

**FACTORS INFLUENCING THE FOLLOW-UP VISITS OF
MOTHERS REGISTERED WITH PREVENTION OF
MOTHER TO CHILD TRANSMISSION (PMTCT) OF HIV/
AIDS PROGRAMME AT THE KATUTURA STATE
HOSPITAL.**

A Thesis submitted in partial fulfilment of the requirements for the degree of

Masters in Public Health

Of the

University of Namibia

BY

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is a true reflection of my own research and has not been submitted for a degree in any other institution of higher learning.

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ABSTRACT

The Ministry of Health and Social Services (MOHSS) has launched a comprehensive programme for the prevention of mother to child transmission (PMTCT) in March 2002. This programme was introduced for the prevention of mother-to-child HIV transmission in Namibia using Nevirapine (an Antiretroviral drug). The programme was initiated at two pilot sites i.e. Katutura State Hospital Antenatal Clinic (KSH-ANC) and Oshakati State Hospital. This programme was aiming to reach 500 HIV positive women, 250 from each site, but this number has been exceeded.

The researcher has observed that problems exist with the follow-up visits of mothers who registered for the Prevention of Mother to Child Transmission (PMTCT) of HIV/AIDS programme at Katutura State Hospital. She observed that not all mothers do come for follow-up visits as scheduled which leads to the question of what could be the contributing factors to the situation. Therefore the reason this study was conducted was to get answers to the following study question: *What are the factors that influence the follow-up visits by mothers registered for the PMTCT programme at Katutura State Hospital?*

The specific objectives for the study are

- To determine the profile of mothers who join the PMTCT programme
- To determine the factors that motivate or demotivate the mothers to stick to or drop out of the programme
- To assess the follow-up modalities and support networks available to mothers in their communities
- To make appropriate recommendations

Qualitative and Quantitative research designs were used. Exploratory and descriptive strategies were used to obtain the data. The study was done in the Khomas Region. The study population includes all HIV positive mothers who are registered with the PMTCT programme at Katutura State Hospital and who have delivered at the same hospital. Convenient sampling was done and a total of thirty (30) mothers were sampled.

The researcher concluded that the majority of these mothers fall in the age bracket of 20-39 years old, and most of them are unmarried as well as unemployed. All the mothers can read and write. 85.7% of the mothers came to know their HIV status during the last pregnancy. The majority of them were counselled before and after HIV tests which is a good practice in the health facility.

Some of the factors that motivate the mothers to stick to the follow-up visits are that they would like to ensure the health of their babies and to enable the babies to live longer; they found out that the babies on prophylaxis treatment do not get sick and that the follow-up visits create a chance for them to interact with health workers about the health status of the children.

Some of the factors cited for not coming for follow-up visits include issues like denial of the HIV/AIDS existence in the family, economical reasons, domestic violence as well as ignorance among communities. It was evident that, although mothers know of supportive activities in their communities, they do not utilize these to support themselves due to fear of stigma and discrimination.

Recommendations formulated included issues related to creating an appropriate way of doing follow-up of children; support services for HIV positive women and their children; training of all health workers on PMTCT, counselling and feeding options; awareness creation for employers and community in general; community participation and family involvement in the care of HIV positive mothers and children.

DEDICATION

This thesis is dedicated to the memory of my late caring father Wilbard Fox Kalili. To my lovely son, Ileni, let this be a source of inspiration and to my husband, I-Ben Natangwe, for his continuing encouragement, support and love.

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ABBREVIATIONS AND ACRONYMS

AIDS	ACQUIRED IMMUNO-DEFICIENCY SYNDROME
ANC	ANTENATAL CLINIC
AZT	ZIDOVUDINE
ARV	ANTIRETROVIRAL
CCN	COUNCIL OF CHURCHES IN NAMIBIA
D4T	STAVUDINE
DDI	DIDANOSINE
EFV	EFAVIRENZ
HIV	HUMAN IMMUNO- DEFICIENCY VIRUS
HAART	HIGHLY ACTIVE ANTI- RETROVIRAL THERAPY
KSH	KATUTURA STATE HOSPITAL
MOHSS	MINISTRY OF HEALTH AND SOCIAL SERVICES
MTCT	MOTHER TO CHILD TRANSMISSION
NVP	NEVIRAPINE
NNRTI	NON- NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITOR

NRTI	NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITOR
NGO	NON- GOVERNMENTAL ORGANIZATION
PMTCT	PREVENTION OF MOTHER-TO-CHILD TRANSMISSION
PHC	PRIMARY HEALTH CARE
POPD	PAEDIATRIC OUTPATIENT DEPARTMENT
PCP	PNEUMOCYSTIS CARINII PNEUMONIA
SADC	SOUTHERN AFRICA DEVELOPMENT COMMUNITY
3TC	LAMIVUDINE
UNGASS	UNITED NATIONS GENERAL ASSEMBLY SPECIAL SESSION
UNAIDS	JOINT UNITED NATIONS PROGRAMME ON AIDS
USAID	UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT
VCT	VOLUNTARY COUNSELLING AND TESTING
WHO	WORLD HEALTH ORGANIZATION
ZDV	ZIDOVUDINE

CHAPTER 1: ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND INFORMATION

Human Immuno Virus (HIV) as the cause of Acquired Immune-Deficiency Syndrome (AIDS) remains a global epidemic and a public health problem since 1983 (MOHSS 1999:3). It is estimated that in the year 2002, HIV/ AIDS claimed more than 3 million lives worldwide and 5 million people acquired the HIV infection, bringing to 42 million the number of people living with the virus. The condition undermines the future as families and communities struggle with the burdens of the sick people and orphaned children, as it mainly targets women, children and young people (MOHSS 2002: 1).

The estimated number of people living with HIV in sub-Saharan Africa stands at 29.4 million, which makes it by far the worst affected region in the world. In the absence of expanded prevention, treatment and care efforts in Africa, the AIDS death toll is expected to continue rising (MOHSS 1999:2).

Namibia, like all countries in sub-Sahara Africa, did not escape the scourge of HIV/AIDS. Ever since the first cases of AIDS were diagnosed in Namibia in 1986, the epidemic has continued to increase steadily. By the end of May 2001, Namibia has recorded a cumulative number of 98159 cases of HIV and AIDS, with 10588 deaths due to AIDS related complications since 1986. This represents a national prevalence ratio of 5.4% (MOHSS 2001:3).

Since 1992, there have been dramatic increases in the HIV prevalence ratio among pregnant women over the years. In 1992 the prevalence ratio among pregnant women stood at 4.2 %. Ten years later, by the year 2002 the prevalence ratio increased to 22.0% of pregnant women who were found to be HIV positive (MOHSS 2002:1).

Many factors contribute to the spread of HIV infection in Namibia. Among them are the high mobility of individuals within the country, alcohol and substance abuse, gender

inequalities, poverty, certain cultural practices, disintegration of traditional family structures and ignorance (MOHSS 2002:1).

HIV and AIDS related deaths have been recorded in Namibia among newborn babies. The prevalence ratio among babies born to HIV positive mothers in Namibia remains unknown as no study to determine its magnitude has so far been undertaken. The chief mode of HIV transmission among children below five years is through the mother to child transmission route (MOHSS 2001:3).

According to the Southern Africa Development Community – Prevention of Mother-to-Child Transmission (SADC- PMTCT) programme, the mother-to-child transmission rate of HIV is about 20% to 25% during pregnancy and childbirth. The transmission rate through breastfeeding is about 15 % if infants are breastfed over 12 months, and approximately 5% if infants are breastfed less than 6 months (SADC 2002: 7).

Interventions to prevent mother to child transmission (PMTCT) therefore focus on interrupting transmission before pregnancy and childbirth and during infancy. Recent scientific evidence suggests that prevention of maternal to child transmission of HIV can be maximized through four key strategies: -

- Primary prevention of HIV among prospective parents
- Prevention of unwanted pregnancies among HIV positive women
- Prevention of transmission from mother to child and
- The care and treatment of HIV positive mothers (SADC 2002:6)

The Ministry of Health and Social Services (MOHSS) launched a comprehensive programme for the prevention of mother to child transmission (PMTCT) in March 2002. This programme was introduced for the prevention of mother-to-child HIV transmission in Namibia using Nevirapine (an Antiretroviral drug). This programme was initiated at two pilot sites i.e. Katutura State Hospital Antenatal Clinic (KSH-ANC) and Oshakati State Hospital. This programme was aiming to reach 500 HIV positive women, 250 from each site, but this number has been exceeded.

“Primary Health Care (PHC) approach has been adopted as foundation and cornerstone of health care delivery system in Namibia” (MOHSS 1995: 5). Therefore this PMTCT programme has been introduced as one of many of the MOHSS programmes aimed at promoting health and preventing diseases among children. The PMTCT programme has been integrated in maternal and child services at KSH ANC. There are nurses who are trained to do voluntary counselling and testing (VCT) and provide follow up support to HIV positive mothers and their babies.

The following figures have been obtained from KSH PMTCT statistics for the period March 2002 – December 2003.

Table 1. 1: PMTCT Statistics from KSH

Topic	Number	Percentage (%)
Total number of new ANC clients	8090	
Total number of women enrolled in the programme	660	8.16
Total number who tested for HIV	584	7.2
Total number of women who tested positive	280	47.9
Total number of deliveries at KSH	8,007	98.9
Total number of deliveries from enrolled HIV mothers	212	75.7
Total number of women who received Nevirapine	208	98.1
Total number of babies who received Nevirapine	207	97.6

Source: MoHSS 2004: 4

The PMTCT programme uses a combination of interventions such as: -

General improvement of antenatal services in the country. This is essential in delivering effective mother to child prevention intervention; provision of ARV drugs to both parents; safe delivery practices; counselling and support and safer infant feeding methods; promotion of family planning and post – natal follow-ups (MOHSS 2001:8).

The researcher works as an HIV/AIDS counsellor at KSH- ANC and is involved in the PMTCT programme activities. She has observed the problem of post delivery follow-ups which are not well attended. Mothers and babies do not come back for after delivery follow-up, as it is stipulated in the guidelines. Only a small percentage come back. Therefore, the researcher decided to do a study to determine the factors that influence the follow up visits by mothers registered for the PMTCT programme.

The programme of HIV prevention of mother-to-child transmission was introduced in March 2002 at KSH ANC. This programme includes the following:

- During health education sessions at antenatal clinics, pregnant women are being encouraged to come with their husbands/ partners for pre-test counselling.
- Those who come out willingly receive comprehensive counselling and after they have given written consent, pregnant mothers are tested for HIV.
- Post-counselling is done for all tested women. Those who test positive receive one dose of nevirapine at the onset of labour.
- Within 72 hours of delivery, the baby receives one dose of nevirapine 2mg/ kg per os. If the mother receives nevirapine less than two hours before delivery or did not receive nevirapine at all, the baby is given a double dose.

1.2 PROBLEM STATEMENT

According to protocol, babies should be brought for follow-ups at 6 weeks, 3 months, 6 months, 9 months, 12 months, 15 months and 18 months. The babies are followed up to determine the proportion of babies testing HIV positive and those testing HIV negative at all these ages (MOHSS 2001:27).

Follow-ups are very important for the following reasons: - To determine if the baby is growing well; At 6 weeks all the HIV exposed babies must receive a prophylaxis by co-trimoxazole for opportunistic infection, regardless of the CD4 and the test results.

At 12 months, the prophylaxis must be considered according to the HIV test results and the CD4 count. Blood is drawn at 3 months, 6 months, 9 months, 12 months, and 18 months to determine the baby's HIV status. If at any time before 18 months, an HIV positive becomes negative, the baby is discharged from the programme. If the HIV test is positive, the baby is put on Antiretroviral treatment (MOHSS 2001:6). In accordance with new information, babies are now only tested for HIV at 18 months (MOHSS 2004:35).

On follow-up, mothers should be given the following: - continuous counselling on infant feeding and psychosocial support, nutritional counselling and family planning information, treatment of opportunistic infections and priority for Highly Active Antiretroviral drugs (HAART). It was observed that only a few babies have been brought back for follow-up since the inception of the project. Babies who were brought for follow up: -

At 6 weeks: 47.2%

At 3 weeks: 37,5%

At 6 months: 50%

(*MoHSS 2003: 2*).

This information shows that there are number of mothers who did well to bring their babies for follow – ups but still there are also some who do not come back for check ups of their babies. This makes it difficult to determine the success of the programme. Therefore, the researcher wants to know why some mothers come and others do not. The researcher is looking for answers to the following research question:

What are the factors that influence the follow-up visits by mothers registered for PMTCT at KSH?

1.3 PURPOSE OF THE STUDY

1.3.1 General Objective

The general objective of the study is to explore and describe the factors that influence the follow-up visits by mothers registered in the PMTCT in KSH's ANC after their respective deliveries.

1.3.2 Specific Objectives

The specific objectives are:

- To determine the profile of mothers who join the PMTCT programme
- To determine the factors that motivate or demotivate the mothers to stick to or drop out of the programme
- To assess the follow up modalities and support networks available to mothers in their communities
- To make appropriate recommendations

1.4 JUSTIFICATION OF THE STUDY

Findings from this study can provide useful information regarding motives of mothers who cease to bring their babies for follow-up, and/or fail to make use of the programme's directives and stipulations, even though they are strongly urged to do so. Information will also be obtained on factors which motivate the mothers to keep up with their babies' follow-ups. The information will help improve the PMTCT programme, and could be used as a good guide in the setting up of similar programmes in other parts of the country. No similar study has been conducted in Namibia, so the findings in this study can provide useful baseline data for programme managers and thus promote the services of the programme and eventually encourage mothers to adhere to programme directives to stick to their follow-up schedules.

It is through testing babies for HIV that it can be determined whether Nevirapine drugs are working. The programme manager also requires this statistical information on babies who become HIV negative after being given Nevirapine to enhance the PMTCT of HIV, which is the core of the programme. Through the effective use of this programme, HIV infections and the number of early orphanhood would be reduced.

