

COMMUNITY PERCEPTIONS, ATTITUDES AND KNOWLEDGE  
REGARDING MOTHER TO CHILD TRANSMISSION OF HIV. A  
BASELINE EVALUATION BEFORE THE IMPLEMENTATION OF THE  
PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV  
PROGRAM USING A SHORT COURSE OF NEVIRAPINE AT  
ONANDJOKWE HOSPITAL, NAMIBIA.

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A minithesis submitted in partial fulfilment of the requirements for the degree of Master  
of Public Health in the School of Public Health, University of the Western Cape.

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**COMMUNITY PERCEPTIONS, ATTITUDES AND KNOWLEDGE  
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COURSE OF NEVIRAPINE AT ONANDJOKWE HOSPITAL, NAMIBIA.**

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## ABSTRACT

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Each year approximately 600 000 infants, most of them in Sub-Saharan Africa are born with HIV infection as a result of mother to child transmission of HIV (UNAIDS 2001). Whereas significant progress has been made in reduction of mother to child transmission of HIV in developed countries, the situation remains desperate in developing countries. Progress has been hampered by shortage of staff, facilities, limited access to VCT and lack of support for women by their partners and communities. The challenge is to increase VCT uptake during antenatal care. Onandjokwe district in Northern Namibia is currently introducing the PMTCT program. It has been found that previous PMTCT programs have failed because they adopted a top down approach where there was no community consultation. A study was therefore conducted to explore the community perceptions, knowledge and attitudes regarding mother to child transmission of HIV through focus group discussions and in-depth interviews of key community members. Focus group discussions were conducted on antenatal and postnatal women, three for each group. In depth interviews were conducted with church leaders, headman, and people living with AIDS and HIV positive women who had been offered nevirapine in pregnancy. A thematic content analysis was used to analyse the data.

The study showed that participants were aware of mother to child transmission of HIV and its prevention although there were some minor misconceptions about the prevalence of MTCT and the points where most transmission occurs. Prenatal HIV testing was considered as a good initiative as it benefited both the mother and the child. Other

benefits of HIV testing were behaviour modification and access to antiretroviral therapy. However there were several impediments to successful VCT. These were cited as fear of a positive result, shame, fear of rejection and abandonment by families and friends. The other problem cited was lack of VCT facilities in the district. A few participants were concerned about the discriminatory attitudes of maternity staff. If some of these barriers to VCT are addressed, the positive attitudes to VCT which the participants had may easily be translated into actual behaviour thereby resulting in increased community participation in the PMTCT program

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## DECLARATION

I declare that *Community Perceptions, Attitudes and Knowledge Regarding Mother to Child Transmission of HIV. A Baseline Evaluation Before The Implementation Of The Prevention Of Mother To Child Transmission of HIV Program Using A Short Course Of Nevirapine At Onandjokwe Hospital, Namibia* is my own work, that it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Sifelani Mtombeni

Signed

Date November 2004



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## **CHAPTER 1: INTRODUCTION**

### **1.1 MAGNITUDE OF THE PROBLEM**

The HIV/AIDS epidemic continues to take a heavy toll among the world's population. In 2003, the epidemic killed more than 3 million people, an estimated 5 million acquired the human immunodeficiency virus (HIV) bringing to 40 million the number of people living with the virus since the epidemic began (UNAIDS 2003). Sub-Saharan Africa is the worst affected region. In 2003, UNAIDS estimates that 26,6 million people in this region were living with HIV, including the 3,2 million who become affected during that year. AIDS killed approximately 2 - 3 million people in 2003 (UNAIDS 2003).

The epidemic in Africa affects more women than men as women are at least 1,2 times more likely to be infected than men. The ratio is highest among the young woman aged 15 – 24 where women were found to be two and half times more likely to be infected than men (UNAIDS 2002). These differences in infection rates are due to a combination of factors. Women and girls are commonly discriminated against in terms of access to education, employment and land inheritance. With increasing poverty levels, African women have found themselves in casual relationship with men as this can serve as a conduit for financial and social security. Women therefore find it difficult to demand safe sex, as they become subordinates or dependents of mainly older men. Women are also biologically prone to infection and HIV is easily transmitted from men to women than the reverse.

The principal mode of transmission of HIV in Africa is heterosexual. The second is mother to child transmission, which is the main mode of acquisition of HIV infection in children, under 15 years. The number of children living with HIV infection is estimated at 2,5 million since the epidemic began (UNAIDS 2003). Each year approximately 600 000 infants, most of them in

Sub-Saharan Africa are born with HIV infection as a result of mother to child transmission of HIV (UNAIDS 2001). The rising number of HIV infected children places an enormous burden on both the families and the health care system. Yet medical intervention currently available, if provided could save lives of 300 000 children per year (UNAIDS 2001). More than one in five pregnant women are HIV infected in most Southern African Nations (UNAIDS 2003). A trend analysis of antenatal clinic sites in eight countries between 1997 show HIV prevalence among pregnant women at 40% in Gaborone (Botswana), and Manzini (Swaziland), 16% in Blantyre, Malawi, 20% in Lusaka (Zambia) (UNAIDS 2003).

