test for HIV",** and she said that her HIV status was negative**: "They told me I was negative".** She also admitted that the baby was given medication at birth: **"They gave him immediately after giving birth right in front of me",** but she did not think to ask what it was for: **"No, I never thought to ask".**

4.3.1.2 Lack of ownership of PMTCT programme by the health staff

She was attending the clinic when her baby was 3 months old: **"…I just started coughing",** that's when I went to the clinic at moment of the interview she was taking TB drugs**: "I'm taking TB treatment".** A positive rapid test was documented in her medical file but the interviewee stated that she was told to be HIV negative, in spite that

4.3.2 Support

She came with her mother who was very supportive.

4.3.3 Knowledge of HIV/AIDS and PMTCT

In spite of being in Grade 9, her knowledge on the topic was so poor that when asked if she had ever heard about AIDS, she answered **"no"**. She carried on saying that **"Just a little bit. Only that it makes you sick, you must eat healthy food and take your HIV treatment".** She shared the fact that the dual therapy she received was, according to her, in order for her baby to be healthy **"I thought they were for the baby, to be able to develop well. I just thought they normally give them to pregnant women at the clinic".** With a smile, she said that she never asked what the treatment was for - she thought it was just a normal thing: **"I didn't ask I just thought that it's a normal thing. They told us to drink these pills and we did".**

4.3.4 Conclusion

The interviewee was 18 years old and in Grade 9. She had VCT 6 months before the interview and was currently receiving TB treatment. She had very poor knowledge on HIV/AIDS and PMTCT, and was ignorant about the fact that she was HIV positive. Although she was on dual therapy, she was unable to go for any HIV results.

INTERVIEW 4

Interviewee profile

Ms DM was 28 years old, single, with one child and unemployed. She was neatly dressed. She was reluctant to talk and made conflicting statements about her reasons for not coming for her results after she was informed that she was HIV positive at the antenatal clinic.

4.4.1 ANC and PMTCT process

She explained that the HIV test was offered to her so that the baby could be helped: **"they wanted to check if one was HIV positive, if they found out positive, obviously they need to help the baby as well, if you want your baby to be safe, you need to find out your status.**

She was told that she is positive after the rapid test: **"… after the test they told me I'm positive… I found out the very same day, I had to go for my scale appointment".**

Responding to the question about what was said to her after the test. She kept quiet for a long time and then said: **"I don't remember".** After thinking about it more, she recalled that: **"… they told me I must check my CD count,** and she mentioned that it was for see how strong are her CD4: **"…to see how strong they are"**. The blood was drew and she was told to come after birth for her CD4 results: **"...They told me to come back, after I gave birth"**

4.4.1.1 Lack of ownership of PMTCT programme by the health staff

She reported that she delivered at the clinic and the nurse who counselled her was not there, she went back and stayed a long time at home: **"…after I gave birth, I couldn't find her, I just stayed at home for long time"**

4.4.2 Unpleasant experiences at the health facilities

4.4.2.1 Blaming the health facility and or health workers

The interviewee was told to go back for her CD4 result: **"…they were telling us we must come back after giving birth…"** and shared her negative feeling towards the health facility, it is known in the community that the clinics are out stock drugs and that has contributed for her for not going back: **"…but sometimes when you get there, there are no pills at all…"**

4.4.2.1 Work load and shortage

She kept on attending the baby wellness clinic and took the opportunity to go for her result, but once more she was not helped because the sister was busy: **"… it's busy over there…I took the baby for scale, and this time I found her and she told me they are busy…**the next time she was told to come on another day because they were busy she was asked to come on an other day what she did not: **"… and again, they told me to come back, and I never did".**

4.4.3 Support

The interviewee has 2 children and she is staying with her late aunt's 3 children without any support from her boyfriend.

4.4.4 Knowledge of HIV/AIDS and PMTCT

She shared what she knew on the topic: **"It (HIV) kills and it's not safe to be intimate without using a condom and to share tooth brush as well, you mustn't share it, because you might be putting yourself at risk". S**he also mentioned that she received some health education at the clinic**: "They mentioned food as well, we must eat right food. If you don't go for treatment, you don't know your status, and if you continue to sleep around, the virus keeps spreading".**

4.4.5 Conclusion

She went back several times to the clinic, but the sister was busy and could not get her result and was discouraged to go back anymore. She is staying with 5 children without any support. She knew that the use of condoms protects against HIV and ARV stops the virus from spreading.

INTERVIEW 5

Interviewee Profile

Ms NS was 36 years old, single, unemployed, with five children, two of whom had died in infancy at three and two months of age respectively. At the time of the interview, she was still mourning the death of the youngest child. She also reported that her partner had assaulted her on the day of the baby's funeral, and that this had hurt her very much. They both abused alcohol and often fought when under the influence of alcohol. She was keen to talk about what had happened but confused events, and sometimes she did not make sense.

She was recruited when she brought her late baby for opportunistic infection

4.5.1 ANC and PMTCT process

Responding to the question as to why she did not come back for a follow-up, she explained how she found out her HIV status: **"I went for testing the time I was pregnant and the results came back positive.** She was started on dual therapy: **"…They told me at the clinic that they'll give me these pills to drink, and I must drink them while I'm still pregnant…"**

4.5.1.1 Lack of awareness of to return for the result.

She said that she never went back for her result because she was not aware that she had to: **"I just left it there, because they never told me to come back, so I stayed".**

4.5.1.2 Lack of ownership of PMTCT programme by the health staff

The next time she went to the clinic was for the baby's immunisation: **"After given birth, I went home until 6 the baby was weeks and I went to the clinic, that when they gave him an injection.** Since nothing was said about her result she just gave up: **"That when I gave up"**

4.5.2 Support

She reported that she does have any support from her partner. When both drink and it ends up in a domestic fight: **"We beat the hell out each other, maybe he heard from someone that I was with so and so…He would just attack me without saying a word".**

4.5.3 Knowledge on HIV/AIDS and PMTCT

As she had failed to disclose her status, she carried on sleeping with her partner without using a condom. Her knowledge on the topic was mediocre that she did not even know the necessity for a condom: **"…They just told you to use a condom they didn't tell us at the clinic, what the consequences of sleeping with someone without a condom".**

4.5.4 Conclusion

The interviewee failed to go back for her results because she was not told to go for this and the matter never came up when she took her child for immunisation.

She does not benefit any support from her partner. Her knowledge on PMTCT and HIV/AIDS was mediocre.

INTERVIEW 6

Interviewee Profile

Ms ND was 17 years old, a secondary school learner, with one child of 7 months. She was fetched from school for this interview. She was a cheerful young lady, but her knowledge of HIV/Aids was superficial. She did concede that she had been informed about her HIV status at the clinic, but had not been informed about the need to return for CD4 results.

4.6.1 The ANC and PMTCT process

The interviewee explained how she got to know her HIV status: **"I first went to the clinic, I was pregnant at the time, and at the clinic they told me to have a test and I did, and I found out I was positive".** She continued by saying that she didn't worry too much and explained why: **"I didn't worry too much about it, because everyone needs to know their status, if you think about it too much, you'll get stressed and die. Yes, it** (stress) **kills and one can get stroke, the only thing you must do is to stay strong, be like other people".**

After the test, some health education on the use of condoms and CD4 counts was provided: **"they said if you become intimate, always use a condom, and always check your CD4 count and if it's down, you must start treatment".** She delivered in July 2008 and reported her status to the sisters, but nothing was said to her: **"And after I gave birth in July I told them about my status but**

they said nothing". The baby was given treatment: **"they gave him a bottle. He had to drink it at a specific time until it got finished".**

4.6.1.1 Lack of awareness of to return for the result.

Responding to the question about what was said about going back for her CD4 result, she said: **"They told me nothing".**

Responding to the question regarding whether or not she had thought about it, she said that she didn't know and had not been told: **"I didn't t know…Well the nurses didn't tell me".**

4.6.1.2 Lack of ownership of PMTCT programme by the health staff

She reported that finding time to go to the clinic is not easy as she is schooling: **"… at school we come out late, by the time I go the clinic it's already late**. When asked what was said about her blood result when she took the baby to be weighed, she answered: **"They say nothing; they just teach us about AIDS, that as a person you must know your status. It's sad walking around not knowing your status. They say you must take your pills, but I forgot the name they said I must drink them when my CD4 count is down".**

4.6.2 Support

She is staying with her mother who is supportive and she did disclose her status to her and her partner who is working and supporting her financially.