1.5 THEORIES

Theory is defined as a set of interrelated concepts, definitions and propositions that present a systematic way of viewing facts/events by specifying relations among variables, with the purpose of explaining and predicting the fact/event (George 1995: 2). Simply stated, a theory suggests a direction in which to view facts and events. The researcher finds the following theory most applicable:

Humanist Theory

The Humanist Theory describes the influence that feelings, emotions and personal relationships have on human behavior. A human being is seen as a valued person in and of him or herself, to be cared for, nurtured, understood and respected. Health care focuses on lifestyle, social conditions and environment/ society. Society provides the values that determine how one should behave and what goals one should strive toward (Stanhope and Lancaster 1996: 250).

Nursing is concerned with promoting health, preventing illness, caring for the sick and restoring health. Nursing's goal through the caring process is to help people gain a high degree of harmony within the self in order to promote self knowledge and self healing, or to gain insight into the meaning of things happening in life. If people are given free choice, they will do what is best for them.

The humanist theory provides facts which assist in understanding the factors which may influence follow-up visits of the mothers registered with PMTCT of HIV at KSH, by

taking into account their feelings, personal relations, social conditions, lifestyles, cultural backgrounds and the society they live in as well as the nursing care provided to them.

1.6 RESEARCH METHODOLOGY

1.6.1 Research Design

This is a descriptive, exploratory study using a pre-tested structured questionnaire to collect and present data on factors influencing follow-up visits by mothers registered in the PMTCT programme at Katutura State Hospital. This study was conducted in Katutura State Hospital in Windhoek. The PMTCT programme has been implemented in Windhoek's KSH since March 2002 to-date.

1.6.2 Study Population

The target population includes all the women who were registered in the pilot PMTCT programme at KSH ANC between March 2002 to December 2003. From these women, only those HIV positive women who delivered are considered. The total population is 280.

1.6.3 Data collection

A structured questionnaire was used to guide the interview and gather the data to be obtained. Such interviews were held face-to-face with HIV positive mothers, either at the KSH when they came for their follow-ups at Postnatal Clinic and some at Paediatric Outpatient Department (POPD) and at ANC.

All interviews were conducted in the language in which the interviewee was most fluent. Data collection was done over the period of five months.

1.6.4 Data Analysis

Data analysis was done using Microsoft Excel 2003 software, and data was summarized using statistical analysis, tables and graphs.

1.7 ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the Ethic Committee of the University of Namibia and from individual respondents. Confidentiality and privacy were observed. Participation in the study was on a voluntary basis.

1.8 OPERATIONAL DEFINITIONS

Prevention of mother to child transmission - includes prevention of HIV infection from mother to child and treatment for women who need ART (WHO 2002: 18).

Follow-up visit- follow-up of infants born by HIV infected mothers to ensure that proper infant feeding support is provided, prophylactic treatment is given, infections are detected early and appropriately managed, and to give HIV tests at 18 months to see whether the children are infected or not (Doherty et al 2003: 34).

Motivate- stimulate the interest of a person in an activity (Allen 1990:773). In this study, stimulate refers to motivating the mother to bring the child for a follow-up visit.

Demotivate- cause to lose motivation/discourage (Allen 1990: 309). In this study, refers to the factors that prohibit the mother from coming for a follow-up visit.

Exclusive breastfeeding – means only breast milk for the first 4 months. No water or other food or pacifiers given to the infant (MOHSS 2004: 28).

Replacement feeding- The process of feeding a child who is not receiving any breast milk with a diet that provides all the nutrients the child needs (MOHSS 2004: 29).

VCT – Is an HIV prevention intervention, which gives the client an opportunity to confidentially explore his or her HIV risks and to learn his or her HIV status (MOHSS October 2004: 4).

1.9 SUMMARY

This chapter described the background information on PMTCT, problem statement, brief description of methodology and the operational definitions of the study. The next chapter deals with the literature review.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

A literature review is an informed assessment of the existing research on the topic under study. A literature review is goal-focused. The goal is to identify limitations in the existing research subject in order to justify the proposed research.

The reasons for conducting this literature review are:

- To study different theories related to topic
- To find out what has not been done and needs to be done on that topic
- To determine connections between other research results by comparing the findings
- To find out definitions and concepts used in other studies
- To determine the best research methods to use in your own research (Bless and Higson-Smith 2000: 20).

The researcher reviewed the evidence by reading literature on issues concerning mother-to-child transmission programmes, voluntary counselling and testing, Antiretroviral drug therapy, optional feeding for the infant, follow up visits and motivational and demotivational factors as related to adherence to follow up visits for mothers to stick to the programme.

2.2 BACKGROUND OF MOTHER-TO-CHILD TRANSMISSION OF HIV

In 2003 an estimated 700,000 children became infected with HIV worldwide. The overwhelming majority of infected children acquired the infection through mother-to-child transmission (MTCT), which can occur during pregnancy, delivery, postnatal and during breastfeeding. In the absence of any intervention, rates of MTCT of HIV can vary from 15% to 30%, without breastfeeding, and can reach as high as 30% to 45% with

prolonged breastfeeding. Transmission during the peripartum period accounts for one to two-thirds of the overall transmission rate, depending on whether breastfeeding occurs or not, and the peripartum and breastfeeding period has thus become the focus for efforts to prevent MTCT (WHO 2004:1).

The transmission of HIV from an infected mother to her child can be reduced to 2% or less by intensive interventions that include a combination of potent antiretrovirals (ARV), obstetrical interventions including elective caesarean section at 38 weeks and complete avoidance of breastfeeding (3-6 months). ARV prophylaxis alone, administered in the period around a vaginal delivery, reduces by between 30% and 50% the rate of peripartum transmission. In resource-constrained settings, elective caesarean section is seldom available and safe, and refraining from breastfeeding is often not feasible or acceptable. Also, even where peripartum ARV prophylaxis is used, infants remain at substantial risk of acquiring infection in the breastfeeding period. Research is ongoing to address approaches to prevent postnatal transmission of HIV. Furthermore, preventive ARV interventions have not yet been implemented on the scale required (WHO 2004:1).

At the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001, governments from 189 countries committed themselves to a comprehensive programme of international and national action to fight the HIV/AIDS pandemic by adopting the Declaration of Commitment on HIV/AIDS. The Declaration established specific goals, including the reduction of the proportion of infants infected with HIV by 20% by 2005 and by 50% by 2010. The follow up to the 2001 UNGASS Progress Report presented in 2003 indicated that by the end of December 2002, 88% of countries had national MTCT prevention policies in place. However, many countries with severe HIV/AIDS epidemics had experienced difficulty in increasing access to MTCT prevention services, including ARV prophylaxis (WHO 2004:2).

According to many studies (Camara et al 2001: 6) conducted in the Caribbean, the risk factors influencing mother to child transmission of HIV are:

- Degree of maternal immune deficiency
- Increased maternal plasma viral load (new infection or late stage of HIV disease)
- Prevalent endemic diseases
- Mastitis
- Low maternal CD4 cell count
- Low maternal serum Vitamin A concentration
- Chorioamnionitis
- Vaginal or traumatic delivery
- Presence of other sexually transmitted infections
- HIV biological phenotype and subtype
- Premature rupture of membranes
- Prematurity
- Breastfeeding

Furthermore there are still a large number of HIV-infected women who do not yet have access to comprehensive prenatal, obstetrical and postnatal care and require specific and innovative strategies for MTCT prevention (WHO 2004: 2).

To accomplish the UNGASS goal, it will be necessary to take the following action:

- a) Ensuring that 80% of pregnant women accessing antenatal care have information, counselling and other HIV prevention services available;
- b) Increasing the availability and access of effective ARV prophylaxis to reduce MTCT of HIV for HIV infected women and their infants;
- c) Ensuring access to treatment, including ARV treatment, for HIV-infected women and provision of follow up and continuum of care to themselves, their partners and children;

- d) Provision of breast milk substitutes where appropriate (WHO 2004: 2).

A comprehensive and integrated approach to prevent HIV in women, infants and young children is urgently required. Interventions focusing on HIV-infected pregnant women need to be complemented by interventions that address primary prevention of HIV infection, particularly in women of child-bearing age and their partners, and prevention of unintended pregnancies among HIV-infected women.

2.3 VOLUNTARY COUNSELLING AND TESTING (VCT) IN ANTENATAL CLINIC

It is stated in the literature that for pregnant women to make informed decisions about reducing the risks of transmitting HIV to their infants, they need to know their HIV status. Voluntary counselling and testing provides an entry point to the PMTCT programme, and PMTCT cannot be delivered without effective counselling on the implications of PMTCT for both mother and infant (Doherty et al 2003:1).

There are many advantages of VCT in the antenatal setting which include:

- Knowledge of the HIV status of a couple or a woman can facilitate early counselling and treatment for the woman and appropriate treatment and follow up of her child.
- Knowledge of her HIV status enables the woman to take decisions on continuation of the pregnancy and on future pregnancies.
- Knowledge of her HIV status enables the woman to take precautions to help prevent transmission to sexual partners.
- Testing provides an opportunity to implement strategies to reduce transmission to the child.
- If the test results are negative, women can be guided in appropriate HIV prevention measures and risk reduction behaviour (Doherty et al 2003: 1).

Even though there are many advantages of HIV testing, on the other hand there are also possible disadvantages of HIV testing in pregnancy which include:

- An increased risk of violence against women
- The possibility that a woman may be stigmatized within her community and by the health worker
- Higher levels of anxiety and psychological sequelae
- Concerns about the additional work load for maternity services. (UNAIDS/WHO 2003: 12).

Large numbers of women are invited to participate in the pilot programmes to reduce MTCT; and HIV counselling and testing during pregnancy must be major components of these programmes. It is essential that protocols adhere to guidelines on voluntary participation after pre-test and post-test counselling and informed consent. Nevertheless, women may consent because they trust the health workers without fully understanding the implications of being tested for HIV. Violence and loss of security for the HIV – positive women and their children (e.g. loss of shelter, food and relationships) have been reported as a consequence of VCT in the developing world. Women are often blamed for bringing AIDS into the family, and the options of these positive women are to cope with this unfair burden silently, or to share their HIV status information with their partners and families at the risk of violence, divorce or abandonment (WHO 1999: 111).

It is clear that morale, motivation and attitudes of the health workers toward HIV are important factors that need to be optimized to improve uptake rates and the quality of counselling in the PMTCT. McCoy et al (2002:15) found that there is inadequacy of counselling and testing in ANC, because only a few pregnant women disclose their status to their partners or families. Namibia is not exempt. We also experience inadequate attention paid to empowering the client to disclose their HIV positive status, a lack of effort or capacity to provide couple counselling and testing, as well as a degree of stigma, ignorance and prejudice in the community.

2.4 THE USE OF ANTIRETROVIRAL DRUGS AND OTHER INTERVENTIONS TO REDUCE MOTHER-TO-CHILD TRANSMISSION OF HIV

The Antiretroviral (ARV) drugs are used to prevent mother to child transmission of HIV. The aim of Antiretroviral treatment is primarily two-fold:

- a) To lower the viral load in the mother, reducing the risk of transmission in-utero and during labour and birth. The duration of treatment determines to what extent the viral load in breast milk remains low and by that reduces the risk of transmission through breastfeeding.
- b) As a post-exposure prophylaxis in the infant who contracted the virus in-utero or during labour and birth, and to a limited extent through breastfeeding (WHO, 2002: 4).

The choice of regimen(s) to be included in a national MTCT-prevention programme should be determined by assessment of feasibility, efficacy, acceptability, safety and cost and relation to the national HIV care strategy. It should be noted that the drug cost may represent only a fraction of the costs of the service that are required in an effective MTCT-prevention programme. Currently, all MTCT-prevention programmes depend on the timely identification of HIV-infected women in pregnancy. Additionally, early paediatric HIV diagnostic services should be included as well as the need for adequate postnatal interventions to reduce the risk of postnatal transmission (WHO 2004: 18).

Practical considerations in choosing ARV regimens for the prevention of peripartum MTCT include:

- Availability of voluntary testing and counselling services;
- Proportion of HIV-infected women who are aware of their serostatus at different stages of pregnancy;
- Proportion of women seeking antenatal care;

- Timing of first antenatal visit;
- Frequency of antenatal visits;
- Quality of antenatal care;
- Proportion of births occurring in health-care facilities;
- Access to early postnatal care;
- Acceptability and ease of dosage schedules;
- Efficacy and safety of different ARV drug regimens, including their potential to compromise future treatment options;
- Access to cost of drugs (WHO 2004: 18).

ZDV, 3TC and NVP are the drugs of first choice to be used to prevent peripartum MTCT. They are the only three ARV drugs that have been formally assessed for safety and efficacy in MTCT-prevention clinical trials. Their administration is relatively simple. All three drugs can be taken twice daily, and appropriate infant formulations are available (WHO 2004: 19). ZDV and 3TC are available in one tablet, thus reducing the number of pills to be taken. The NVP tablet is used in a single dose formulation for intra-partum use only. NVP syrup is also available for infant use within 72 hours of delivery.

It is important to note that there are limitations with using alternative ARV drugs. EFV, an alternative NNRTI, is teratogenic, and is not recommended in pregnancy. If EFV has to be used, then it should only be taken after the first trimester of pregnancy. The dual NRTI combination d4T+ddi should be avoided in pregnancy, due to the potential increased risk of lactic acidosis with this combination in pregnant women. PIs are still expensive, and they may not be affordable in resources-constrained settings (WHO 2004:19).

The ACTG 250 study performed by Mirochnik et al in seven hospitals in the USA and Puerto Rico aimed to define the dosage regimen that maintains a serum concentration of nevirapine above 100 mg / ml throughout the first week of the life of the infant. The dosing schedule arrived at was a single dose to the infant between 48-72 hours after birth. No toxicity was noted in infants or their mothers (WHO, 2002: 7).

The HIV NET 012 study is a randomized controlled trial conducted in Uganda, which compared the use of a maternal single 200mg oral dose of nevirapine during labour and an infant 2mg/kg dose of nevirapine within 72 hours of birth; with a maternal 600mg oral dose of AZT (Zidovudine) at onset of labour and 300mg orally every 3 hours during labour with an infant 4mg/ kg twice daily dose of AZT for 7 days after birth. At 6-8 weeks of age, 11.9% of infants in the NVP (Nevirapine) group were HIV infected, compared with 21,3% in the AZT group. Similarly at 14-16 weeks of age, 13% of infants in the NVP group were infected, compared to 25% of infants in the AZT group. At 14 weeks of age 95% of all infants were still breastfeeding (Lancet 1999: 354). This study shows that Nevirapine is safe and significantly reduces the MTCT rate compared to a short course of AZT.

Namibia decided to use nevirapine because of its simplicity, low cost and potential for widespread use. Nevirapine is a fast-acting and potent Antiretroviral and takes a long time to be eliminated from the body. Consequently it was deemed to be a valuable option to reduce the risk of MTCT, since it is absorbed quickly in the body, passed readily to the placenta and it remains active in the body of both mother and infant for a period which can limit infection via breast milk.

In industrialized countries, the combination of Antiretroviral drug treatment, along with other preventative measures such as delivery by caesarean section and counselling, has resulted in reducing the mother-to-child-transmission, while resource poor countries have not yet experienced the same level of success (Nyblade 2002: 3).

Roets et al did the research on the prevention of intrapartum HIV/AIDS transmission from mother to child in labour wards in Bloemfontein, South Africa. The aim of the study was to determine which preventive practices registered midwives use to lower the risk of mother to child transmission of HIV/AIDS, and therefore to lower child mortality (Denosa Curations 2003:12). It is believed that two-thirds of the children with HIV/AIDS are infected in the intrapartum period. By means of effective interventions midwives can

reduce the risk of the intrapartum transmission of HIV/AIDS from mother to child by 10% to 20%.

These interventions include:

- Avoiding artificial rupture of membranes
- Avoiding performing an episiotomy
- Avoiding deep suctioning of the airways of the neonate that could cause trauma of the mucosa
- Avoiding exposure of the neonate to maternal blood and amniotic fluid by rubbing the neonate dry immediately after birth and bathing it as soon as possible after birth (DENOSA Curations 2003:12).

In a large part of the world, programmes using ARVs for PMTCT have tended to focus only on the survival of children. This results in low uptake in PMTCT programmes. Programmes often are targeted at women only. Yet, interventions to reduce the risk of MTCT are not likely to succeed if they address women in isolation. Successful interventions must involve the entire community (Nyblade 2002: 4).

Fear of stigma and discrimination against people living with HIV and AIDS discourages some women from taking precautionary measures that can greatly reduce the risk of PMTCT such as choosing not to breastfeed (Nyblade 2002: 3).

It has been found that in order for PMTCT programmes to succeed, these programmes must be able to provide information, education, services and support to the significant others (i.e. families, community) in women's lives. Counselling and support should be available on a continuous basis, not just when the woman is first tested (Nyblade 2002: 4).

According to PMTCT Botswana (2002: 1), the lessons learned were as follows: -

Technical interventions, such as PMTCT on infant and young child feeding stand a much better chance of achieving their desired levels of impact and coverage if a variety of scientific and social considerations are taken into account simultaneously.

Involving all relevant partners from the start is essential. In Botswana, social services are coordinated at the district and community levels by the Ministry of Local Government, whereas technical staff supervision is under the Ministry of Health. It soon becomes apparent that working with the community members and structures was a missing element in bringing the two ministries together. Getting the best price/affordable price for infant formula will eventually allow the government to focus precious resources on strengthening capacities of individuals and institutions.

The community consultation prior to programme implementation ensured the full participation of community members on the programme. Establishment of an integrated district health system needs to be implemented in order to provide the necessary infra-structural framework. Without such basic infra-structural support and good referral systems, implementation of MTCT programmes will not be possible.

It is also crucial that appropriate monitoring and evaluation systems be established early in the programme. Provision of adequate counselling services is very important. Due to shortage of staff, Namibia is like Botswana in that they both use community counsellors, who had been through an intensive counselling course with appropriate exit examinations and accreditation processes.

Formula feeding is not the culturally accepted norm in the African community where breastfeeding is the preferred practice. Although women agree not to breastfeed in the counselling sessions this may cause them to be stigmatized within their communities. They may therefore return to the practice of breastfeeding. Outreach programmes and proper community consultations were instituted in order to overcome these difficulties in a support network with NGOs (PMTCT Botswana 2002:1).

For the mother, postnatal care helps preserve her own health and link her with health and social care and support services for herself and her family. Since many maternal deaths occur in the postpartum period, good postnatal care can help to ensure the survival of mothers, which is critical to the survival of their infants.

Regarding postnatal nutritional support, preliminary analysis of data from Kenya suggests that HIV positive women who breastfeed may be at greater risk of weight loss and postpartum mortality than HIV infected women who do not breastfeed. It strongly suggests that programmes to prevent MTCT should also provide nutrition and health support to HIV infected women during the postpartum period (Preble and Piwoz 2001: 22).

Social support as well as health care is also necessary for mothers and infants affected by HIV/AIDS. Many African children now live in communities where the AIDS epidemic has severely weakened the economic base and social fabric through illness, death and related losses in productivity. Some children have family members living with HIV/AIDS causing psychological stress and economic hardship. Others have already lost their mother and/or father to the disease making them orphans in an environment of linked social support. Even in settings where intensive PMTCT packages are introduced, and the total number of HIV infected children is reduced, there will still be HIV positive children born and orphans needing care and support, since none of the MTCT interventions are 100% effective (Preble and Piwoz 2001:23).

According to UNAIDS (2003: 6) there is potential for enhancing community aspects of PMTCT interventions through:

- The improvement of health professionals' attitudes
- Increased quality of voluntary counselling and testing
- On-site rapid HIV testing of mothers
- Use of other antiretroviral drugs (ARVS) during labour (e.g. nevirapine)
- Involvement of male partners
- Strengthened medical and psychosocial support services for mothers.

2.5 FOLLOW UP VISITS

The report on evaluation of PMTCT of the HIV initiative in South Africa (Doherty et al 2003: 26) reports the following findings:

The evaluation found fairly low uptake of infant HIV testing at 12 months across most provinces. A large proportion (50%) of the infants born to mothers who received nevirapine were not followed up and tested. The HIV status of these infants is therefore unknown and could potentially vary substantially from the result of infants that were followed up and tested. Therefore, it was not possible to draw a conclusion on the impact of the effectiveness of the programme from those data.

However, infant follow up rates have been achieved in provinces like Western Cape (78%) and KwaZulu-Natal (78%) possibly due to the extensive coverage of these provinces with PMTCT services which allowed easier follow up of infants at the clinic level. Another factor which improved follow-up of infants in the above provinces was the expansion plan which focused on geographical areas and facilities. This facilitates improved tracking of mothers and infants between delivery centres and feeder clinics (Doherty et al 2003: 27).

In the other seven provinces the follow up rates are low. This may be due to the fact that in many provinces, PMTCT services have not been extended to many feeder clinics as expansion has been focused primarily on hospitals. Mothers therefore have to return to the primary PMTCT site, usually a hospital, in order for the infants to be tested for HIV (Doherty et al 2003: 27).

Reasons for low rate of follow-up visits include:

- Inadequacies in the routine monitoring system
- Poor referral networks between hospitals and clinics
- Limited numbers of clinics offering PMTCT

- Tracking/coding systems using patient held records not implemented or ineffective
- Mothers' reluctant to disclose their HIV status to health workers (Doherty et al 2003: 27).

The high loss of follow-up visits means that of those infants born to HIV positive women involved in the PMTCT programme, the majority will have their HIV infection status determined for the first time when they present with the HIV disease, and therefore they are not receiving the routine medical care recommended for HIV infected children (e.g. prophylactic co-trimoxazole under 12 months). They also do not access other medical interventions that might benefit their health such as nutrition support and multivitamins in the case of growth faltering.

In order to determine transmission rates in infants receiving care through the PMTCT programme and to facilitate improved clinical management of infants born to HIV positive women, either the follow-up of infants up to 12 months needs to be drastically improved, or an alternative method of determining infants' HIV status needs to be adopted.

According to Doherty et al (2003: 29) in South Africa the HIV ELISA test is done at 12 months and repeated at 15 months in the event of a positive result. It has been found that delays in testing in order to make a reasonably accurate diagnosis in infants have the following repercussions:

- Unacceptable rates of loss of follow-up
- Inability to adequately evaluate the effectiveness of the PMTCT programme
- Inability to provide appropriate clinical and social support to families
- Immeasurable emotional costs to families waiting for the HIV status of an infant
- Direct and indirect costs of providing co-trimoxazole to HIV negative babies
- Large numbers of HIV negative babies treated as HIV positive for the first year of life.

Using earlier Nucleic Acid Testing has the following benefits:

- *Reduction in the loss to follow up*

Offering testing of infants at 6 weeks provides some incentive for mothers to adhere to this follow up visit schedule, and they may be more willing to disclose their status in order for their infants to be tested. Women who learn that their infants are positive at this early stage may be more motivated to return for frequent clinic visits in order to maintain the health of their infants and the benefit from ongoing care.

- *Improved monitoring of the effectiveness of the PMTCT programme*

Earlier testing of infants enables the national department of health to have more accurate records of HIV transmission rates in which to evaluate programme effectiveness. This is an important monitoring tool as unacceptably high vertical transmission rates may be due to problems in other aspects of the programme such as poor uptake of nevirapine, inappropriate obstetric practices or poor infant feeding counselling.

- *Reducing the numbers of children requiring long term follow up*

The HIV status of infants could be tested at a 6 week visit and HIV uninfected children discharged from specific HIV follow up as early as 10 -14 weeks of age with certain provisos. Only HIV infected children (about 10% of the total HIV exposed non breastfed children) would require specific further follow up and prophylaxis for opportunistic infection.

- *Reduction in mother/family anxiety*

Earlier infant diagnosis relieves the majority of HIV positive mothers of the emotional burden of having infected their children. The emotional and human value of this is beyond measure.

- *Informed formula feeding choice*

Earlier knowledge of the HIV status may enable mothers to make a more informed decision regarding feeding choice. Mothers who have been breastfeeding may want to change to formula milk if they know that their infants are negative or women opting for formula may want to consider relactation in the event that the infant is HIV positive. This would still need to occur within the context of adequate infant feeding counselling and an assistance of the individual home circumstances.

- *Reduction in cost of and use of co-trimoxazole*

All infants born to HIV positive mothers are given co-trimoxazole from the age of 6 weeks until 12 months. Since the majority of these infants do not require this, some saving and a reduction in side effects experienced from the drug can be achieved.

- *Earlier entry into infant HIV management protocols*

Holistic medical management of an HIV infected child requires that the child's HIV infection status be established as early as possible. Prevention of opportunistic infections, treatment of intercurrent infections and emotional support for the child and family, derived from counselling and peer group, improve the child's quality of life (Doherty et al 2003: 30).

Women diagnosed with HIV infection during pregnancy need education, counselling and support. Education improves adherence to Antiretroviral treatment regimens and feeding

practices. Counselling and support improves quality of life. Most women when diagnosed with HIV during pregnancy are unable or unwilling to tell partner, family or friends, resulting in emotional isolation. In Cape Town, South Africa in the publicly funded PMTCT programmes, education and counselling is limited to before and after HIV testing. Programmes lack capacity to provide on-going education and support (Besser 2002: 1).

Mother-to-mother-to-be (m2m2b) is a mentorship program for HIV infected pregnant women. Recently delivered HIV infected mothers return to the antenatal clinic as mentors to educate, counsel and support HIV infected pregnant women. At the clinic, mentor-mothers share personal experiences and encourage adherence to treatment plans for pregnant women. Knowledgeable pregnant women and mothers are empowered in their respective families and communities. Empowerment contributes to destigmatization of HIV infection and community health. Mothers will need counselling support for social and psychological support, and infants born to HIV positive mothers require adequate follow-up. Proper care practices have to be ensured at the household level, including sufficient dietary intake, hygiene and bonding. Infants fed by breast milk substitutes are likely to display a relatively larger number of infections which require health care. Regular follow up can be conducted during routine visits for growth monitoring and immunization (WHO 1999:21).

A comprehensive network of health centre and community volunteers ensures outreach activities, active tracking and home visits. In other countries such a system is being built gradually. Most of these strategies are essential to ensure compliance and follow-up for prevention of mother to child transmission of HIV (WHO 1999: 21-22).

The challenges to provide follow up care are numerous and include:

- Difficulties identifying HIV positive women and their infants at clinics due to inadequate tracking mechanisms
- Many women opting not to disclose their status to clinic staff

- Poor access to health facilities due to long distances and a lack of affordable transport

2.6 INFANT FEEDING OPTIONS

The objective of health services should be to prevent HIV transmission through breastfeeding and optimize nutrition for the HIV exposed newborn while continuing to protect, promote and support breastfeeding as the best choice of infant feeding for women who are HIV negative and women who do not know their HIV status. Meeting this objective requires:

- Organizing counselling services
- Providing infant feeding counselling for all pregnant women during Antenatal care and mothers' post partum
- Facilitating access to replacement feeding where appropriate
- Preventing any “spill over” effect of replacement feeding to those who are HIV negative and of unknown status
- Providing appropriate follow-up care and support for HIV positive women and their children, particularly up to the age 2 years

According to MOHSS (2004: 28-30), the following are the feeding recommendations for HIV-positive women:

- **Exclusive breastfeeding from birth to four months and abrupt stopping**

An HIV positive mother may choose to breastfeed her baby if she considers it to be the best way of feeding. Exclusive breastfeeding provides the best infant nutrition for growth and development. Giving the baby any drinks, water or foods other than breast milk and use of pacifiers or dummies or artificial teats interferes with exclusive breastfeeding. In addition, it may cause gut infection and irritation that will make the baby more susceptible to HIV transmission.