4.6.3 Knowledge on HIV/AIDS and PMTCT

At the beginning of the interview, she seemed to have some knowledge on CD4 count monitoring: "…**and always check your CD4 count and if it's down, you must start treatment".** When asked what she knew about HIV/AIDS and PMTCT, she said she didn't know: **"I don't know".** She continued by saying: **"I just heard little about it, that it kills"**

4.6.4 Conclusion

The interviewee failed to go back for her result because she was not informed that she was supposed to go back after the test. In any event, going back to the hospital would be difficult due to school commitments, but she knew that she needed to check her CD4 count so that she could start with ARV's. Her knowledge, for a grade eleven learner was mediocre.

INTERVIEW 7

Interviewee Profile

Ms SN was 39 years old, single and unemployed, and had left school in primary school. She looked old and was shabbily dressed. She lived on a farm and said that she was destitute and could not afford the taxi fare to go and attend the ante natal clinic. Her partner had deserted her earlier on during her pregnancy. She only went once to the clinic when she was 8 months pregnant, and did not return, although she had been told that she was HIV positive. She said she was not told anything with regard to her results. She had no knowledge about HIV.

She was recruited when she brought her child to the Hospital for opportunistic infection.

4.7.1 ANC and PMTCT process

The interviewee explained that she found her HIV status during ANC: **"When I found out I was infected, it was during the time I went for a scale (while pregnant)"**.

4.7.1.1 Poor quality patient-health care provider communication

She was given an appointment but she didn't go since she delivered earlier she thought that the appointment was therefore cancelled: **"when they drew blood they told me to come around the 18th, (I think it might have been in July because I gave birth in August) to get my results but I couldn't".** She

delivered at home: **“I gave birth so ever since I haven’t been able to get my results.**

4.7.2 Knowledge on HIV/AIDS and PMTCT

When sharing her knowledge on the topic, she said: **“at the clinic they said that we must be cautious and get tested so that we can ourselves”.** The interviewee said outright that she didn’t know how to protect herself and she was not told how to do so at the clinic: **“Well truly speaking, I really don’t know…”**

4.7.3 Support

4.7.3.1 Limited individual financial resources

She does not have any resource of income and she considered herself to be poor and could not afford the taxi fare: **“I’m poor, and I can’t afford to travel by taxi”,** so she had to travel by foot and ended up getting tired: **“…so I have to wake up early, so that I can be able to get a number and by the time I’m finish I’m tired, I don’t have money to be able to get my result and another don’t know, they didn’t tell us”.**

She continued to explain why she didn’t go back for her results: **“The reason I could get my results is that where I live is too far from the clinic (in Krechal)**.

She does not have support from the baby’s father who left her **already left me by then. He left in 2006 December, and I got pregnant around that time. That’s the last time I saw him”.**

4.7.4 Conclusion

The interviewee had highlighted her reasons for not going back for her results. She delivered earlier than the appointment day, and she stayed far from the health facility, and would therefore have to wake up early and walk, which was strenuous for her, and she was unemployed, without any money for a taxi fare.

INTERVIEW 8

Interviewee Profile

Ms LNM was 19 years old, single and unemployed. She looked ill, pale, and was shabbily dressed. She told a long story, and said that she only went to the clinic when she was almost full-term, at which time she was told to come back for her CD4 results, which she did not, because she did not have time to go to the clinic. On the day of the interview, her baby had been admitted to hospital, and the parents of the baby's father had come to fetch them in order to take the baby to a specialist. She had no insight into the cause of her child's failure to thrive.

4.8.1 ANC and PMTCT process

She explained that she was 9 months' pregnant when she went to the ANC, and had gone for HIV testing: **"Well I went for a scale I was 9 months, and I did go for a HIV testing, only to find out that I am HIV positive. I went the first time, and around the 10th I went again and it's when they drew blood from me, and around the 15th I gave birth".**

4.8.1.1 Poor quality patient-health care provider communication

She never had the opportunity to return: **"I never got the chance to get my results so that is the reason why I don't know my CD4 count result".** She explained that she thought that it was too late now**: "It's too late now it has**

been months now". She added that she didn't have time and her baby was sick: **"I don't get time, plus my child is very sick".**

4.8.1.2 Lack of ownership of PMTCT programme by the health staff

She explained that the baby has been sick for awhile. Her baby was currently ill admitted at the Hospital but her boyfriend's family wants to consult a special doctor: **"…his father's family wants to take my child to see a Special Doctor; they say he's not getting better here so the best thing is for them to take him to a special doctor".**

4.8.2 Knowledge on HIV/AIDS and PMTCT

The interviewee knowledge on the topic was superficial.

4.8.3 Support

The boyfriend's family was supportive. She is unemployed and depends financially on her boyfriend.

She explained that her fear was that he would leave them if she disclosed her status to him: **"The real reason I didn't tell him is because I felt that he would leave us (both me and the baby), secondly he won't be able to support the baby, and I'm not working"**

4.8.4 Conclusion

The interviewee communicated well, and said that her reason for not going back to the clinic was that she did not have the time, since she had moved away from the place where the test had been done and needed to take care of her sick child and poor quality of communication as well as lack of ownership of PMTCT by the health staff had contributed in her failure to go back.

INTERVIEW 9

Interviewee Profile

Ms PZ was 38 years old, single, and lived locally, travelling by taxi to work. She is working for the department of health. She was well dressed, very cheerful and articulate about her reasons for not coming back for CD4 result after being informed of her HIV status when she was pregnant. She was a Christian and was concerned about the lack of confidentiality among nurses. She therefore confided in a friend, who then supplied her with medication.

4.9.1 ANC and PMTCT process

Responding to the question as to why she did not come back for her CD4 results she laughed and said she was though it was in the baby's interest that the mother get tested: **"Okay… I was pregnant at the clinic they tough us, if maybe you are infected there's a chance that the baby might be alright and for the baby to be safe it's up to you as the mother to take care of the baby, for the sake of my baby I went to do the test, because she's the innocent one…and I did my test and I think I was 6 or 7months pregnant".**

The rapid test was positive and she was emotionally affected: **"I went for HIV test it came positive. I didn't cry at first when I was told, but eventually I did…"**Blood was drew for CD4: **"They drew blood for the second time",** and

she was told to go back: **"… I was supposed to go back to check my CD4 count".**

4.9.1.1 Poor quality patient-health care provider communication

She expected to be contacted when the results were back: **"But nothing happened after that, no-one made a follow-up, like maybe to tell me the results are back (are you okay or maybe you understand…), I just thought when the results are back they'll call, because I don't live far from the clinic"**.

She reiterated that she expected to be contacted or that the health worker would initiate a discussion in this regard when she attended the ANC: **"I was waiting, I thought I had to wait for them they'll tell me, but nothing happened. Until now…That I'm here with you".**

4.9.1.2 Lack of ownership of PMTCT by the health staff

She continued with antenatal care, but nobody informed her of the outcome of the CD4 count test. She then thought that it was for epidemic purposes that they were being tested: **"I thought maybe it's the way they do things, just to discover how many people are like this and at the end of the day, they just…you know, they count the number and that's it".**

4.9.2 Unpleasant experiences at health facilities

4.9.2.1 Lack of privacy and confidentiality

She said that it was a mistake for her to go for the test at the local clinic, and she explained why: **"I fell I made a mistake by doing my test here locally because you do understand that…people who work with this kind of things, they don't swear to secrecy, they talk after they have discovered that people are infected"**. She continued to say that the lack of confidentiality at the local clinic contributed a lot to her not going back there and furthermore to pursue the PMTCT process: **"so that's one of the things that made me to stay at home. I just say to me you know what, I'm not going to go through this…"**

She was now working, had a medical aid, and was still contemplating pursuing the process, but definitely not around here: **"since I'm employed, I started on the 1st of November 2007 and have a medical aid, I've been thinking a lot about going to a private doctor you see……but not around here. I still want to pursue it here… No, I don't want to do it here…Because people talk".**

4.9.2.2 Blaming the health facility and or health worker

She has resentment against the health professional around: **"…people are desperate for jobs, they just want some quick money…they don't have hearts just shouting at people all the time".** She reported that after she gave birth by C-section her baby was not given Nevirapine: **"… I was about to be**

discharged, that's when they realized that the baby needs medication…", She had then a negative feeling towards the health facility discouraged her to go back :**"…you get people who are negligent, people who are working here. They don't follow procedures, like checking your records…"**

4.9.3 Knowledge on HIV/AIDS and PMTCT

Her knowledge on topic was good to give her baby more chance, a supportive friend suggested her to request an elective c-section: **"…my friend said let's go to the doctor and ask him if you can deliver the baby by c-section…"** and without any discussion with the nurse she decided to not breastfeed: **"…I decided not to breast-feed…"**

4.9.4 Support

She share that she has got a very good friend who is supportive since she disclose her status: **"…I'm lucky because I had a support from one of my friends".** She relied on God: **"I told myself that I was going to live, you know as a Christian I just said God because you live, I'm going to live until the last day of my life, that's what I told myself. That's it…. It keeps me going".**

She saw herself as being stress-free and didn't take any specific medication - only Panado if she had a headache: **"I absolutely take nothing, I'm okay… laughs, I'm stress free, and I don't even take medication. When I have headache, I just take Panado".**

She explained that she does not have any support from her partner who had left her when she fell pregnant: **"… after I fell pregnant, he just disappeared…"**

4.9.5 Conclusion

The interviewee explained that she was going for ANC when she was informed of her HIV status. She knew that she was supposed to come back for her CD4 result, as she was still attending ANC and after giving birth, she had brought her baby to the clinic to be weighed and immunised. The lack of ownership of PMTCT by the health staff, poor quality of communication, lack of confidentiality and privacy among the nurses at the clinic and their unethical conduct prevented her from going back there.