- **Replacement feeding (infant formula, cow and goat milk)**

Replacement feeding can be an option of choice provided it is acceptable, affordable, sustainable, feasible and safe. The risk of replacement feeding should be less than the potential risk of HIV transmission through infected breast milk, so that infant illness and death from other causes do not increase. Commercial infant formula is already modified but cow and goat milk for the first 6 months needs to be modified. The baby on exclusive replacement feeding needs water. In order to achieve exclusive replacement feeding the mothers should be taught:

- The dangers of mixed feeding
- How to prepare infant formula
- How to correctly and safely modify cow or goat milk

2.7 SOCIO ECONOMIC STATUS

Poverty and unemployment are the major contributions to the spread of HIV. Young people especially females, have the highest unemployment rates (National Planning Commission 2001: 41). Most women depend on their male partners for financial support; therefore it is difficult for them to negotiate safe sex. Unemployment leads to prostitution in order to generate income, but at the same time women risk being infected with HIV due to multiple sexual partners without using condoms.

2.8 HIV STATUS PRIOR TO LAST DELIVERY

According to the 2004/05 statistics (MOHSS 2005: 12) the HIV status of 72% of women who delivered during that period is unknown. The success of the PMTCT programme lies in pregnant women knowing their HIV status. HIV related stigma and discrimination are major barriers to voluntary counselling and testing, and pregnant women typically resist being tested for fear that, if they were found to have HIV, they will be subject to stigma and discrimination. If HIV/AIDS is destigmatized and women are confident that they will

not be discriminated against if they are known to be HIV-positive, they might be more likely to seek out treatment and take preventative measures to avoid passing the disease on to their children, and also to take measures to enhance the quality of their own lives (Nyblade 2002: 5).

2.9 AGE GROUPS

Adults and children estimated to be living with HIV/AIDS as of the end 2004 are 29,4 million. 2,5 million people with HIV/AIDS were children younger than 15 years old (MOHSS May 2005: 2-4). About 6000 of the new infections that occurred each day were among persons 15 to 24 years old, while almost 2000 each day were children younger than 15 years old. Most of the infections in children younger than 15 years old occurred through mother-to child transmission of HIV (MOHSS May 2005: 2-5).

The age group specific HIV prevalence in pregnant women is as follows in 2004 in Namibia:

9.9% in the age group 13-19 years

18.7% in the age group 20-24 years

25.9% in the age group 25-29 years

23.3% in the age group 30-34 years

24.1% in the age group 35-39 years

10.9% in the age group 40-44 years

13.0% in the age group 45 years and over (MOHSS 2004: 54).

2.10 HIV STATUS OF PARTNER

The partner testing was very low during the period April 2004-2005 in Namibia i.e. 11%. The majority of partners are reluctant to come to counselling and testing for one reason or another. These men do not know their HIV status; consequently they are at risk of getting infected or re-infecting their partners. All the partners need to know their HIV status in

order to protect their wives/partners from re-infecting them. According to MOHSS (2005: 16) about 56% of the partners tested HIV negative while 29% tested HIV positive during 2004/05; these were the partners of HIV positive pregnant women who were 2679 that year, 2004/05. This shows clearly that discordant couples are quite common. The term “discordant couples” means one partner is HIV positive while the other one is HIV negative. Couple counselling is not yet done routinely in Namibia, but in view of the above findings it needs to be promoted.

2.11 SUMMARY

The literature study gave an overview of factors that can influence the follow up visits by mothers registered in PMTCT of HIV programmes. Transmission of HIV from mother to child, routine counselling and voluntary testing, PMTCT interventions during pregnancy, delivery and postpartum, as well as benefits and effects of follow up visits were discussed. The research design and methodology is presented in the next chapter.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Research methodology is concerned with the researcher's ultimate goals and the general plan for achieving these goals. Research methodology includes the planning, structuring and execution of research with the emphasis on the actual research process (Uys and Basson 1991: 8).

The fundamental purpose of this study was to explore and describe the factors that influence the follow-up visits by mothers registered with the Prevention of Mother to Child Transmission (PMTCT) in Katutura State Hospital after their respective deliveries. The specific objectives of this study are:

- To determine the profile of mothers who join the PMTCT programme
- To determine the factors that motivate or demotivate the mothers to stick to or drop out of the programme
- To assess the follow up modalities and support networks available to mothers in their communities
- To make appropriate recommendations

The aim of this chapter is to describe the research methodology that was applied to find answers to the research question which is: *What are the factors that influence the follow-up visits by mothers registered for PMTCT at KSH?*

3.2 RESEARCH DESIGN

Both quantitative and qualitative research designs were applied in this study. Descriptive exploratory research methods were used to obtain data by means of interviews using both an unstructured and a structured questionnaire. In this study, the factors influencing

follow-up visits by mothers registered in the PMTCT programme are explored and described.

Descriptive research presents a complete picture of the specific details of a situation, social settings, relationships and it focuses on the “how” and “why” questions (De Vos 2002: 109). The intention of the researcher was to obtain accurate information from the HIV positive mothers registered in the PMTCT programme on factors that influence their follow-up visits either positively or negatively. The researcher wanted to describe the situation as it is concerning the follow-up visits.

Exploratory research is conducted in an attempt to gain insight into a particular area of problems (De Vos et al 2002:109). This study is also exploratory because it attempts to gain insight and understanding on the profile of mothers who join the PMTCT programme, modalities and support networks available to mothers and the factors that motivate or demotivate the mothers to stick to or drop out of the programme.

3.3 RESEARCH METHODS

For the purpose of this research, an approach of triangulation, that is a combination of quantitative and qualitative, was used. Triangulation is the process of supplementing and checking results of different research methods. Some sociologists think that it is best to use a combination of different research methods to get a clearer picture of what is going on in society. Combining two methods can also lead to enhancement of the validity of the study findings (Brink 1996:119).

Quantitative data are those kinds of information that are measured or analysed numerically and this usually involves computerisation of statistical measures and tests of significance. Quantitative research allows for easy comparisons and reproduction of the results (Brink 1996:120).

Qualitative research has to do with the value of information rather than numbers. Qualitative research allows for an in-depth data collection from a small number of informants (Brink 1996:120). In conjunction with structured interviews, non-structured interviews were also conducted in this study with two mothers who did not come for follow-up visits.

3.4 STUDY POPULATION

Study population includes all the members or units of a clearly defined group (with distinguishing criteria) of people, objects or events (Uys and Basson 1991:86). The population for this study is all the women who registered in the PMTCT programme at Katutura State Hospital Antenatal Clinic, between March 2002 and December 2003 , with a total of 660 (MOHSS 2004:4). From these women, only those HIV positive women who delivered at hospital and had children of nine months old or more were considered, because they are in a better position to give information on follow up visits.

3.4.1 Inclusion:

The mothers who are included in the study are those who are living in the Windhoek area. These are HIV positive mothers who delivered in the hospital. These mothers were interviewed at the POPD and ANC when they came for their respective follow-ups. Mothers who were willing to participate were selected. Mothers who came back for their follow-ups and those who did not come back were included.

3.4.2 Exclusion:

This study excluded those mothers who are registered at other sites of pilot PMTCT programmes such as Oshakati State Hospital (where a similar pilot programme is also conducted). Those who live outside Windhoek area were also excluded and those who are HIV negative.

3.5 SAMPLING

A sample is a small portion of the total set of population, which together form the subjects of the study (De Vos 2002:199). In a study a sample is selected because it is not feasible in terms of resources, time and finances to study the whole population. Therefore time and effort are concentrated on a small group in order to produce better results (De Vos 2002: 199).

The target population was 660 ie. all the mothers who registered with PMTCT programme at KSH. In this study, the sample consisted of 30 respondents of which 28 respondents are mothers who brought their children for follow-up visits, while 2 respondents are mothers who did not bring their children for follow-up visits after their respective deliveries at the hospital. All these mothers have registered at the Katutura PMTCT programme of HIV and stay in the Windhoek area. Only 30 mothers interviewed because of limiting factors such as time and follow –up procedures used in the hospital which made it difficult to access research subjects.

The sample was conveniently selected because the issues to be studied concerning factors influencing follow-up visits is better known by those who have delivered already and have attended four times or more follow-ups and by those who drop out or never come back for follow-ups at all. Convenience sampling is used where the sample is drawn from the section of the population that is easily accessible. The emphasis in this kind of sampling is on the convenience of the researcher, and not all elements of the population are given an equal chance of being included in the sample (Uys and Basson 1991: 93). Non-probability sampling was used because the researcher has to rely on mothers who come for follow-ups and are willing to provide information to the researcher.

Steps followed were first, identifying the target population that was accessible to the researcher. The researcher visited the Paediatric Outpatient Department (POPD) where the mothers take their children for follow-up visits. The researcher chose the mothers who have children of nine months or older and had attended the follow-up four times or

more. Some mothers were found at the Antenatal Clinic, those who came to report if the baby became HIV negative. The researcher interviewed 28 mothers using a questionnaire with open and closed ended questions.

Two mothers who did not come for follow-up or drop out were interviewed by means of non-structured interviews. The researcher is working as an HIV counsellor and is involved in the PMTCT of the HIV programme at the Antenatal Clinic, Katutura, and is familiar with those who did not turn up, because their files are kept there.

The researcher contacted them by phone and visited the paediatric unit and ARV clinic to see if she could find others. In this study two mothers who did not turn up for their regular follow-ups were interviewed with their permission to take part in the study. One mother was found at the Paediatric Ward when her baby was admitted, while the other was found at the ANC where she came to book for ANC because she was pregnant again.

3.6 DATA COLLECTION

Data was collected in the Antenatal Clinic and Paediatric Outpatient Department at Katutura Hospital, where the mothers used to bring their children for follow-ups. The researcher was the primary data collector. A structured interview with open and closed-ended questions was used. The data collection started in March to May 2005.

Interviews were done for the following reasons:

- To clarify questions
- To produce additional information through observation of non-verbal behaviours

In addition to structured interviews, non-structured interviews were conducted. Non-structured interviews were done for the participants who did not turn up for their regular follow-up visits. They were done with two participants, but every one was interviewed individually. In non-structured interviews, there is usually only the researcher and one informant. The researcher has questions to guide the informant (LeBeau 1998: 69).

The non-structured interviews were done for the following reasons:

- The participant is allowed more freedom in answering
- The researcher can collect in-depth information

Information was gathered on whether Nevirapine was given to the baby, starting with Prophylaxis treatment, and whether an HIV test was done and the results.

3.7 PILOT STUDY

A pilot study was done with two mothers who came for follow-ups visits. A pilot study is a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate (Bless and Higson Smith 2000: 155).

No problems were encountered during the pilot study, mothers could answer all the questions as expected. These two mothers were then excluded from the study.

3.8 DATA ANALYSIS

In this study, tables, percentages and graphs have been used. The tables, percentages and graphs are a way of presenting the findings of the study. Analysis and interpretation of data was completed with the assistance of Microsoft Excel 2003 Software.

3.9 ETHICAL ISSUES

The researcher has a responsibility to provide benefits to people in general and to stay within the law. The ethics followed in the study are discussed below.

3.9.1 Permission

In this study permission was obtained from individual respondents/ participants as well as from the UNAM Post graduate Studies Committee, where the proposal was reviewed by the Committee to ensure the proposal adheres to the standards of scientific research.

3.9.2 Right of privacy and voluntary participation

Participation in this research was voluntary. Direct consent for participation was obtained from mothers involved. This consent is informed in the sense that the participants were made aware of their participation. Privacy was also ensured by getting consent from participants and by explaining positive and negative aspects. Co-operation was negotiated. The participants were free to withdraw from the study at anytime if they felt that they could not carry on participating in the study, and the researcher has respected such rights.

Participants were assured that they would not be put under pressure to divulge information they would not like to disclose or which they would feel uncomfortable talking about to the researcher.

3.9.3 Anonymity

Anonymity is where someone does or says something, but no one knows the identity of who said or did it (Le Beau 1998: 33). Participants were convinced that anonymity would be respected. Anonymity was maintained, as no names were used except code, and the participants were assured of this. The researcher also ensured that anonymity of everyone was protected in the report by ensuring that it is not possible to relate particular data to a particular person.

3.9.4 Confidentiality

Confidentiality is when someone tells you something and you do not tell others what that person has said (Le Beau 1998: 33). The participants have been assured that the information given will be treated with confidentiality. They were assured that data would only be used for the stated purpose of the research, and that no other person would have access to interview data. The researcher protects the participants by respecting their cultural beliefs.

3.9.5 Benefits

The benefits of the research have been explained to the participants. This allows the respondents to feel free to give honest and complete information. They were informed that the research findings would be used to understand the behaviour of clients of the PMTCT and to improve the existing programme by providing its database.

3.10 RELIABILITY, VALIDITY AND TRUSTWORTHINESS OF THE DATA

Reliability can be defined as the accuracy or precision of an instrument. In general, reliability refers to the extent to which independent administration of the same instrument (or highly similar instrument) consistently yields the same results under comparable conditions (De vos 2002:168). Reliability increases when the researcher is familiar with the research environment. In this case, the researcher was familiar with the research environment.

According to De Vos (2002) validity refers to the degree to which an instrument is measuring what it is intend to measure. There are different types of validity such as: content validity, face validity, criterion validity and construct validity.

Content validity is concerned with sampling adequacy of the content of an instrument, while face validity refers to whether the instrument appears to measure the relevant

construct. In order to increase face validity and content validity the instrument was presented to two study supervisors who are experts in the field of research and nursing for evaluation and validation. The researcher collected data herself to ensure validity.

The pilot study that was conducted is another way of ensuring the validity and reliability of the data of this study. The results from the qualitative interview were integrated in the existing framework (Iiping et.al 2004:28-29). The interview transcripts were co-coded by the supervisor who is an expert in qualitative research. The researcher has stayed long in the field for data collection and is working in the post-natal clinic where she observed the trends of mothers who comes for follow-ups.

3.11 SUMMARY

In this chapter, the research methodology was discussed in depth. It was indicated that triangulation was the most appropriate approach. Study population, sampling, data collection methods, reliability and validity were described. Ethical issues that were adhered to by the researcher were also indicated.

CHAPTER 4: FINDINGS AND DISCUSSION OF RESEARCH FINDINGS

4.1 INTRODUCTION

This chapter focuses on the findings and analysis of data obtained from interviews.