On the other hand, she relied on her faith in God and did not believe that HIV would kill her.

She was now working and had a medical aid, so she was prepared to go for further treatment at private doctor surgery.

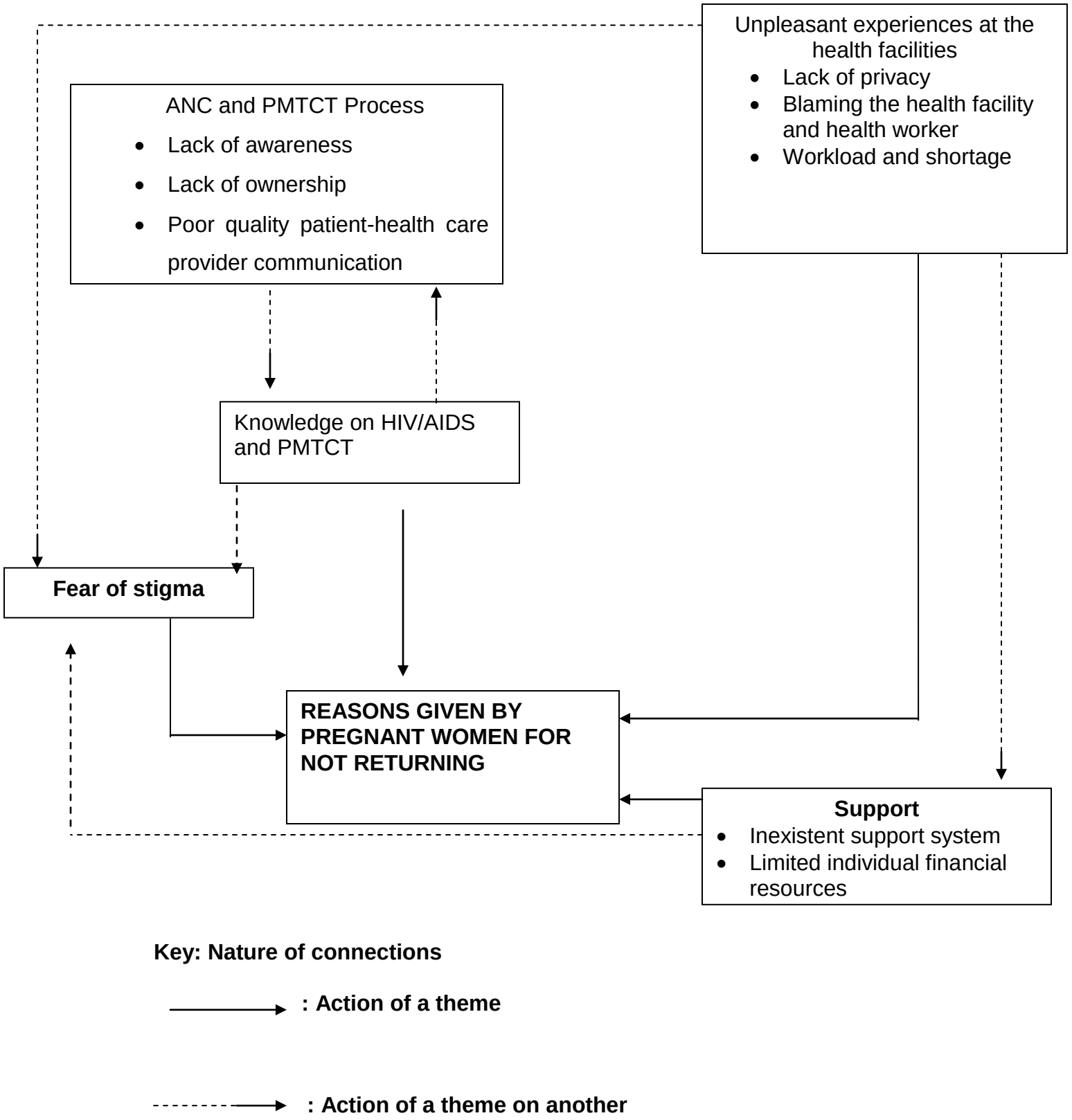
She was trying to do the right thing, by eating healthily and leading a stress-free life. She was on her own.

INTEGRATED RESULTS

Table 1 Highlighted themes and sub theme

THEMES	SUB THEMES
ANC and the PMTCT process	Lack of awareness to return for the results. Lack of ownership of PMTC programme by the health staff Poor quality of communication
Unpleasant experiences at health facilities	• Lack of privacy and confidentiality • Blaming the health facility and or health worker • Work load and shortage
Fear and stigma	
Knowledge of HIV/AIDS and PMTCT	
Support	• Inexistent support system • Limited individual financial resources

Figure 4. Integrated schema



Key: Nature of connections

: Action of a theme

: Action of a theme on another

The figure 4 (Integrated schema) is showing mainly the synergy flow of the themes as reasons of failure to return for the results. It is also showing the negative influences of one theme on another, like negative experiences from the health facilities had had a negative effect on the support that patients should have expected from the health workers and both negative experience and lack of support entertain fear of stigma as well as poor knowledge on the HIV/AIDS and PMTCT that should have been provided during the ANC and PMTC process.