The study sample consists of twenty-eight mothers who came for their follow up at Katutura State Hospital and two mothers who did not come for their regular follow-ups. Section A is about structured interviews, while Section B is about non-structured interviews.

4.2 SECTION A: STRUCTURED INTERVIEW

4.2.1 Biographical information

The information to be discussed is: sex, nationality, age, region of origin, residential address, home language, employment status, marital status, and religion and education level of the participants.

4.2.1.1 Sex and nationality

All respondents were women. This is so because the study population which was focused on was women. All the respondents were Namibian; no non-Namibian was involved. However, this does not imply that non-Namibians are refused enrolment in the programme. Health care services are open to all people in Namibia's public health facilities.

4.2.1.2 Age

The majority of the respondents (46,4%) are between the ages of 30-39, followed by the age group of 20-29 (12 respondents) which makes up 42,9%. In the age group of 40 years and above only 3 respondents (or 10,9%) took part. There was no respondent under 20 years which correlates with the finding of the report on the HIV Sentinel Survey of 2004

which reported that HIV prevalence is lowest in those woman less than 20 years of age (MOHSS 2004: 6). It also shows that the most affected age group by HIV in Namibia is those in the age bracket of 20-39 years. This finding is displayed in Table 4. 1.

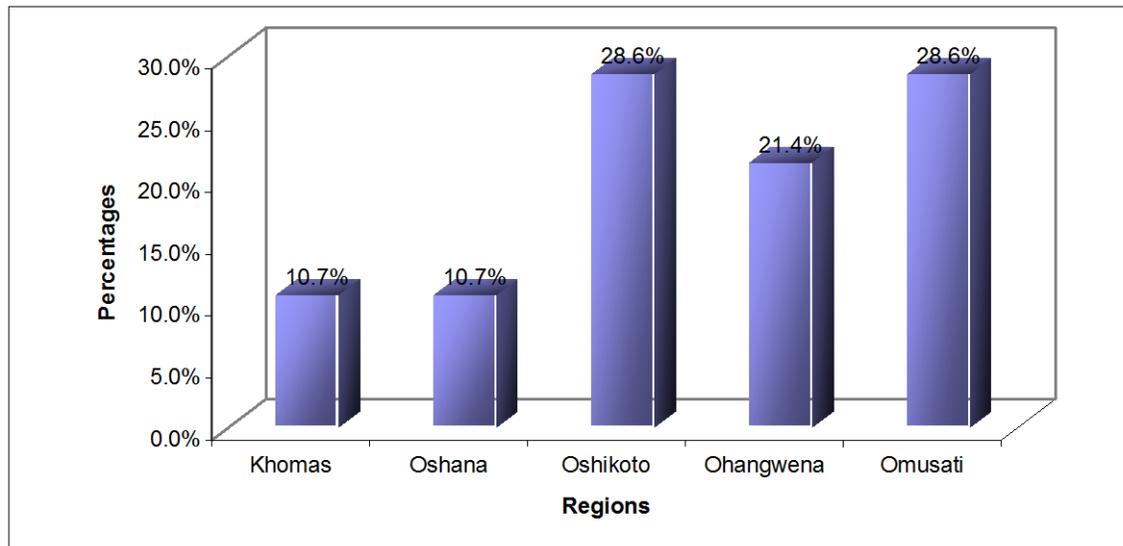
Table 4. 1: Age of Participants

Age groups	Frequency	Percentage (%)
Under 20	0	0
20 – 29	12	42.9
30 – 39	13	46.4
40 – 49	3	10.9
50 and above	0	0

4.2.1.3 Region of Origin

It is shown in this study that most respondents come from Omusati and Oshikoto Regions, both representing 28,6%, followed by Ohangwena Region with 21,4% and lastly Oshana and Khomas Regions with 10,7% respectively as shown in Figure 4. 1 below. It is clear that women with HIV attending and enrolled in the PMTCT programme are mostly from outside Khomas where the study was done. Possibly they are here for employment or have moved to Khomas where they are not known and cannot be stigmatized by their own community.

Figure 4. 1: Region of Origin



4.2.1.4 Residential Address

Most of the respondents (46,4%) were from the informal settlements around Windhoek, 39,4% from Katutura , while Khomasdal and City each have 7,1 %. Low income groups live in Katutura and informal settlements and usually use State Hospital facilities, unlike people from Khomasdal and other city suburbs who normally use private medical practitioners.

4.2.1.5 Home Language

Out of 28 respondents 96.4% are Oshiwambo speaking while 3.6% speak Afrikaans. Oshiwambo speaking people represent more than 60% of the Namibian population. (Census 2001: 47).

4.2.1.6 Employment Status

The majority of respondents are not employed i.e. 53,5%, while 42,9% are employed and only 3,6% are self employed. Unemployment poses a problem to follow-up visits because

an unemployed person cannot afford to pay transport monthly to hospital and buy formula milk. Unemployment causes dependency of these mothers on their partners for support. However it is comforting to note that 42,9% are employed and could possibly depend on themselves economically.

4.2.1.7 Monthly Salary of Respondents and their Partners

Twenty five (89,3%) of the respondents' partners are working and 10,7% are not working. More than half of the respondents i.e. 53,6% do not know their partners' salaries. This shows that there is little communication between partners on income matters. Lack of communication can cause the tendency of not negotiating safe sex and also not disclosing the HIV status to the partner for fear of being deserted. Women who are unemployed and oppressed by their partners are likely to be in a relationship which lacks communication (Iipinga et al 2004: 7).

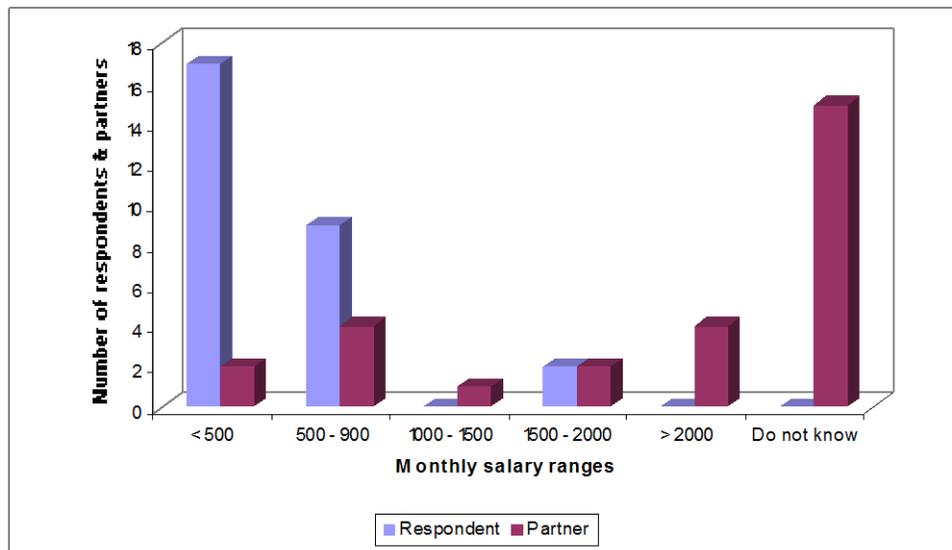
Table 4. 2: Monthly Salaries of Respondents and of their Partners

Range in N\$	Respondents' salary (%)	Partners' salary (%)
<500	7.1	0.0
500-900	32.1	14.3
1000-1500	0.0	3.6
1600-2000	7.1	7.1
>2000	0.0	14.3
Do not know	N/A	53.6

N = 28

Five respondents (32.1%) indicated that their monthly salary varied between N\$ 500 and N\$ 900, while 7.1% of respondents' monthly salaries are less than N\$ 500 and 7.1% of respondents' monthly salaries ranged from N\$ 1600 to N\$ 2000. Most of the respondents fall in the low-income group. This finding confirms the assumption that HIV is mostly among the poor and the less educated (Iipinga et.al2004:8). The monthly salary they are getting is not enough to cater for all the necessities of somebody who stays in the city. These mothers have to turn again to their partners for further support.

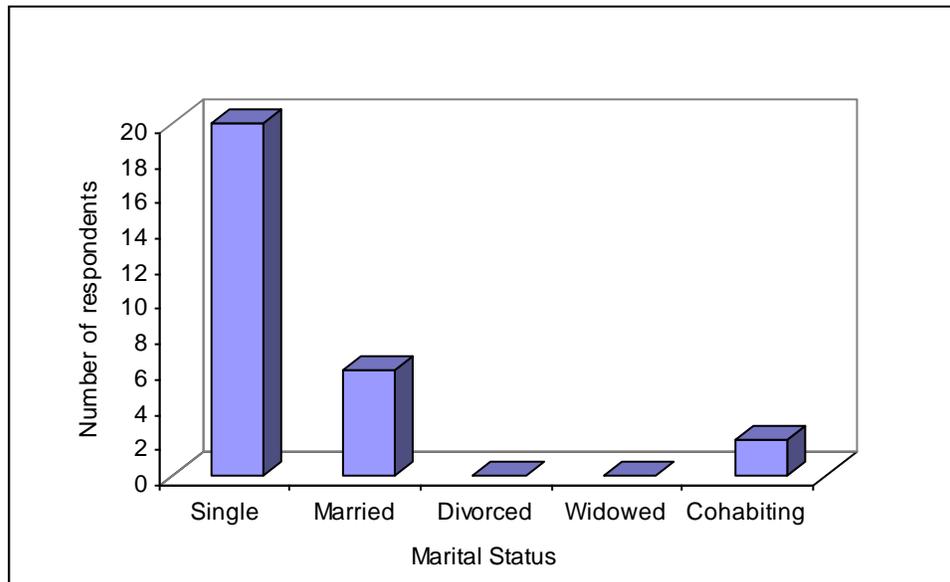
Figure 4. 2: Monthly salary of respondents and their partner



4.2.1.8 Marital Status

In this study the majority of the respondents are unmarried i.e. 78.6 %, while married respondents are 21.4%. Most of the respondents are living together with their partners i.e. 57,1%, while 42.9% are not staying with their partners. Even though most respondents are unmarried, the fact that they stay together with their partners means that they are getting also moral and financial support from their partners. In the literature review it has been found that in order for PMTCT programmes to succeed, these programmes must be able to provide information to the significant others (i.e. partners) in women’s lives (Nyblade 2002: 4).

Figure 4. 3: Marital status



Marital status is seen as an important factor; therefore if there is more than one parent in a household, you can rely on two persons for knowledge and attitudes about anything. One can expect that married women have more moral and financial support from their partners; therefore the possibility of bringing the child for follow-up visits is higher. Also the unmarried women who have supportive partners and those with high self-esteem have a tendency to come for follow up.

4.2.1.9 Religion

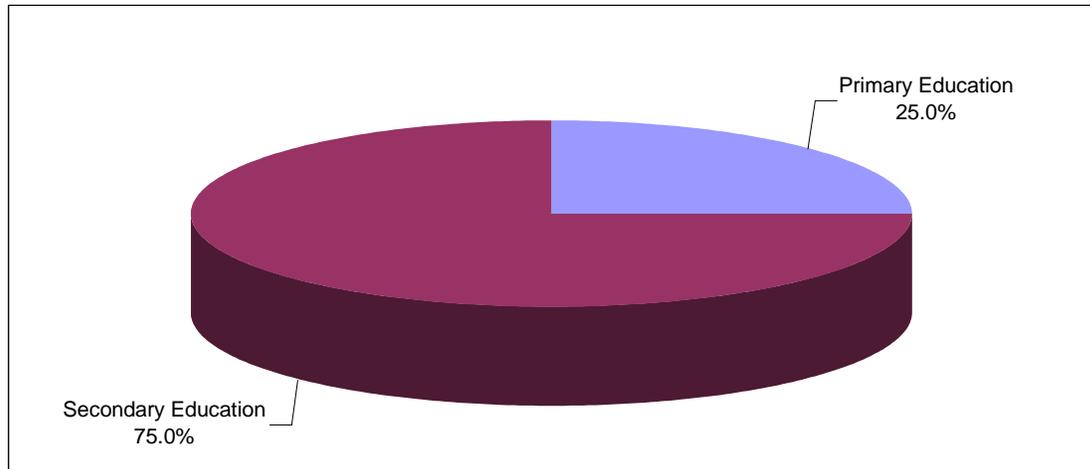
Out of the 28 subjects, 22 (78.6%) respondents are Lutheran, 7.1% respondents are Roman Catholic, while the other 14.3% respondents are Anglican.

4.2.1.10 Education

It was revealed in this study that all the respondents i.e. 28 (100%) have attended school and can read and write. Over half of the respondents, 21 (75%) had secondary level education, while 7 (25%) respondents had primary education. No respondents have ever

attended tertiary education. This educational background is a good sign that they can access treatment information from literature available in their own language and otherwise. However, literature states that being educated does not necessarily translate into behavioural change (Iipinge et al 2004: 35).

Figure 4. 4: Level of Education



The literacy rate in Namibia is 81% for persons of 15 years old and above (Census 2001: 3). The higher the literacy rate, the easier to disseminate health information on HIV/AIDS, PMTCT and follow-up visits using booklets and audio-visual material. In our culture from early on, young men grow up in a world where they are taught to dominate decision-making in their households. Young women are expected to rear children and perform domestic work, even though they are educated. All this makes it difficult for women and men to communicate, so different are their respective worlds (Iipinge et al 2004: 25). Therefore, there is a need to empower women so that they can take a role in decision making.

4.2.2 Awareness of own HIV status

Most of the respondents happen to know that they were HIV positive during the last pregnancy i.e. 85,7%, while 10,7% knew it before their last pregnancy and the other 3,6% came to know their HIV status only after delivery.

The respondents were asked why they went for HIV testing and in Table 4. 3 such reasons are presented.