Figure 5. Interactions between themes

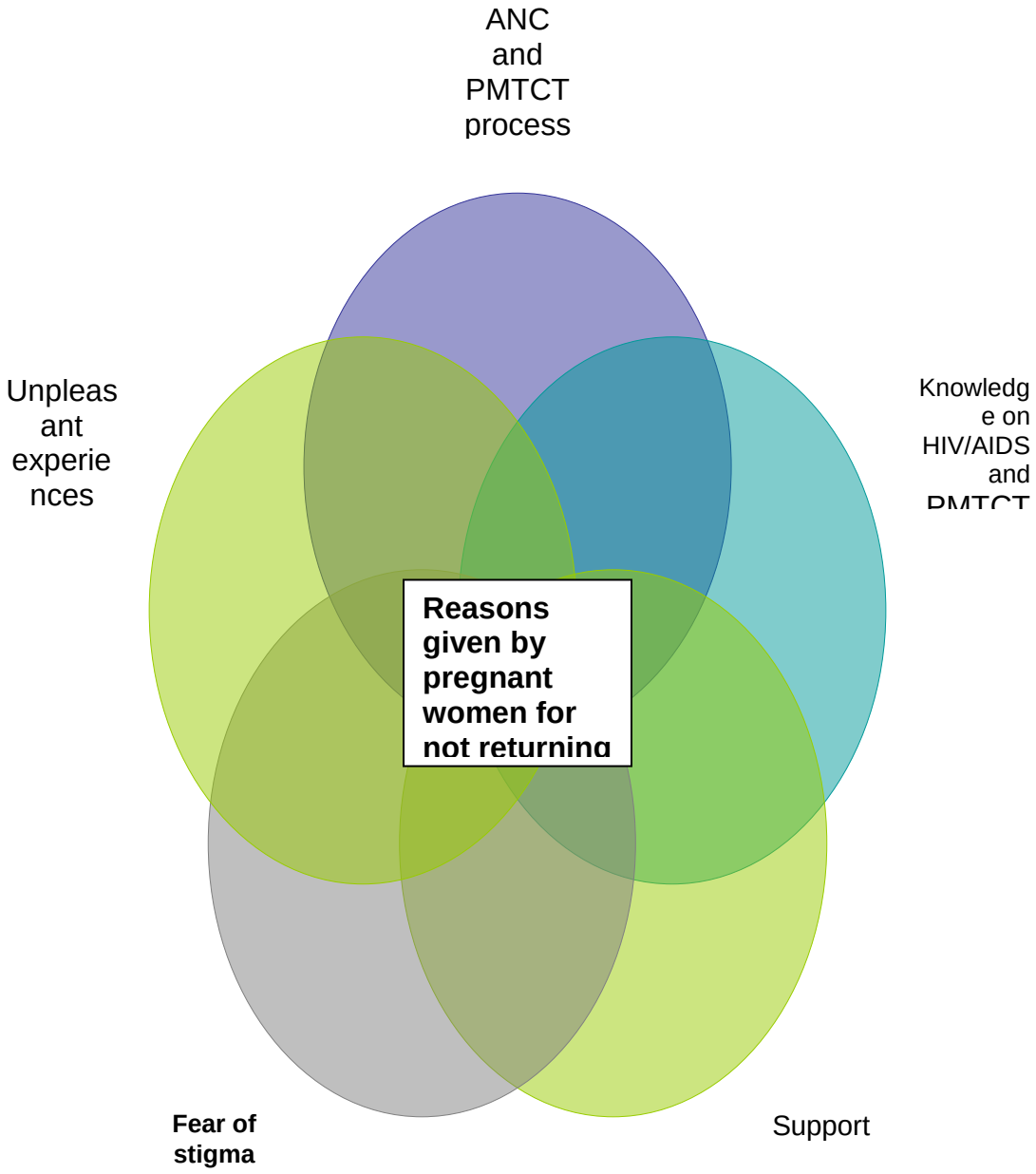


Figure 5 (interactions between themes) is showing how themes are linked, like unpleasant experiences from the health facilities was a contributor to pursue

ANC and PMTCT what will negatively affect the knowledge on the topic and could perpetuate pre-existing fear of stigma.

CHAPTER FIVE

DISCUSSION

.

5.1 INTRODUCTION

This study sought to explore the reasons given by pregnant women for not coming for their result (CD4) after they had been informed of their HIV status. The researcher assigned himself the objective of exploring the reasons why women who had been tested for HIV through VCT at the antenatal clinic in Embhuleni Hospital failed to return for their results, as well as to understand the reasons given by women for not returning for their results following voluntary testing and counselling for the human immunodeficiency virus, and to establish what information was given to the women before they were tested, in addition to assessing the availability of a personal support system (family, friends, etc) and their understanding regarding HIV, for which they were tested.

The researcher followed the same framework as in Chapter four to discuss the findings.

5.2 ANC and PMTC process

The analysis of the interviews highlighted some problems which occurred during the ANC and PMTCT process, namely: lack of awareness of to go back for the

result, lack of ownership of the PMTCT programme by the health staff, poor quality of communication the researcher noted that all ten respondents had at least mentioned one of these problems.

5.2.1 Lack of awareness to return for the result

Lack of awareness was found in 4 out of 9 cases (interviewees 2, 3, 5, 6). According to these four women, they were not aware that they had to come back for their results. The new PMTCT Guidelines are clear when it comes to the follow-up schedule of HIV positive pregnant women enrolled in the PMTCT and/or HAART programmes. **A two-weekly follow-up date must be given to women after their CD4 cell count has been taken - every health facility should have a mechanism in place to follow up on CD4 cell count results from the lab, discuss results with clients and trace women who do not return for their results** (National Department of Health, 2008).

This information actually is given to them at the time of post-counselling, and they should have been reminded of it whenever they went to any health facility (National Department of Health, 2008).

It is important to note that some mothers may in fact be told about to come back and just do not remember what they have been told when they return home, and it is possible that mothers were not being told at all. The interviewee 3 is really a disgrace for PMTCT programme. A documented rapid HIV done during ANC was found in her medical file, and she was in dual therapy and she has been treated for pulmonary tuberculosis, but she claimed to be told that she is HIV. It may

have been a denial or wrong coding, if so she should be helped accordingly in due time by a proper counselling. Poor quality of counseling and not understanding of what the HIV test result meant could have entertained this lack of awareness to go back for the result. Similar observation has been reported (Catania J., 1990, Rispel, 2009).

5.2.2 Lack of ownership of the PMTCT programme by the health staff

The researcher has identified lack of ownership of the PMTCT programme by the health staff by using conversation analysis. Conversation analysis examines the minute details of talk-in-interaction, something which became generally accessible with the advent of tape recorders. The centre of attention is not the speakers' intentions in their statements, but what specific speech segment accomplishes (Steiner et al, 2007). After their positive rapid test, at least once all the interviewees have attended health facilities for either the sake of their baby's health or for their own. This attendance could have been an opportunity for the health professionals to remind them about their results and then their CD4 result. The fact that the subject was no longer discussed after the test, it has compromised all the next steps of PMTCT and led to missed PMTCT opportunities. Our finding is supported by Risspel who has defined missed opportunity of PMTCT as a failure to use an opportunity for PMTCT at an appropriate health service encounter. A study done in Cap town has mentioned that inadequate planning of and preparation for the PMTCT programme was indicated as a major drawback, resulting in a stressful atmosphere of confusion

and frustration among health care who did not know what was expected of them when comes to PMTCT (Delva W., 2004)

5.2.3 Poor quality patient-health care provider communication

Besides the other reasons that they had given, interviewees 2, 7 and 9 explained that they were expecting the clinic to take the first step in contacting them for their results. The researcher has noted a break in communication between the interviewees and health professionals resulting in poor quality of communication. The PMTCT was introduced to them by the health professional, who should have made sure that the results were given.

5.3 Unpleasant experiences at Health Facilities

Many experiences faced by community members at health facilities have contributed to some interviewees not coming back for their CD4results.

5.3.1 Lack of privacy and confidentiality

Interviewees 1 and 9 reported lack of privacy and confidentiality at the health facilities. Confidentially encourages patients to be honest with their physicians and reminds the latter of their commitment to honour their patient's privacy (Holleman et al., 2007). It is another way of respecting the patient's autonomy (Moodley, 2007). HIV testing and follow-up is based on confidentiality and trust on the health professionals' part, and in the case of a lack of confidentiality, it is understandable that pregnant women opt out of PMTCT.

5.3.2 Blaming the health facility and health worker

Some of the interviewees have blamed the health facility for mismanagement and lack of courtesy.

- **Mismanagement**

Interviewees 1, 2 and 9 had reported cases of mismanagement. What is significant with regard to these 3 respondents is that 1 and 2 had enough knowledge of HIV and PMTCT, and 2 were on PMTCT for her previous baby.

The same problem may have occurred elsewhere, but gone unreported due to the ignorance of the patient. This was the reason for interviewee 1 not coming back, since she was afraid to see the nurse who she had reported. In the case of respondent 9, it served to reinforce the bad opinion that she had about the health system.

- **Lack of courtesy**

Interviewee 1 reported that she went through a very bad experience, because her baby was not given any HIV prophylaxis on discharge and she was hurt by this. Her baby was once admitted to hospital and she tried to discuss the matter in a polite manner with the nurse who was in charge of her baby

Courtesy can be regarded as being polite and considerate, and is one of the Batho Pele principles. This goes beyond a mere polite smile, and saying 'please' and 'thank you'. It requires service providers to empathise with fellow citizens and treat them with as much consideration and respect as they would like for themselves.

The public service is committed to continuous, honest and transparent communication with citizens. This involves communication of services, products, information and problems which may hamper or delay the efficient delivery of services according to promised standards. If applied properly, the principle will help demystify the negative perceptions that citizens in general have about the attitudes of public servants. (Department of Public Service and Administration, 2009). Batho Pele principles are taught to patients by health professionals, and are either given to them in a brochure format or displayed at every health facility or government office. One can read the following: "*You should be treated with courtesy and consideration".* The discrepancy between how health professionals behave and what it is displayed on the walls with regard to Batho Pele principles is definitely a barrier to effective PMTC.

- **Short of stock medication**

The interviewee mentioned that in community people are used to say that the clinics are short of medications for chronic diseases. This popular believe is one of the interviewee 4 reasons for failure to go back knowing that she is having a chronic condition. This is a serious issue, as patients are not supplied with their chronic medication due to limited budgets and cost curtailment, and this has created a situation of mistrust between the community and government health providers.

5.3.3 Workload and shortage

The overcrowded clinics and hospitals around the Mpumalanga Province is an issue that has distorted the quality of service delivered by healthcare workers and may discourage patient from going for their CD4 results. Literature has identified same findings. This observation confirms the findings of Nguyen, who has reported that in terms of health workers' perceptions of the factors that lead to their failure to provide good quality PMTCT, workload was one of these factors (Nguyen et al., 2009). Other authors also identified workload as factor limiting PMTCT program (Delva, 2004; Nuwagaba-Biribonwoha, 2007; Risspel, 2009).

5.4 Fear of stigma

Interviewees 1 shared her fear of stigma as reason contributing to their failure to go back. This finding consistent with some literature which has suggested that fear of stigma is a barrier to HIV and PMTCT (Termman et al*.,* 1995; Pool et al*.,* 2001).

5.5 Knowledge of HIV/AIDS and PMTCT

The overall knowledge with regard to HIV/AIDS and PMTCT of all interviewees was very low. It was disappointing to see that interviewees 3 and 6, who were about to complete their matric, seemed to have very limited knowledge on the topic. However, interviewees 1, 2 and 9 had an acceptable level of knowledge in this regard, but this still did not encourage them to come back for their results.

5.6 Support

- **Non-existent support system**

Embhuleni Hospital is situated in Elukwatini, a deep rural area in the Albert Luthuli Municipality. The municipality covers an area of 5.573 Km^2, with an estimated population of 191 379 people, and is served by two hospitals, Embhuleni and Carolina. However, there is no adequate support system and neither of the hospitals has a psychologist, and there is also no private clinical psychologist. At Embhuleni Hospital, there is one social worker.

These observations confirm the findings of Rispel et al. in their study conducted in Cape Town, where it was observed that only 6% of HIV positive women reported participating in a support group (Rispel et al., 2009), in contrast with what is already known, namely that psychological support does help HIV positive women to deal with stigma and isolation, acquire HIV knowledge and to promote positive living (Miller et al*.,* 1998; Summers et al., 2000).

- **Limited individual financial resources.**

Interviewees 1 and 7 have shared their financial vulnerability to pursue PMTCT. This finding consistent with the literature, it has been reported that the socio-economic context of South Africa is a barrier to the provision of PMTCT services (Skinner et al., 2005; Peltzer et al., 2007).

CHAPTER SIX

CONCLUSION and RECOMMANDATIONS

6.1 INTRODUCTION

The researcher dedicated himself to understanding the reasons given by pregnant women for failing to go for their results at Embhuleni Hospital. Ten HIV positive women were identified as HIV positive ANC were interviewed using the Free Interview Attitude, with the following exploratory question.

The analysis highlighted themes and sub-themes in which reasons for this phenomenon were given, and recommendations needed to be made to address this phenomenon and avoid this wastage of resources. These recommendations will follow the same framework as used elsewhere in this study

6.2 The ANC AND PMTCT PROCESS

6.2.1 Lack of awareness to return for the result

The researcher recommends that a clear and explicit explanation is given to HIV positive women with regard to PMTCT after VCT, which should include:

- Written dates for follow-ups during and after pregnancy until the woman starts with HAART.

- Every HIV positive pregnant women bringing a relative or trusted and supportive friend to their next ANC visit after VCT (PMTCT supporter). The opportunity can then be used to emphasise the importance of the of CD4 result therefore follow-up process.
- A follow-up panel at every clinic and hospital, which will develop a strategy for following up on those who fail to continue with PMTCT.

6.2.2 Lack of ownership of PMTCT programme by health staff

The researcher recommends that:

- Every health professional should attend a PMTCT workshop in order to ensure that knowledge on the topic has been mastered by all healthcare providers.
- Every health professional must be instructed that whenever an HIV positive or exposed child is brought to a health facility, an enquiry must be made with regard to the PMTCT process, including CD4 counts and follow- ups, so that any failure to pursue this process can be referred to the PMTCT follow-up panel.

6.2.3 Poor quality patient-health care provider communication

To avoid misunderstandings regarding how to get CD4 result and continue with PMTC, the researcher recommends that a clear follow-up schedule card is designed for PMTCT follow-ups such as ANC or RtHC.

6.3 UNPLEASANT EXPEREINCES AT HEALTH FACILITY

6.3.1 Lack of privacy and confidentiality

The researcher recommends that:

- An ethics workshop is conducted to provide health professionals with more information about ethical issues related to HIV.
- Pregnant women are told that if their privacy is not protected during PMTCT, they should not stop the PMTCT process but rather report the matter to the PMTCT panel, so that corrective and disciplinary measures can be taken.

6.3.2 Blaming the health facility and or health worker

The researcher recommends that management and clinic staff, as well as community leaders, form a panel for community health education on what to expect from a health facility and what needs to be rectified in order for health facilities and the community to be on the same page.

The researcher recommends that every health professional should attend a workshop on PMTCT as mentioned above.

It is a well-known saying that the public service is discourteous and unsympathetic to the public, and this needs attention in order to improve the quality of service delivery. The temptation to recommend to health professionals that they should be more courteous is strong, but one must bear in mind that keeping one's head, especially when overwhelmed in a very overcrowded clinic or public hospital, is not easy. The researcher recommends that the government provide a debriefing system for its employees, as well as training with regard to courtesy and good attitudes.

6.3.3 Workload and shortage

The current shortage of health workers leads to a heavy workload, which is a real threat to the quality of health services. The researcher recommends that the government design policies and strategies to improve working conditions for health workers, in order to attract them to and retain them in the public sector.

6.4 Fear of Stigma

Fear of stigma is a significant barrier to HIV/AIDS and PMTCT. The researcher recommends that health education for the community focuses on the ways in which HIV infects and affects people must be considered.

6.5 KNOWLEDGE OF PMTCT AND PMTCT

The knowledge of HIV/AIDS and PMTCT was low, and this led to poor compliance. The researcher recommends that during group and individual VCT sessions, health education must focus on basic knowledge on the topic.

6.6 SUPPORT

6.6.1 Non-existent support system

It is already known that psychological support is effective in helping HIV positive women deal with stigma and isolation, as well as to acquire HIV knowledge and promote positive living (Miller et al*.,* 1998; Summers et al., 2000). It is a pity that very few HIV positive pregnant women have the opportunity to be in a support group in South Africa (Rispel et al., 2009). The researcher recommends that:

- Every single HIV positive pregnant women must be offered an opportunity for psychological support.
- Every pregnant women to have a PMTCT support as recommended above
- Every healthcare provider must ensure that psychological support is available before HIV testing takes place.

6.6.2 limited individual financial resources

The literature has provided evidence of socio-economic contexts as a barrier to PMTCT services (Skinner et al., 2005; Peltzer et al., 2007).

Improvement in services to rural areas will require creative thinking, and innovation such out reach and mobile clinic or other cost effective way to help patients to join the health facility.

REFERENCES

- Antelman, G. et al. 2001.Predictors of HIV-1 disclosure: a prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *AIDS*, 15: 1865-1874.
- Bassett, M.T. 2002. Ensuring a public impact of programs to reduce HIV transmission from mother to infants: the place of voluntary counselling and testing. *American journal of public health*, 92(3):347-51.
- Bodgan, R. and Biklen, S., 1982. *Qualitative research for education: An introduction to theory and methods.* Boston: Allyn and Bacon, Inc.
- Britten, N. et al. 1995. Qualitative research methods in general practice and primary care. *Family practice*, 12(1).
- Buekens, P., Curtis, S. and Alayon, S. 2003. Demographic and health surveys: Caesarean section rates in sub-Saharan Africa. *British Medical Journal*, 326(7381):136.
- Catania J. et al.: Psychosocial predictors of people who fail to return for their HIV test results [letter]. AIDS 1990, 4261-262.
- Chaisilwattana, P. et al. 2002. Short-course therapy with zidovudine plus lamivudine for prevention of mother-to-child transmission of human immunodefi ciency virus type 1 in Thailand. *Clinical and Infectious Diseases*, 35(11):1405–1413.
- Dabis, F. and Ekpini, E.R. 2002. HIV-1/AIDS and maternal and child health in Africa. *Lancet*, 359(9323):2097–2104.

- Davis, F. et al. 2002. Effectiveness of short course of zidovudine + neverapine to prevent mother-to-child transmission (PMTCT) of HIV1: the Ditrame PLUS Anrs 1201 Project in Abidjan, Cote d'Ivoire. XIV International AIDS Conference, Barcelona 7-12 July 2002.
- De Cock, K.M. et al*.* 2000. Prevention of mother-to-child HIV transmission in resource poor country : translating research into policy and practice. *Journal of the American Medical Association*, 283(9)1175-1182.
- Delva W. et al.: Implementation of single-dose nevirapine for prevention of MTCT of HIV – lessons from Cape Town. SAMJ Vol. 96, No. 8
-
- Department of Health. 2005. *National HIV and Syphilis Prevalence survey*. Pretoria: Department of Health.
- Department of Health. 2007. *HIV and AIDS and STI Strategic Plan for South Africa, 2007 - 2011.* Pretoria: Department of Health.
- Desgrées du Loû, A. 2005. The couple and HIV/Aids in Sub-Saharan Africa: Telling the Partner, Sexual Activity and Childbearing, *Population*, 60 (3): 179-198.
- Draper B. and Abdullah, F. 2004. A review of the prevention of mother – to –child transmission programme of the Western Cape provincial government, 2003- 2004. *SAMJ,* 98 (6): 431-4.
- Dorenbaum, A. et al*.* 2002. Two–dose intrapartum/newborn neverapin and standard antiretroviral therapy to reduce perinatal HIV transmission: a

randomized trial. *Journal of the American Medical Association*, 288(2):189-198.