Table 4. 3: Reasons for HIV Tests

The reasons given for why one decides to be tested for HIV	Frequency
Feeling tired and weak and feel sick	2
To know her HIV status	14
It was routine, she is tested regularly	1
In order to protect the baby in case the result is positive	8
Due to the partner's behaviour, which is suspicious	1
The last child has had blood drawn and was found HIV positive	1
When she heard about PMTCT	1
Partner having an affair somewhere	1

This findings show that often women are tested in order to know their HIV status, which is a good attitude. Knowledge of one's own HIV status can be a motivating factor for HIV-positive and negative people alike to adopt safer sexual behaviour, which enables positive people to prevent their sexual partners from getting infected, and those who tested HIV negative to remain negative (MOHSS 2004: 11).

For pregnant women to make informed decisions about reducing their risks of transmitting HIV to their infants, they must know their HIV status (Doherty et al 2003: 17). This study supports the theory that pregnant women decide to be tested for HIV in order to protect the baby. Once the result is positive, these women have hope through PMTCT interventions. Worldwide, the most successful intervention in the HIV epidemic is the prevention of mother to child transmission. PMTCT includes routine counselling and testing, ARV to mother and baby, modified obstetrical practices and safer infant feeding options (MOHSS May 2005: 44; WHO 2004: 5).

Most women in Africa have no definitive way to know their HIV status until they themselves fall ill with identifiable symptoms of AIDS or until they give birth to a baby who is diagnosed with HIV/AIDS (Preble and Piwoz 2001: 8). This information concurs with the results that some women get tested because they feel sick, weak and tired and or their last children were diagnosed as HIV positive.

Distrust of partner and multiple partners also plays a role in the decision to be tested. This concurs with the results of a study done by LeBeau in Namibia in 2002, which indicates that men are more likely to have multiple partners than women. Even when females knew that their husbands had other partners, they did not tend to ask them to use a condom because they feared violence at the hands of their partners. More important however, they feared losing a partner who often was the sole source of financial support (Ipinge et al 2004: 12; LeBeau 2002: 45).

4.2.3 Disclosure of HIV Status to Partner

Most of the respondents, which is 71.4%, informed their partners about their HIV status. Only 28.6% did not inform their partners about their HIV status. There is a high percentage (71,4%) of women who disclosed their HIV results to the partners. This is a good practice because when both partners are aware of each other's status, the negotiation of safer behaviours may be easier and more collaborative (MOHSS October 2004: 132).

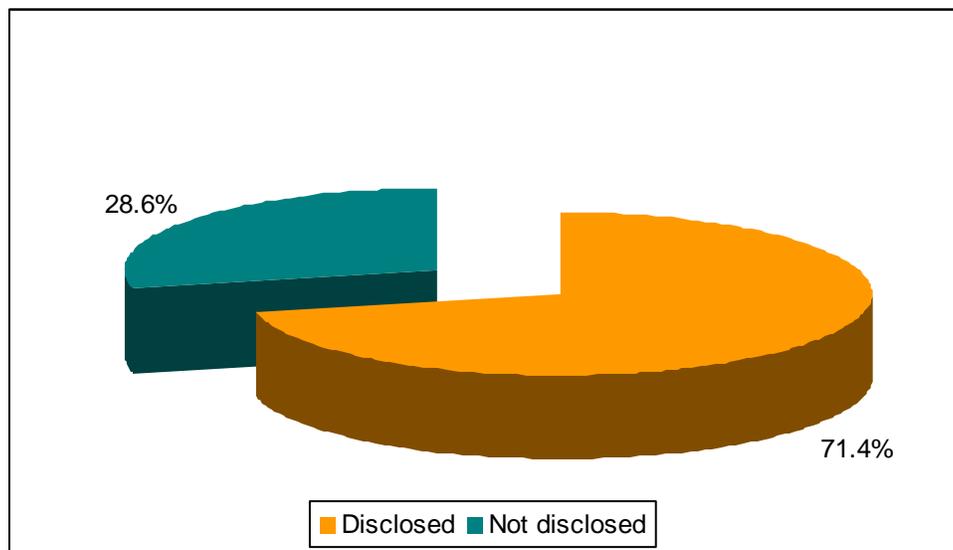
For pregnant women known to be infected with HIV, the avoidance of re-infection during pregnancy and lactation is important to lower the risk of MTCT. This can only be achieved if the partners are involved in preventive interventions, particularly VCT and infant feeding options (Doherty et al 2003: 21)

There are 28,6% who did not inform their partners about the HIV positive status. This is common in many countries. According to literature, only a few pregnant women disclose their status to the partners (Ipinge et al 2004: 20). This reflects inadequate attention paid

to empowering the client to disclose their HIV positive status, a lack of effort or capacity to provide complete counselling and testing as well as the degree of stigma, ignorance and prejudice in the community.

According to the study done in the Western Cape women felt that they did not disclose because it would result in serious social and domestic consequences (Doherty et al 2003: 21). This information correlates with the results as reasons given above.

Figure 4. 5: Disclosure of HIV Status to Partner



4.2.4 Male partner's reaction when informed about the HIV status of female partner

Most of the partners' reactions when informed about the HIV status of their female partners were acceptance. They did accept it, although, there are some who denied it when informed, i.e.10% were angry when informed about the HIV status of their partners.

Reasons given by those who did not disclose their status are:

- ❖ Scared of partner's reaction such as physical abuse, blame and committing suicide

- ❖ During their discussion about HIV, the partner not ready for test
- ❖ Boyfriend may abandon her when he finds out she is pregnant
- ❖ Dependency because their partner is the breadwinner
- ❖ Married women afraid of being divorced when they reveal their HIV status

Doherty et al (2003: 21) and Iipinge et al (2004: 20) confirm such findings in their studies, i.e. that disclosure may result in domestic violence and other social evils.

4.2.5 Partner's awareness of own HIV status

53.6 % of the respondents think that their partners know their own HIV status while 35,7% think that their partners do not know their HIV status. The other 10,7 % did not know whether their partners knew their HIV status or not. These results show that some women talk about HIV with their partners, which is a good indication in order to protect each other by safer sex and to live positively. However there are still partners who do not talk about HIV and AIDS issues at home and in their relationships, and this is one of the contributing factors to increase HIV in our country. Although Namibians know basic factors about HIV/ AIDS, people do not go for HIV tests before getting involved in sexual intercourse (Iipinge et al 2004: 68).

4.2.6 Disclosure of HIV status to other people

When respondents were asked if they have informed any other person about their HIV status, it came out that only 55.5 % of the respondents have told their family members about their HIV status; 11.1% told their friends, 5.5% told other people such as a Deacon at church, while 27.7% did not tell anybody about their HIV status. The 27.7% who did not tell others is still a significant proportion of those who live with the virus in isolation.

The reasons given for not telling anyone about their HIV status:

- Some respondents said that “Someone whom I trust is not staying in Windhoek”.
- 64% of the respondents express that “There is nobody I trust to keep my secret”.

- A few respondents are worried and afraid to tell their story, but are thinking of whom to tell in their families in future.

The stigma and discrimination against people with HIV/AIDS are still high in Namibia. The literature reports on family members who were rejected by their families after they revealed their HIV status to their families or the public (MOHSS 2004: i).

4.2.7 Gravidity of the respondents

Over half of the respondents, i.e. 60.7%, are between Gravida 2-3, while 14.3% are Gravida 1, 17.9% are Gravida 6 and above, and the other 7.1% are between Gravida 4-5 as given in Table 4. 4.

Table 4. 4: Pregnancies of Respondents

Gravidity of mothers	Percentage (%)	Frequency
Gravida 1	14.3	4
Gravida 2-3	60.7	17
Gravida 4-5	7.1	2
Gravida 6 and above	17.9	5

N = 28

Table 4. 5: Living Children of Respondents

Living children	Number of respondents	Percentage (%)
1 child	4	14.3
2-3 children	18	64.3
4-5 children	1	3.6
6 or more children	5	17.9

N = 28

All of the respondents said their last children are still alive. Those women who are most affected are those at the beginning of their reproductive age. Most of them, 64,3% have 2-3 children already.

4.2.8 Counselling

In this study it is shown that 92.9% of the respondents were pre-counselled before testing, and only 7.1% were not pre-counselled. It is disturbing to note that there are still people tested before taking the pre-test counselling.

The guidelines are clear that nobody should be tested for HIV without being pre-counselled. Most of the respondents, 92.9%, requested HIV pre-counselling themselves, while for 3.6% it was requested by the doctor, and for the other 3.6%, it was requested by a nurse. It is encouraging to see a big proportion of respondents getting VCT by themselves although there are still those who need encouragement to do so. This agrees with reports that the VCT uptake is increasing. Possibly the campaigns are effective (MOHSS 2005: 16).

The majority of respondents had been post-test counselled when they received their HIV results. Only 7.1% of the respondents were not post-test counselled. This post-test counselling session is very important in providing adequate information concerning being HIV positive. Therefore if it is not done, it may cause bad effects to the client such as self destructive (suicidal) behaviour, risk of infecting others and denying the disease and refusing to accept social responsibilities that go with being HIV positive (du Pisani & Otaala 2001: 44).

The counselling sessions helped most of the respondents i.e. 89.3%, while 10.7% expressed that they were not helped by the counselling sessions, either pre or post counselling. Those who were post-test counselled were helped to accept their HIV status and to be able to live a positive life, to share the experience with their partners and disclose to them. This correlates with the literature which revealed that during post-

counselling, the person should be informed about living positively, safer sex, reinfection, prevention and care, should disclose the results to someone and know about support groups available (MOHSS 2004: 14).

4.2.9 Antiretroviral drugs therapy for mother and child

Mothers were asked if they have received ARV or not. The study shows that 89.3% of the respondents received the Nevirapine 200mg tablet before delivery as per ARV guidelines (MOHSS 2003: 19). Only 10.7% did not receive Nevirapine, because of the negligence from the health workers, or the respondent came too late to the hospital so that there was no chance to give the mother the tablet. There is a need to improve on training nurses about PMTCT and to give more information on PMTCT to the clients. The proportion of the mothers who did not receive Nevirapine is significant and this should not happen at all. However, the health workers might have been negligent or they did not really know that mothers should receive Nevirapine. It seems that the health workers in the delivery ward are not aware of the PMTCT guidelines or they are totally ignorant about HIV transmission.

Respondents were asked the time they got their Nevirapine. Most of the respondents (75%) received Nevirapine more than or equal to 2 hours before delivery, while 14.3% received it less than 2 hours before delivery.

The respondents were also asked if they were already on HAART before they became pregnant. The majority of the respondents i.e. 85.7% were not on long-term therapy of HAART Drugs (High Active Antiretroviral Therapy) while only 14.3% were on HAART drugs. This is a sign that most mothers' CD4 counts are still above the cut-point for HAART as per Namibian ARV guidelines. According to Namibia ARV guidelines the HIV infected pregnant mothers with CD4 more than 250/mm³ and who are asymptomatic do need not to start ARV therapy. They will only be followed up routinely at ANC and CD4 counts repeated every six months. Pregnant women with CD4 less than 250/mm³ will receive ARV therapy monthly (MOHSS 2004: 22).

Those respondents who were on HAART drugs started before the delivery of their last child. None has started HAART after delivery. This shows understanding among clients regarding HIV and pregnancy.

All the children of the respondents received Nevirapine syrup at birth. This is a good sign; it shows that the nursing staff are conscious of the PMTCT programme. This is important in order to reduce the HIV transmission from mother to child (MOHSS 2002: 19).

82.1% of the children received Nevirapine in a single dose, while 17.9% received a double dose. This double dose is usually given in cases where the mother did not receive Nevirapine at all or she received it less than 2 hours before delivery. According to the literature a Nevirapine 2mg/Kg single dose is to be given to the newborn at 48-72 hours of age or at discharge; while a double dose is to be given to those mothers who did not receive it. Those newborns older than 72 hours of age should not be treated (MOHSS 2003: 19).

4.2.10 Age of babies of the respondents

Mothers were asked about the ages of their babies in order to ascertain if they are at the age of being tested for HIV. Only 28.6% were tested. The others are not yet at the age of being tested or were tested but results are still outstanding.

Table 4. 6: Age of the Babies of the Respondents at the Time of Interview

Age	No of babies	Percentage
9 months – 11 months	6	21.4
12 months – 18 months	14	50.0
More than 18 months	8	28.6

N = 28

All the babies have received their prophylaxis treatment as per schedule. This is an adherence to the ARV guidelines of the MOHSS which say that HIV exposed infants must be provided with Pneumocystis Carinii Preumonia (PCP) Prophylaxis every month, given vitamins and iron supplements until 2 years old, or continue the treatment if the HIV test is positive (MOHSS 2004: 34).

4.2.11 Feeding Options and reasons for the choice

In this section the researcher wanted to determine the types and reasons or the feeding options the mothers practice. The finding options are presented in Table 4. 7 below.

Table 4. 7: Feeding option and reason for choosing it

FEEDING OPTION	NUMBER OF RESPONDENTS	PERCENTAGE (%)	REASONS
Exclusive breastfeeding	6	21.4	<ul style="list-style-type: none"> ◇ Breastfeeding is cheaper. ◇ No money to buy formula milk. ◇ Advised by nursing staff. ◇ Cultural influence.
Exclusive formula feeding	12	42.9	<ul style="list-style-type: none"> ◇ It is safe because there is no virus in it. ◇ Do not want to increase the chance of baby being infected.

Mixed feeding	1	3.6	<ul style="list-style-type: none"> ◇ Advised by maternity staff.
Breastfeeding and formula feeding	9	32.1	<ul style="list-style-type: none"> ◇ These mothers give exclusive breastfeeding for 0-4 months and stop completely. Then they start on formula feeding and other food. ◇ It is safe and appropriate way.

This study shows that there are mothers who were breastfeeding and at the same time giving formula milk and food. This habit is wrong because it increases the chance of the child's being infected with the virus. (MOHSS 2004: 29). Wrong information has been given by the nursing staff. On the other hand, there are good results because mothers chose the best and appropriate method to feed their children. There is a link between unemployment, income status of the respondents and infant feeding options (Iiping et al 2004:25). Those mothers who are unemployed and those with low income are the ones who choose exclusive breastfeeding, while the other mothers who are employed and have good salaries prefer exclusive formula feeding.