- Dowell, J. et al. 1997. Scottish statement on qualitative research in primary health care.
- Geddes, R. et al. 2004. Prevention of mother- to- child transmission of HIV programme: Low vertical transmission in KwaZulu-Natal, South Africa. SAMJ, 98(6): 458-62.
- Global Expanded Inter-agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children. 2007. Report Card on Prevention of Mother-to-Child Transmission of HIV and Paediatric HIV Care and Treatment in Low- and Middle-Income Countries: Progress on Scaling-up 2004-2006. Johannesburg: PMTCT High Level Global Partners Forum.
- Fadnes, L.T. et al. 2009. Need to optimise infant feeding counselling: a cross-section*al* survey among HIV-positive mothers in Eastern Uganda*.* BMC Peadiatr. 9 (Jan 9) :2.
- Field, P.A. and Morse, J.M. 1989. *Nursing research: the application of qualitative approaches*. London: Chapman.
- Guay, L.A. et al. 1999. Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial. *Lancet*, 354(9181):795–802.

- Health Systems Trust. Court ruling favours children orphaned by AIDS. Health Systems Trust News. Available at: http://www.hst.org.za/news/20031210 (accessed on 10 July 2007).
- Hoepfl, M., 1997. Choosing qualitative research: a primer for technology education researchers. *Journal of technology education,* 9 (1).
- Hollos, M. & Larsen, U. 2004. Which African men promote smaller families and why? Marital relations and fertility in a Pare community in northern Tanzania, *Social Science and Medicine,* 58 (9): 1733-1750.
- Jackson, J.B. et al. 2003. Intrapartum and neonatalsingle-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: 18-month follow-up of the HIVNET 012 randomised trial. *Lancet*, 362(9387):859-68.
- Joint United Nations Programme on HIV/AIDS. AIDS Epidemic Update 2005. Geneva: World Health Organisations and UNAIDS. Available at: http://www.unicef/protection/files/HIV/AIDS.pdf (accessed on 17 October 2006).
- Jones, S. A. et al. 2005. Exploring socio-economic conditions and poor follow-up rates of HIV-exposed infants in Johannesburg, South Africa. AIDS care, 17(4), May. 466-470.
- Karcher H. et al. 2006. Outcome of different nevirapine administration strategies in preventing mother-to-child transmission (PMTCT) programs in Tanzania and Uganda. *MedGenMed,* 8(2) April 12:12.

- Karcher H. et al*.* 2007. Risk factors for treatment denial and loss to follow-up in an antiretroviral treatment cohort in Kenya. *Tropical Medicine and International Health,* 12(5):687-94.
- Ladner, J.et al. 1996. A cohort study of factors associated with failure to return for HIV post-test counselling in pregnant women: Kigali, Rwanda, 1992-1993. *AIDS*, 10(1):69-75.
- Lallemant, M. et al. 2000. A trial of shortened zidovudine regimens to prevent mother-to-child transmission of human immunodefi ciency virus type 1. Perinatal HIV Prevention Trial (Thailand) Investigators. *New England Journal of Medicine*, 343(14):982–991.
- MacMillan, J. et al*.* 1993*.* Research in education: A conceptual introduction. 3rd ed. Washington: Pyramid.
- Mash, B. (ed). 2000. Introduction: illness, the patient, and the family. *Handbook of Family Medicine*. Oxford University Press Southern Africa: (4) 4-7.
- Manzi, M. et al. 2005. High acceptability of voluntary counselling and HIV testing but unacceptable loss to follow up in prevention of mother-to-child HIV transmission programme in rural Malawi: scalping up requires a different way of acting. Tropical Medicine and International Health, 10(12): 1243-1250.
- McIntyre, J. 2000. Approaches to reducing vertical transmission of HIV from mothers to infants. *Journal of Continuing Education*, 18: 3007-3111.

- McIntyre, J. 2005. Preventing mother-to-child transmission of HIV: successes and challenges. BJOG: 112:196.
- Miller, G.E.et al. 1998. Social relationships and the progression of human immunodeficiency virus infection: A review of evidence and possible underlying mechanisms. *Annals of Behavioral Medicine,* 18: 49-57.
- Moodley, D. et al. 2003. A multicenter randomized controlled trial of nevirapine versus a combination of zidovudineand lamivudine to reduce intrapartum and early postpartum mother-to-child transmission of human immunodefi ciency virus type 1. *Journal of Infectious Diseases,* 187(5):725–735.
- Msellati, P. et al. 2001. Operational issues in preventing mother-to-child transmission of HIV-1 in Abidjan, Côte d'Ivoire, 1998-99. *Bull WHO,* 79: 641-647.
- National Department of Health. 2008. *Policy and guidelines for the implementation of PMCT programme.*
- Nuwagaba-Biribonwoha, H. et al. 2007. Challenges faced by health workers in implementing the prevention of mother-to-child HIV transmission (PMTCT) programme in Uganda. *Journal of Public Health*, 29(3):269-274.
- Ogunbanjo, G.A. 2001. Statistics for General Practitioners: What is ‘bias’ in research? *SA Fam Pract*, 23 (3).

- Painter, T.M. et al. 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. *BMJ*, (4 September): 329:543.
- Patton, M.Q. 1990. *Qualitative Evaluation and Research Methods*. 2nd ed. Newbury Park, CA: Sage Publications, Inc.
- Paoli De, M.M., Malongi, R, and Klepp, K.I. 2004. Factors influencing acceptability of voluntary counselling and HIV-testing among pregnant women in northern Tanzania. *Aids Care*, 13(5):605-15.
- Pool, R. et al. 2001. Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda. *AIDS Care,* 13(5): 605-615.
- Peltzer ,K., Mosala, T., Shisana, O., Nqeketo, A. and Mngqundaniso, N. 2007. Barriers to prevention of HIV transmission from mother to child (PMTCT) in a resource-poor setting in the Eastern Cape, South Africa. *African Journal of Reproductive Health,* 11; 57-66.
- Perez F. et al. Implementing a rural programme of prevention of mother-to-child transmission of HIV in Zimbabwe: first 18 months of experience Tropical Medicine and International Health volume 9 no 7 pp 774–783 July 2004.
- Piwoz E. 2001. Women's perceived risk of HIV infection and mother-to-child transmission (MTCT) in the first 12 months post delivery: The 3rd

conference on global strategies for prevention of HIV transmission from mother to infants, September 9-13, Kampala, Uganda.

- Progress report on the global response to the HIV/AIDS epidemic, 2003. Geneva: UNAIDS. Available at: http://www.unaids.org/ ngass/en/global/ungass00_en.html . (Accessed on 7 June 2004).
- Rispel, L.C et al. 2009. Assessing missed opportunities for the prevention of mother-to-child HIV transmission in an Eastern Cape local service area. *SAMJ*, 99 (3):174-179.
- Shaffer, N. et al. 1999. Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: a randomized controlled trial. Bangkok Collaborative Perinatal HIV Transmission Study Group. *Lancet,* 353(9155):773–780.
- Shapiro. 1992. Goals and Methods Research: The Challenge for Family Medicine. *Family Practice*.
- Sherman, G.G 2004. PMTCT from research to reality — results from a routine service *South African Medical Journal,* 94: 289-292.
- Simon, A. 1981. *Scottish consensus statement on qualitative research in primary health care.*
- Skinner, D. et al. 2005. Barriers to accessing PMTCT services in rural areas of South Africa. *African Journal of AIDS Research,* 4(2): 115-123.
- Steiner, K. et al. 2007. Interviews. Learning the craft of qualitative research interviewing. 2nd edition. Pg 219-239.

- Strauss, A. and Corbin, J. 1990. Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage Publications. Inc.
- Stringer, J.S, et al. 2003. Comparison of two strategies for administering nevirapine to prevent perinatal HIV transmission in high-prevalence, resource-poor settings. Journal of Acquired Immune Deficiency Syndrome, 32(5):506-513.
- Summers, J. et al. 2000. The influence of HIV-related support groups in survival in women who lived with HIV: a pilot study. *Psychosomatics,* 41: 262-268.
- Temmerman, M. et al. The right to know HIV-test results. *Lancet*, 345: 960-970.
- The Petra study team. 2002. Efficacy of three short-course regimens of zidovudine and lamivudine in preventing early and late transmission of HIV-1 from mother to child in Tanzania, South Africa, and Uganda (Petra study): a randomised, double-blind, placebo-controlled trial. *Lancet,* 359(9313):1178–1186.
- United Nations. 2001. Declarations of commitment on HIV/AIDS.UN General Assembly special session on HIV/AIDS. New York: United Nations.
- UNAIDS and Wold Health Organization. 2003. Aids epidemic update *2003.* Geneva: UNAIDS.
- UNAIDS/WHO AIDS. 2006. Epidemic update. Geneva: December 2006.

- Verga, C. et al. 2008. Factors influencing teen mothers' enrolment and participation in prevention of mother-to-child HIV transmission services in Limpopo Province, South Africa. Qual Health Res, 18(6):786-802.

- Vrolijk, A.,et al.1980. Gesperksmodellen. Allen a.d. Rijn: sn.

- Wilson, D. 2004. Handbook of HIV medicine: Prevention of mother-to-child transmission of HIV. 3rd ed. Cape Town: Oxford University Press Southern Africa, p. 358-67.

- World Health Organization. 2004. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants, Geneva: WHO.

- World Health Organization. 2006. Antiretroviral drugs for testing pregnant women and preventing HIV infection in infants: Towards Universal Access. Geneva: World Health Organization.

APPENDIX

APPENDIX 1: Approved Research Protocol

REASONS GIVEN BY PREGNANT WOMEN FOR NOT RETURN FOR THEIR RESULTS AFTER VOLUNTARY COUNSELLING AND TESTING (VCT) FOR HUMAN IMMUNODEFICIENCY VIRUS AT EMBHULENI HOSPITAL

STUDY PROBLEM

Mother to Child transmission (MTCT) of HIV is considered as the major source of Human Immunodeficiency Virus (HIV) infection among children.[1,2] There are more than 2 million pregnancies in positive women each year and more than 1800 infected children are born daily worldwide. In South Africa, more than 250 000 HIV positive - women will become pregnant each year, without any intervention more than 70 000 of their children will be infected.[2]

The international community, through governments, has committed itself to reducing HIV infected children by20 % by 2005 and 50 % by 2010.[1] National programs have been developed on the basis of the aforementioned recommendations in order to reduce HIV mother to child transmission by introducing antiretroviral therapy in mono-therapy or bi-therapy in pregnant women certifying the accessibility to all women

An observation made at Embhuleni Hospital is that pregnant women who were advised and accepted the test, 40% came back for their results, the others were either not willing to know the outcome of the test or did not come for the results in anyway.

This apparent waste of resources needs to be explained, i.e. why the vast majority of women tested do not return for their results despite the voluntary counselling and testing (VCT).

This study aims to explore the reasons why women who have been tested for HIV through VCT at the antenatal clinic at Embhuleni Hospital never return for their results.

LITERATURE REVIEW

In recent years, HIV transmission among children appears to have been persistent in a linear fashion. However, medical interventions have sought to reduce HIV mother to child transmission (MTCT). These medical interventions are available. It is suggested that the lives of 300 000 children each year could be saved if the available resources are used.[3]

Wilson D. et al. have stated that in 1990, the HIV prevalence among pregnant women attending antenatal clinics in South Africa was less than 1 %, but 10 years later in 2000, the prevalence had risen to 24.5%. An estimated 550 000 children are infected in this way in South Africa each year. Without any

prevention, more than 40% of children born to HIV-infected women will be infected by HIV during pregnancy, during labour and delivery and by breast feeding.[2]

Several private initiatives mostly in Africa and The Caribbean have made this prevention strategy possible. The strategy used in the world has three steps:

- To prevent reproductive women from contracting HIV;
- To avoid unwanted pregnancy among seropositive women;
- To prevent HIV seropositive mother to children transmission during pregnancy, labour, childbirth, and breast feeding via VCT and antiretroviral therapy, safe childbirths and food replacing mother's milk.[2]

Internationally, between April 1999 and July 2004, out of 600 000 pregnant women attending antenatal clinics, more than 12 000 sero-positive women were treated.[4]

In Uganda, however, it was shown that Nevirapine administered in single dose to a seropositive pregnant woman during the labour, and her child by the first 72 hours of birth helps to reduce the vertical transmission risk by 50 % among babies born to infected women and fed exclusively till age of 14-16 weeks.[5]

Many authors have described the barriers to HIV VCT:

- The first one is the barrier on the acceptability of voluntary counselling and HIV-testing. [6,7.]

- The second is the barrier to disclosure of the HIV status to the sexual partner, the health staff or to the family. [8, 9, 10, 11.,12]

There are very few studies dealing with the failure of women to return for the results. Some authors reported some difficulties in VCT program and recognized that not all of those who were tested came back for the result[6], others admitted that there were inevitable dropouts at each step of VCT process and noted that not all women agreed to be tested, and not all those who were tested returned for results, but these studies did not give the proportion of women who did not come back for the results and also did not give the reasons for the failure to return.[11]

Bassets proposed the universal testing with the option to opt out from receiving the results. In this approach, women would be tested, but they would be allowed to opt out of being informed of the result.[11]The Zvitambo study in Zimbabwe showed that many women were willing to be tested, but only 20% chose to receive results.[12]

AIM OF THE STUDY

To explore the reasons given by pregnant women for not returning for their results following voluntary counselling and testing (VCT) for human immunodeficiency virus, at Embhuleni Hospital

OBJECTIVES

1. To understand the reasons given by women for not returning for their results following voluntary testing and counselling for human immunodeficiency virus.
2. To establish the information given to the tested women before they were tested
3. To assess the availability of a personal support system (family, friends, etc).
4. To assess their understanding of HIV for which they were tested.

RESEARCH QUESTION

What reasons do pregnant women give for not returning for their results following voluntary counselling and testing (VCT) for human immunodeficiency virus, at Embhuleni hospital?

STUDY DESIGN

This will be a descriptive exploratory qualitative study using free attitude interviews for data collection.

SETTING

The study will be conducted at the respondents' places of residence in the neighbourhood of the Embhuleni Hospital in Mpumalanga.

METHODS

Materials

The Ante-natal care (ANC) clinic register of the Embhuleni Hospital will be consulted to trace patients who consented for voluntary counselling and testing who have not come back for their results after 30 days of testing. These patients will be visited at their places of residence by the research team (interviewing nurse and the researcher) to request them to be respondents for the study. The nature of the study will be explained to each respondent. If they consent to participate in the study, each will be requested to sign the informed consent form and be enlisted. A date will be booked on which the interview will be conducted.

Study Population

The study population will be all the pregnant women attending antenatal clinic at Embhuleni Hospital, who accepted HIV VCT, but did not come back for their results after 30 days of testing.

Study Sample

Purposeful sampling of 8-10 women.

Inclusion criteria

- Pregnant women enrolled for antenatal care at Embhuleni Hospital;
- Pregnant women tested after VCT who accepted me to visit them;
- Pregnant women who had have VCT and who did not come back for the results after 30 days;
- Pregnant women at least 16 years of age;
- Women fluent in SiSwati or IsiZulu.

Exclusion criteria

- Pregnant women who have refused HIV VCT;
- Pregnant women counselled, tested and came for results.

Data collection

Exploratory Question:

SiSwati Version: ***Ngicela ungichazele kutsi yinindzaba ungeti kutohlola imiphumela yakho yengati*?**

English Version: *Can you tell me in as much detail as possible, why you did not come back for your HIV results?*

The data collection technique will be the free attitude interview which will be conducted by a trained nurse in the use of the technique. The main exploratory question will *be: Can you tell me in as much detail as possible, why you did not*

come back for your results? All the interviews will be audio recorded and field notes will be taken. The respondent will not be stopped while talking except for clarification. The interviewer will give reflective summaries at the conclusion of each idea under discussions.

The data collection form (Appendix 3) in part I will gather respondent details and in part II, will be used to further prompt the respondent on relevant areas not covered during discussions flowing from the exploratory question.

The interviews will continue until there is no further information gained by the addition of respondents (information saturation). In this study, this is estimated at about 8-10 respondents.

Each tape-recorded interview will be followed by the verbatim transcription. The services of a qualified linguist will be enlisted to translate the transcribed scripts from SiSwati into English. Backward translation from English into SiSwati will also be done to ensure correctness of the translation and that the original meaning of the statements in the transcripts is preserved.