There is a need for training of nurses to update them on the feeding options appropriate to HIV positive mothers so that they can give the right information to the clients. According to the literature, there is a risk involved in each feeding method chosen. Exclusive breastfeeding is not the norm in most cultures; family, friends and neighbours may pressure mothers to give water, other liquids, or foods to the baby. Feeding on demand, at least 8-10 times per day, may be difficult for women who work outside of the home. The infant continues to be exposed to HIV as long as the HIV-infected mother breastfeeds (MOHSS May 2005: 6-10).

Formula feeding is expensive and requires training and practice to prepare the milk formula correctly. There is the risk of diarrhoea or other infections if it is prepared incorrectly. The baby may be at risk for respiratory infections and allergies (MOHSS May 2005: 6-11).

Problems experienced with family members or partners concerning the feeding of the baby: Respondents were asked if they experience problems from family members regarding the feeding option chosen. The following answers were given:

- Partner asking why baby stops breastfeeding, the respondent lies to him telling him that the child should drink formula if on treatment.
- Unemployed parents are struggling to feed the baby with formula feeding.
- Family members questioning too much why respondents do not breastfeed the child.
- Partner does not want to buy food and the child ends up having malnutrition.

Most of the mothers who experience these problems are those who did not inform their family members or their partners about their HIV status and those who do not have money to buy formula milk or food. There is a need to encourage mothers to disclose their HIV status to their partners and their close family members who will help them in times of need or helplessness.

4.2.12 Children 's HIV status

Most of the children have not yet been tested for HIV (71.4%). Only 28.6% were tested for HIV. This has happened because the policy was changed, so that babies are tested only at 18 months.

Therefore those 71.4% do not know yet their children's HIV status. 28.6% who were tested all are HIV negative. This result is encouraging as it shows that the programme is working.

- Mothers are very happy about their children, because their children are HIV negative.
- There were no HIV positive results on those babies whose mothers were interviewed.

A study done in South Africa at different pilot sites which implemented PMTCT between April 2001 – March 2002, found 1907 live babies born by HIV positive women. A total of 949 of those infants were tested for HIV, and of these only 18% (N-170) tested HIV positive. No information is available either on infant feeding practices of the infants for whom follow-up tests were conducted. No information is available on the other 50% of infants who were not followed-up and for whom HIV status could be vastly different for a variety of reasons. Those babies were tested, some at 9 months and others at 12 months. The researchers indicated that it is not possible to draw any conclusions on the impact or effectiveness of the programme from this data (Doherty et al 2003: 26). HIV tests for infants are done to determine the HIV status of the infant in order to make clinical management decisions and also to evaluate the effectiveness of the PMTCT programme (Doherty et al 2003: 28).

4.2.13 Follow up visits

All the interviewed mothers are those who came for their babies' follow-up at Katutura (POPD) Paediatric Out Patient Department or the Antenatal Clinic.

The majority of the respondents (92.9%) started their babies' follow-up at 6 weeks as it is supposed to be. Only 3.6% started late at 3 months and the other one, 3.6%, started at 9 months because she was not given the correct information by the nursing staff. All the respondents agree that follow up visits are important. It is disappointing to observe that health workers provide incorrect information to patients, which may influence their treatment and put them at risk of infecting the babies.

4.2.13.1 *Importance of follow-up visits: Reason given by respondents.*

A question was asked to elicit if mothers felt follow-up visits were important and why so. They gave various reasons such as:

- It is important for the health of the child and to know the child's HIV status (65%).
- Medication given helps the child to be healthy and prevents the child from getting sick (44%).
- During the visit, you get a chance to inform the nurse and doctor of any problems the child is having, and they can be treated early (10%).
- Medication helps to boost the immune system of the child (10%).

This shows that the respondents understand the importance of follow-up for the benefits of themselves and their children. The literature revealed that mothers are motivated to return for follow-up visits in order to maintain the health of their infants and to benefit from ongoing care. The infants get a chance to receive prophylactic treatment i.e. co-trimoxazole and multivitamins (Doherty et al 2003: 22) and the mother is informed of the HIV status of the child.

4.2.13.2 *Factors motivate mothers to stick to follow-up visits.*

The respondents were asked what motivates them to stick to the follow-up visits and they provided the following reasons:

- They find that medications help their children - 50%.
- They want their children to be healthy - 75%.
- They want their babies to be helped and become HIV negative - 75%.
- Hoping God will help their babies to be alright by becoming HIV negative - 10%.
- They accept HIV/AIDS just like other diseases - 5%.
- They do not want their babies to get infected with HIV virus - 75%.
- They want their child to live longer - 15%.

- They just do it for the love of mother for their children - 5%.

These results show that the majority of mothers stick to follow-ups because they want their children to be healthy and not to be infected by the HIV virus. They want their babies to be HIV negative.

According to the literature, HIV positive mothers stick to follow-ups in order to be relieved from the emotional burden or anxiety of having infected their children once the child tested HIV negative. On the other hand, if the child is infected, medical management can be provided such as receiving priority for ARV therapy and prevention of opportunities for infections and maintaining the health of the child so that he/she can live longer (Doherty et al 2003: 31).

4.3 COMMUNITY SUPPORT FOR MOTHERS

The question was asked about the support networks available in the community. Some of the respondents (39.3%) mentioned that there are no community support networks available in their community, while the same 39.3% said they do not know, and the other 21.4% mentioned that there are community support networks available in their community although they never approach them. It can be concluded that they are scared when seen approaching the support centre and/ or NGOs.

We learn from literature that some communities have such programmes as mother to mother support groups which focus on the counselling and support of HIV positive mothers to live positively after deliveries (WHO 1999: 21). In some countries community volunteers do visits in order to assess the situation in which the mother and the child are to ensure exclusive breastfeeding and provide care needed (PMTCT Botswana 2002: 1).

In our country we also need social mobilization for wider participation and ownership of community leaders and groups of people. Such activities should include awareness raising campaigns and establishing support groups or strengthening links between groups.

This should be done through the use of community networks to encourage community support and action.

Lutheran Self Help Group provides food and care for those who can help themselves, but respondents never approached them for help. Respondents had heard about CCN, but never had been there to ask for help. Maxwilili Centre provides food to the kids. However participants did not approach them maybe due to fear of stigma attached to HIV/AIDS if seen approaching this centre.

4.3.1 Suggestions from the mothers on how to improve follow-up visits or PMTCT programmes as a whole

- The programme is important, as they are encouraged to accept their HIV status; therefore it should continue.
- Most mothers feel that there is no need for programme improvement; it is good. Maybe one day there will be cure.
- Some mothers experience problems at work when they come every month for follow-ups.
- The programme should also be at the rural clinic and other hospitals around the country.
- All pregnant women must be tested whether they agree or not.
- More advice should be given to the people so that they go for testing.
- Mothers must be motivated to carry on with treatment as ordered by medical doctors.
- The people must be encouraged to pray. God is listening.
- Mothers must be provided with formula feeding for their babies because some partners are not working and there is no source of income.
- Distance is a problem, because there is not always money to come to the hospital.
- This programme should be available wherever there are ANC services available.

Communication plays a vital role in changing knowledge in mother to child transmission of HIV as well as influencing values, social norms and correct understanding of MTCT. Therefore, there is a need to provide adequate information to women and families on safe pregnancy, delivery and newborn infant care and promote access to key services by follow-up visits. Activities focus on strengthening progress for women, their male partners, families and peers by developing their skills and confidence and challenging harmful norms (MOHSS 2004: 45).

New policies or laws must be developed to protect the rights of the vulnerable individuals or increase their access to services. e.g. Mothers to be released from their duties to bring their children for follow-ups.

According to the PMTCT report in Namibia by the end of 2004, 24 out of 35 hospitals in the country are providing PMTCT services. This is a positive development, because the MOHSS has heard the outcry of the nation on the need for these services to be spread throughout the country (MOHSS 2004: 40).

4.4 SECTION B: QUALITATIVE DATA ANALYSIS

This section will deal with the two (2) respondents who did not come for follow up visits as scheduled. They are presented as Case 1 and Case 2.

4.4.1 Biographical information

4.4.1.1 Age group

These two women fall in the age group of 26-29 years, implying that they are still in the most affected age bracket as stated in the epidemiological report of Namibia (MOHSS 2004: 54).

4.4.1.2 Region of origin

One of the respondents comes from Kavango and the other one comes from Omusati Region. Omusati and Kavango Regions have prevalence rates of HIV infection estimated at 25-29% and 20-24% respectively (MOHSS 2004: 8), which are outside the study area.

4.4.1.3 Residential area

One lives in the informal settlement while the other woman lives in the formal settlement location. The one who comes from the informal settlement is unemployed which is a common attribute of those in the informal settlements in Namibia (LeBeau 2003: 34).

4.4.1.4 Marital status

Both women are married and staying with their husbands. One would conclude that HIV/AIDS does not spare those in marriages. However, those in marriages at least have partners to talk to about personal issues if need be.

This study shows that cultural and social norms play a role in these respondents' lives to make decisions. Culturally men believe that they have to bear more children to show their superiority or manpower. Women are expected to have more children and care for them, although they are aware of their HIV status. Women have indicated a lack of control in making decisions about sex (Iipinge et al 2004: 41).

4.4.1.5 Education

The two respondents can read and write. One has a grade 10 while the other has tertiary level education. One would expect educated people to behave differently but as the literature states, knowing all the facts on HIV/AIDS does not translate into favourable behaviour and responsible sexual practices (Iipinge et al 2004: 78)

4.4.2 Awareness of own HIV status

Both women knew their HIV status before the second last delivery and before their first enrolments with the PMTCT programme. However, they never stuck to the follow-up as required due to various reasons in their lives. The positive aspect is that they knew that there was a good chance to protect their babies from being infected, as the literature indicates (WHO 2004: 10) and that was the reason they registered with the PMTCT programme.

4.4.3 Counselling

Both women were pre-counselled and post counselled. One woman was pre- and post counselled alone, for the reason that she was going to be married. She disclosed her HIV result to the boyfriend who accepted it, because he actually knew already that he is HIV positive. This correlates with the information from the Namibia Demographic and Health Survey (1992: 51) that women engage in sexual relations prior to marriage. Most men and women have sexual relationships without using condoms (Iiping et al 2004:17).

The other woman was pre and post counselled together her husband. The husband was found to be HIV negative, while she is HIV positive. Discordant couples are common in Namibia. This means that people are not tested before being involved in sexual relations, and condoms are not widely used. According to Iiping et al (2004: 34) the HIV infection rate is rising and the primary reason for the rise is that people, often being fully aware of the situation, simply do not take necessary precautions.

4.4.4 Feeding options

One respondent uses formula feeding in order to minimize the risk of HIV transmission to the child. While the other respondent has got twins, both were breastfed for the first month and later she got formula milk and food from Catholic AIDS Action. One can

conclude that breastfeeding is normally the best way to feed the infant. However, an HIV positive mother can choose to use formula feeding to reduce the risk of HIV transmission to her infant. The risk of replacement feeding should be less than the potential risk of HIV transmission through infected breast milk, so that infant illness and death from other causes do not increase; otherwise there is no advantage in replacement feeding (MOHSS 2004: 28).

It is shown also in the research done in Zambia that knowledge of HIV status does not appear to affect the practice of continuing breast feeding beyond 6 months, most likely for economic and social reasons and to avoid the stigma associated with not breastfeeding. There is fear of stigma attached to people with the HIV virus. That is why this mother is still breastfeeding at one year. Lack of provision of formula feeding to those who cannot afford it also plays a role (Nyblade 2001:3).

4.4.5 ARV for mother and child

Both women received Nevirapine 200g per os 2 hours before delivery and their babies got Nevirapine syrup single dose. This is done according to Namibia ARV guidelines which stipulated so (MOHSS 2003: 19). One woman is on ARV therapy and has adhered to it, while the other one is not yet eligible for ARV therapy. This shows that factors like sexual relations, immune system, psychological factors, social and economic status play a role in somebody's body and life

4.4.6 Reasons for not coming for follow up visits

The two respondents never brought their children for follow-ups. The reasons provided include: denial of the existence of HIV/AIDS, not being in control of own health, financial constraints, lack of support from the partner and lack of knowledge on the importance of follow-up by the family members.

Fortunately both their babies are HIV negative. They both feel that follow-up visits are important even though they did not attend them as ordered. One concluded that it is important to sensitize the community about the importance of follow-up and the PMTCT programme at large.

Poverty is also a contributing factor to the lack of follow-up. These mothers depend on their partners for financial support, and this makes it difficult to make decisions on their own. Ignorance also plays a role because one husband knows that his wife is infected but carries on exposing himself to the virus and wants more children. Although counselling is done, people tend to make their own decision at the end of the day, which puts them at risk (Ipinge et al: 35).

4.5 SUMMARY

In this chapter both quantitative and qualitative data were presented and integrated with the findings in the literature. The next chapter presents the conclusions drawn from these data and appropriate recommendations are given.

CHAPTER 5: CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

In the previous chapter, the findings and the discussions of the findings were presented. In this chapter the conclusions, limitations and recommendations emanating from the findings of this study are given.

The purpose of the study was to explore and describe the factors that influence the follow-up visits by mothers registered with the PMTCT programme at the Katutura State Hospital for the period of 2002 – 2003.

The specific objectives of the study were:

- To determine the profile of mothers who join the PMTCT programme
- To determine the factors that motivate or demotivate the mothers to stick to or drop out of the programme
- To assess the follow up modalities and support network available in their communities
- To make appropriate recommendations

5.2 CONCLUSIONS

The conclusions for this study are made based on the above specific objectives.

Objective 1: To determine the profile of the mothers who joined the PMTCT programme

The researcher concluded that the majority (i.e. 89.1%) registered for PMTCT fall in the age bracket of 20–39 years old. This finding is in line with the finding of the Epidemiological report, which states that the HIV prevalence rate is highest in the same age bracket (MoHSS 2004: 6).

More than half the respondents (i.e. 53.5%) are unemployed while the rest are either employed or self employed. About 46,4% of the respondents live in the informal settlements around Windhoek, which is already a high risk factor for diarrhoea for those who choose formula feeding, as there is no access to an optimal environment, including sanitation, electricity for food preparation, utensils and skills to prepare the feeding.

Most of the mothers who joined (i.e.78.6%) are single mothers, which is actually a problem factor in negotiating safe sex and creates dependency on their partners when mothers are not employed.

The study also found all respondents can read and write, implying that they can access general and treatment information related to HIV/AIDS. Most respondents (85%) came to know their HIV status only during the last pregnancy. Most of these mothers have disclosed their HIV status to their partners. However, there are a few (28.6%) who did not disclose because of various reasons such as being afraid of being blamed for bringing HIV to the other partner, domestic violence, no contact between partner and economic dependence.

Feeding options chosen by many respondents are breastfeeding exclusively for 4 months and formula feeding and supplements after 4 months. Mothers who experience problems when not breastfeeding are those who did not disclose their HIV status to the family members and partners and do not have means to buy food or formula milk. Cultural factors also play a role.

All the babies were given their Nevirapine syrup single dose or double dose, for those whose mothers were also given Nevirapine 200mg/os >2hrs before delivery and for those who did not get it <2hrs before delivery respectively. Among those children of mothers who were coming for follow-ups 28,6% (8 babies) tested HIV negative at 18 months. Some are not yet 18 months. The mothers are satisfied with their children's results.

Objective 2: To determine the factors that motivate or demotivate mothers to stick to or drop out of the PMTCT programme

The factors that motivate the mothers to stick to the programme include the following. Mothers want their children to be healthy and become HIV negative; they found out that the prophylaxis medications given to their children are helpful, because the children do not become sick; they want their children to live longer and they do it for the love of mother for their children.

The factors identified as demotivating for mothers to stay in the programme include family members who are in a denial stage and do not want to believe HIV/AIDS exists, stigma attached to people living with HIV/AIDS, financial related issues and domestic violence.

Objective 3: To determine the follow-up modalities and support network available in their communities

Almost all the respondents indicated that there are no follow-up modalities available to them in their communities. The support groups available for HIV/AIDS are few, and there is no proper channel of communication between the hospital and these groups. There is no specific support group for these mothers after delivery where the mothers are referred to after discharge by the health workers.

Objective 4: To make appropriate recommendations

5.3 RECOMMENDATIONS

Based on the findings the following recommendations are made with regard to the training, counselling and feedings options:

Training: The researcher feels that extensive training should be conducted for all health workers with regard to PMTCT programmes especially with the guidelines as specified and laid down by the Ministry of Health and Social Services. It is important that all

health workers especially in the maternity units and paediatric department are conversant with the programme. The PMTCT programme should be part of the basic training of all health workers in the pre-service education.

Counselling services and referral system: There is a need to equip all health workers with counselling skills to enable them to provide relevant information to the patients as well as to the general public. The Ministry also needs to develop a formalised referral system with all local organisations working in the HVI/AIDS areas.

Feeding options: There is a need to explore the issues around available feeding options based on cultural and economic factors. Researchers in the training institutions such as International Training and Education Centre on HIV (I-TECH), University of Namibia (UNAM) and other developing partners should provide funding for such research.

It is recommended that a campaign should be conducted to create awareness among employers and community in general. This would facilitate the ease in disclosure by family members who are HIV positive. The community and family involvement should be strengthened in the care of mothers and children. Information on HIV/AIDS and PMTCT should be provided to the community leaders, elders, and men who do not usually use the prenatal clinics. Their ignorance enables stigma and misconception persist, making it less likely that men and elders will be supportive of mothers coming for follow-ups.

Further research should be done into feeding practices used by HIV positive mothers, quality of antenatal counselling i.e. pre and post counselling.

5.4 LIMITATIONS

There are some limitations which were encountered during this study as described below.

The number of mothers interviewed cannot justify generalisation of the results to a larger population. The mothers usually travel out of Windhoek after delivery as most of them come from regions outside the study area. Therefore it was difficult to catch these mothers, since they do not come on the same day to the POPD or to ANC.

There is no proper system in the Katutura Hospital to deal with follow-ups of mothers and their children. It is difficult to trace the mothers who did not come for follow-ups because some give telephone numbers or cellular phone numbers but when you call them such a person is not known there or has moved to another area.

The residential addresses are also a problem. Some are incomplete, some never exist and some are correct but the person was not ready to participate in the study as participation was on a voluntary basis.

The confidentiality associated with HIV/AIDS made it difficult for the researcher to get more people in the study due to stigma attached to people living with HIV/AIDS.

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ANNEXURE 1: Case 1

BIOGRAPHICAL INFORMATION

Age: 26 years old

Region of origin: Omusati Region

Residential address: Wanahenda in Katutura

Home language: Oshiwambo speaking

Marital status: Married

Religion: Member of Lutheran congregation.

Employment: She is employed and earns a monthly salary of >N\$ 2000.00.

Education: Attend tertiary Education and graduated from Polytechnic of Namibia in 2003.

Partner: Her husband is working and stays in Walvis Bay.

Pregnancies and children alive: She is Gravida, has one child now, she is 3 months pregnant during the time of interview.

AWARENESS OF HIV STATUS: She has known her HIV status since 1996. She was tested first in Oshakati Hospital because she was going to be married. She disclosed her HIV positive result to her boyfriend who just accepted it, because apparently he knew already that he was HIV positive. She also told her family about the HIV result.

COUNSELLING: Pre- counselling and post-counselling was done. She believes that counselling helps her to accept her HIV status, carry on and live a productive life and live positively.

FEEDING OPTIONS: She chose to use formula feeding. She decided not to breastfeed because it reduces the risk of HIV transmission to the child, and also she was a student at Polytechnic of Namibia. She had to go back to school after delivery.

ARV FOR MOTHER AND CHILD: She got her Nevirapine 200mg per os more than 2 hours before delivery, and the baby got a single dose of Nevirapine. Currently she has been on ARV long term therapy since 2004 (2 years later after delivery of her last child).

FOLLOW-UP VISITS: This child has never been brought for follow-up, the reason being that the grandmother took the child along to the village. Although this grandmother was informed about the HIV positive status, she is in denial of the existence of AIDS. Fortunately this child is 2 years old and is HIV negative. I believe that if the baby is not infected in utero and born through caesarean section, then the risk of transmission is reduced. Not breastfeeding, just using formula milk also minimizes HIV transmission. This mother, although she did not bring her child for follow-up visits, feels that follow-up is important. It helps to see if the child is well, or needs treatment while it is early. It is not good to keep quiet at home and go only when the child is sick.

SUGGESTION: She suggested that the PMTCT program should be extended to the rural clinics, and hospital and medications be made available there.

ANNEXURE 2: Case 2

BIOGRAPHICAL INFORMATION

Age: 29 years old.

Region of origin: Kavango Region

Residential address: Babilon, an informal settlement in Windhoek.

Home language: Rukwangali.

Religion: She belongs to Deeper Life Church.

Employment: She is unemployed. She depends on the husband for financial support.

Education: She attended primary and secondary school up to grade 12.

Partner: Her husband is working as a security guard and they stay together in Babilon.

Pregnancy and child alive: She is Gravida 6, has 4 children, one abortion and one intrauterine death.

AWARENESS OF HIV STATUS: She and her husband decided to be tested because they wanted a child. Although she had an 11 year old girl whom she had before marriage. They were tested at Katutura Health Centre. The husband was found HIV negative while she is HIV positive. The husband accepted it and decided to stay with her. Discordant couples are common in Namibia. Such couples need proper counselling to ensure that they understand the situation and support their partners (MOHSS 2005: 16).

COUNSELLING: They were both pre-counselled and post counselled. Although they were counselled on safe sexual practice to prevent infection and re-infection, the husband did not use a condom because he wanted a child.

FEEDING OPTIONS: She was breastfeeding for the first month and later she got help from Catholic AIDS Action which provides formula milk and foods. She chooses to breastfeed because the husband could not afford to buy formula milk for both kids.

ARV FOR MOTHER AND CHILDREN: She got Nevirapine 200mg per os two hours before delivery and both babies got Nevirapine syrup each single a dose. One twin was sick and diagnosed with TB. He was put on TB treatment. Now he is cured from TB.

FOLLOW UP VISITS: These twins were never brought back for follow-up visits. The reasons given for not coming back are:

- Husband quarrels most of the time if asked for money for transport.
- The second twin use has been admitted several times in hospital.
- Husband tells her to stay home and leave those follow-ups.
- Problem of carrying two babies every month.

Luckily both children have tested HIV negative. This mother delivered another baby girl in 2004. She also got Nevirapine 200mg per os, and the baby got Nevirapine syrup. At the time of the interview the child is one year but still breastfeeding. The reason given by her; “I believe is God. He will help my child not to be infected by the virus, “ God do miracles”.

These findings correlate with the literature which indicates that poverty is seen as the primary underlying factor in the spread of HIV. Cultural norms which maintain women in a social status that is lower than men and in which women are required to depend on men for social and economic support are additional elements that lead women to HIV risk taking behaviour e.g. –carry on delivering babies even though she knows her HIV status or is unable to bring the children for follow-up visits due to lack of money for transport.

SUGGESTION: She suggested that the Government of Namibia should provide formula milk for infants and food to those who are in need.

ANNEXURE 3: QUESTIONNAIRE

1. BIOGRAPHICAL INFORMATION :

Age :

Sex :

Nationality :

2. DEMOGRAPHICAL DATA :

2.1 Region

2.2 Residential Address

2.3 Home Language

2.4 Employment Status:

not employed

self employed

2.5 Monthly basic salary.

* < N\$ 500. 00

* N\$ 500. 00 - N\$ 900. 00

* N\$ 1000. 00 - N\$ 1 500. 00

* N\$ 1 500. 00 - N\$ 2 000. 00

* >N\$ 2 000. 00

2.7 Marital Status :

- * Single
- * Married
- * Widowed
- * Divorced
- * Cohabiting
- * Separated

3. RELIGION :

- * Lutheran
- * Roman Catholic
- * Anglican
- * No religion
- * Other specify

4. EDUCATION INFORMATION :

4.1 Have you ever attended school?

- * Yes
- * No

4.2 What is the highest level of school you have attended?

- * Primary (Grade 1 - 7)

- * Secondary (Grade 8 - 12)
- * Tertiary
- * None

5. PARTNER'S/HUSBAND'S EMPLOYMENT STATUS

5.1 Is your partner working?

- * Yes
- * No
- * Doesn't work

5.2 Monthly salary of husband/partner :

- * < N\$ 500. 00
- * N\$ 500. 00 - N\$ 1000. 00
- * N\$ 1000. 00 - N\$ 1 500. 00
- * N\$ 1 500. 00 - N\$ 2 000. 00
- * N\$ 2 000. 00

6. Are you currently living with your partner?

- * Yes
- * No

AWARENESS OF HIV STATUS :

7. When did you know that you are HIV positive?

- * Before last pregnancy
- * During last pregnancy
- * Post delivery

8. Why did you decide to get tested for HIV?

.....

9. Did you tell your partner about your HIV status?

- * Yes
- * No

10. If yes to No. 9 what was his reaction?

- * Denial
- * Acceptance
- * Angry
- * Aggressive
- * Move out of home
- * Other, specify

11. If no to No. 9, why would you not want to inform your partner?

.....

.....
.....
.....

12. Do you think that your partner knows his own HIV status?

* Yes

* No

* Don't know

13. Did you tell anyone else about your HIV status?

* Family members

* Friends

* Other, specify

* None

15. How many pregnancies have you had so far?

16. How many living children do you have?

17. Is your last child alive?

* Yes

* No

18. If no to No. 17, how old was the child when he/she died?

COUNSELING :

19. Have you ever been counselled before getting tested for HIV?

* Yes

* No

20. If yes to No. 19, who requested it?

* Yourself

* Doctor

* Other specify

21. Were you counselled when you received your HIV result?

* Yes

* No

22. Do you think that the counselling session helped you?

* Yes

* No

ANTRIETROVIRAL DRUGS THERAPY FOR MOTHER & CHILD :

23. Did you receive Nevirapine tablets?

* Two hours before delivery

* Less that 2 hours before delivery

* Not given

24. Are you on long term therapy of highly active Antiretroviral drugs?

* Yes

* No

25. If yes to No. 24, when did you start them?

* Before delivery of your last child

* After delivery of your last child

26. Did your child get Nevirapine syrup?

* Single dose

* Double doses

* Not given

PROPHYLAXIS TO THE BABY AND BABY'S HIV STATUS

27. How old is the baby?

28. Is your child receiving prophylaxis treatment?

* Yes

* No

29. How do you feed your baby? For each option give reasons why you chose it?

* Breastfeeding

* Formula feeding

* Mixed feeding

30. Do you experience problems with the family members or partner concerning the feeding of your baby? Please explain.

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.....
.....
.....

31. Has your child ever been tested for HIV?

* Yes

* No

32. What is the HIV status of your child now?

* Negative

* Positive

* Don't know

33. How do you feel about the HIV status of your child?

.....
.....
.....

FOLLOW UP VISITS AFTER LAST CHILD'S DELIVERY :

34. Did you ever come back for your follow-up visits after delivery of your last child?

* Yes

* No

35. If yes to No. 33 at what intervals did you come?

* 6 weeks

* 3 months

* 9 months

* 12 months

* 15 months

* 18 months

36. If no to No. 33, could you please give reasons why you did not bring back the child for follow-up visits?

* Not informed

* Sickness of mother

* No money to come to the clinic

* Discrimination against

* Afraid my husband/partner will find out my HIV status

* Other specify

37. What motivates you to stick to follow-up visits?

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.....
.....

38. What demotivates you to stay with the programme?

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.....
.....

39. Do you think follow up visits are important?

* Yes

* No

40. Give reasons to the answer.

.....
.....
.....

41. Are there any community support networks available in your community?

* Yes

* No

* Don't know

42. If yes, mention them and the type of assistance they provide you.

.....
.....

COMMENTS/SUGGESTIONS :

43. Do you have any suggestions on how to improve the follow-up visits or the whole programme of prevention of mother to child transmission of HIV?

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ANNEXURE 4: LETTER FROM UNAM RESEARCH COMMITTEE