The transcribed and translated scripts will be handed to an independent research assistant to verify the correctness of the translated version of each interview, making cross reference to the audio-taped interviews for clarification.

Data analysis

The researcher will analyse deductively the data collected by identifying the emerging themes and grouping them into conceptual categories, and finally integrating them into common phenomena. The analysis will follow the following steps:

- Immersion and crystallization of raw data.

  The researcher will review the transcripts several times so as to make sense of the data give by the interviewees.

- The structured transcripts.

  The researcher will develop an analytic structure based on the general sense resulting from the transcripts, based on logical deduction of cause and effect. The structure of the transcripts will generate categories, themes and their relatedness.

- Cutting and pasting

  The researcher will cut out themes from different parts of the transcript and paste them into their categories – with the aid of a computer (word programme).

- Integration

  The researcher will be looking for connections between the generated categories in order to clarify, explain and integrate the different themes.

Reliability, Validity and Objectivity

Reliability

Reliability is the extent to which a test achieves repeatability of results every time it is used. Reliability of the information will be ensured by sticking to the exploratory question, allowing the respondent to exhaustively discuss the question. The respondent will only be prompted with further questions contained in the interview form for relevant matters not covered in the exploratory question. This will ensure consistency and repeatability of the discussions for each respondent.

Validity

To ensure content validity, the transcribed and translated records, as well as the analysed data will be made available to the respondents for their comment as to the credibility of information. Each and every respondent will receive a copy of her interview in SiSwati, so that she can verify if the transcript is really what she said during the interview. Furthermore, translations and transcriptions will be verified by a second, independent person. This will also ensure objectivity of the information gathered.

To ensure face validity (which deals with relevance of the research tool as evaluated by the respondents) the research team will explain to each respondent the tools being used for the study (audiotapes and material for note-taking), and the process that will be followed during the gathering of information. Furthermore, it will be explained to each respondent that they

are free to seek clarity any time while the study is in progress and afterwards on anything pertaining to the study.

Triangulation

A detailed record of all original tape recordings, field notes, notebooks, transcripts and other data collection tools will be kept. This will allow the research team to look at information from various perspectives, thereby triangulating results of information gathered.

BIAS

- Selection bias will be introduced through the purposeful selection of the respondents. However, since this study is to focus on the depth of information, the bias thus introduced should not play a significant role.
- Interview bias will be minimize by using sticking to the exploratory question and the standardized data collection form for each respondent (Appendix 3)
- Interpretation bias will be minimized by feeding the data back to the respondents for their validation.
- Language bias will be minimized by enlisting the services of a qualified linguist to ensure the correctness of the translation from English to SiSwati and also the backward translation.

ETHICAL CONSIDERATION

The permission to conduct the study will be sought from the Family Medicine Department Research Committee (DRC), then from the Research Ethics and Publications Committee (REPC) of the University of Limpopo (Medunsa Campus). The researcher will also seek permission from the district health manager of Embhuleni Hospital.

Participation in the study will be individualized for each respondent. The nature of the study will be explained, before permission for participation is sought. If a respondent consents, he/she will be requested to sign the informed consent form (Appendix 2). Confidentiality and anonymity will be assured to each respondent. The respondent will be informed that he/she is free to leave the study at any point while it is in progress – no questions will be asked.

TIME FRAMES:

ACTIVITY	**TIME FRAME**
Data collection	February 2009
Data entry	June 2009
Data analysis	November 2009
Draft Report	November 2009
Final Report	December 2009

BUDGET

Items	Costs (R)
Researcher ’s return trip petrol cost	1000
Analysis	1,400
Work typing	300
Publication	2,400
Recorder	200
Audio tapes	50
Unforeseen spends	1,000
Total	**10,225**

All costs will be borne by the researcher.

References

1. WHO. Antiretroviral drugs for treating pregnant women and preventing HIV in infants, Geneva 2004;1-5. Available from: http://www.who.int/hiv/pub/guidelines/pmtct/en/. Accessed July 4th 2007.
2. Wilson D, Naidoo S, Bekker LG, Cotton M, Maartens G. Handbook of HIV medicine: Prevention of mother-to-child transmission of HIV. 3dr ed. Cap town: Oxford University press Southern Africa; 2004. p. 358-67.
3. UNAIDS: Children and young people in a world of AIDS. August, 2001. At http://data.unaids.org/Publications/IRC-pub02/JC656-Child_Aids_En.pdf. Accessed 4 July 2007
4. UNAIDS: Questions and answers: Selected issues, prevention and care, XI/1, November, 2003. At http://data.unaids.org/Global-Reports/Bangkok-2004/UNAIDS_Bangkok_press/docs/QA_PartIII_en.doc. Accessed 04 July 2007
5. Guay LA, Musoke P, fleming T. Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmissionHIV-1 transmission in Kampala, Uganda. HIVNET 012 randomized controlled trial. Lancet 1999, 354:795-802.
6. Paoli De MM, Malongi R, Klepp KI. Factors influencing acceptability of voluntary counselling and HIV-testing among pregnant women in northern Tanzania. Aids care 2004;13(5):605-15.

7. Maman S, Mbwambo Jm, Hogan NM, Kilonzo GP, Sweat M. women's barriers to HIV-1 testing and disclosure: challenge for HIV-1 voluntary counselling and testing. Aids care 2001;13(5):595-03.
8. Pool R. Attitudes to voluntary counselling and testing For HIV among pregnant women in rural south-west Uganda. Aids care 2001;13(5):605-15.
9. Olga A, Grinstea D, Steven E, Gregorish K, Kyung-Hee Choi, Coates T. et al. Positive and negative life after counselling: the voluntary HIV-1, counselling and testing efficacy study. Aids care 2001; 15: 1045-52.
10. Gretchen A, Mary C, Smith F, Kaaya S, Mbwambo J, Gerald I et al. Predictors of HIV-1 serostatus disclosure: a prospective study among HIV-infected pregnant women in Dares Salaam, Tanzania. Aids care 2001;15:1865-74.
11. Bassett MT. Ensuring a public impact of programs to reduce HIV transmission from mother to infants: the place of voluntary counselling and testing. American journal of public health 2002;92(3):347-51.
12. Piwoz E. Women's perceived risk of HIV infection and mother-to-child transmission (MTCT) in the first 12 months post delivery. In: the 3rd conference on global strategies for prevention of HIV transmission from mother to infants; September 9-13, Kampala Uganda 2001.

APPENDIX 2: Clearance certificate

UNIVERSITY OF LIMPOPO
Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

P O Medunsa
Medunsa
0204
SOUTH AFRICA

Tel: 012 - 521 4000
Fax: 012 - 560 0086

MEETING: 06/2008

PROJECT NUMBER: MREC/M/130/2008: PG.

PROJECT :

Title:	Reasons given by pregnant women for not returning for their results following voluntary counseling and testing (VCT) for human immunodeficiency virus, at Embhuleni Hospital
Researcher:	Dr DK Nzaumvila
Supervisor:	Dr LH Mabuza
Co-Supervisor:	Ms NH Malete
Hospital Superintendent:	Dr Ngwenya (Embhuleni Hospital)
Department:	Family Medicine and Primary Health Care
School:	Medicine
Degree:	M Med (Family Medicine)

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 6 August 2008

RESEARCH & PARTNERSHIP
2008 -08- 06
MEDUNSA CAMPUS

PROF GA OGUNBANJO
CHAIRPERSON MREC

Note:
i) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.**
ii) **The budget for the research will be considered separately from the protocol.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

APPENDIX 3: Permission letter from Embhuleni Hospital

health
Department:
Health
Mpumalanga Province

Stand No. 40 B
Nhlazatshe – Diepgezet Road
ELUKWATINI B
1192

Enq: Dr R.A. Ejike

Private Bag X100
ELUKWATINI
1192

Tel.: +27 17 883 0093/4
Fax:+27 17 883 0044

Litiko LeteMphilo | UmNyango WezaMaphilo | Departement van Gesondheid

Embhuleni Hospital

TO WHOM IT MAY CONCERN

RE: REASONS GIVEN BY PREGNANT WOMEN FOR NOT RETURNING FOR THEIR RESULTS FOLLOWING VOLUNTARY COUNSELLING AND TESTING (VCT) FOR HUMAN DEFICIENCY VIRUS AT EMBHULENI HOSPITAL.

This letter serves to confirm that Dr D.K. Nzaumvila had obtained an authority from Embhuleni Hospital to do his research.

Hope you'll find the above in order.

Thank you.

Dr R.A. Ejike
Medical Manager

DEPARTMENT OF HEALTH
EMBHULENI HOSPITAL
2010 -01- 14
Date
MEDICAL MANAGER