## **1.2 BACKGROUND**

In the settings where prolonged breast-feeding is the norm and interventions for preventing mother to child transmission of HIV are not widely available, about 25 – 35% percent of HIV infected mothers pass on HIV to their infants (Dabis et al 2001). Namibia is one of the Southern African nations heavily affected by the HIV/AIDS epidemic. It is ranked as one of the top 5 AIDS affected countries. According to the 2002 HIV sentinel serosurvey, prevalence varies by region from 9 percent to 43 percent, with an overall estimate of 22% crude prevalence rate for sexually active adults (USAID Namibia 2003). The epidemic is being driven by an array of factors: poverty, internal labour migration, presence of major transportation corridors connecting Namibia to other high prevalence neighbouring states, sexual norms and attitudes, geographical inequities, and unequal power dynamics between men and women among other factors.

Heterosexual sex is the main transmission route for HIV in Namibia, mother to child transmission is prevalent, and about 6000 infants are infected annually in the absence of any PMTCT program (USAID 2003).

The Namibian government has expressed its commitment to reversing the course of the HIV/AIDS epidemic through its primary health care approach adopted at Independence in 1990. It has established partnership with the civil society, private sector and donor community in a bid to tackle the epidemic. One of these partners is USAID, which is strengthening the capacity of the health care system to deliver prevention of mother to child transmission of HIV (PMTCT) and antiretroviral (ARV) services through training, upgrading of staff skills, provision of ARV's, HIV testing costs and expansion of counselling services.

Onandjokwe Hospital, a mission hospital in northern Namibian, with a catchment population of about 150 000 people has been selected as one of the pilot PMTCT centres in 2004. It has been observed that previous program for PMTCT have often been top down, with no community input and targeting women only. Such programs have been found to be unsuccessful and not sustainable. It is against this background that a study is proposed to explore the perception, knowledge and attitudes of the community regarding perinatal transmission of HIV. Such information would assist in the design and implementation of the PMTCT program in the district.

### **1.3 STATEMENT OF THE PROBLEM:**

The researcher has decided to undertake this study because of the high prevalence of perinatal HIV transmission in Namibia. The problem is that in other developing countries where prevention of mother to child transmission of HIV programs have been introduced, uptake for voluntary counselling and testing for HIV in pregnancy has been low. It is therefore necessary to understand the community perceptions, attitudes, norms and practices that hinder the PMTCT program.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.0 INTRODUCTION**

Vertical transmission is the principal mode of acquisition of HIV in infants and children under 15 years of age. There have been significant advances in strategies for the prevention of mother to child transmission of HIV. These include antiretroviral prophylaxis during pregnancy and delivery, improved obstetric care and infant formula feeding. These strategies require access to voluntary counselling and testing. This chapter reviews the strategies for PMTCT, the role of VCT and the impact of community perceptions and attitudes on various components of the PMTCT program. Barriers to VCT uptake are also highlighted.

The literature used in this study was mainly obtained from MEDLINE. Most of the original papers were sourced from the libraries at the Universities of Western Cape and Cape Town. Other relevant literature materials were obtained from the internet (using key words Acquired immunodeficiency syndrome, mother to child transmission of HIV, voluntary counselling and testing for HIV, Attitudes and knowledge, perceptions) from peer review journals, government publications as well as documents from the WHO and UNICEF resource centres in Windhoek, Namibia. A total of ninety two articles and publications were reviewed.

### **2.1 STRATEGIES FOR PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV**

Research in recent years has led to major medical breakthroughs in both prevention and treatment of HIV in United States and Europe. Significant advances have been made since the land mark PACT076 showed that HIV transmission rates could be reduced by 66% using a long course of zidovudine (Connor et al 1994). Subsequent treatment of HIV infection with highly active antiretroviral therapy (HAART) has further reduced the transmission rates in developed

countries (Lindegren M et al 1999, Mayaux M et al 1997). The improvements in maternal health, increased access to perinatal counselling and testing for HIV, reduction in maternal viral load due to HAART treatment, and use of infant replacement feeding and improved obstetric care have all led to a significant reduction in prenatal transmission in the developed regions (Bulterys M et al 2000, Lindegren M et al 1999, Mayaux M et al 1997).

While mother to child HIV transmission in the developed world is rapidly declining, the situation remains gloomy in resource poor countries. The HIV transmission rates range from 25 – 30% and a significant proportion of mother to child transmission occurs through breast feeding where this is widely practiced (Nduati et al 2000). The Breastfeeding and HIV International Transmission Study Group (2004) reports in their meta-analysis of studies on HIV transmission through breast feeding that late postnatal transmission represents at least 24% and possibly as much as 42% of the overall rate of mother to child transmission of HIV-1. Other factors contributing to the variation in transmission rates include the differences in obstetric practice, maternal viral load and micronutrient deficiencies (Peckham C et al 1995, Scarlatti G et al 1996).

The escalation in HIV infection rates has seen many countries adopting the PMTCT programs as one of the components of national AIDS programs. The UNAIDS/UNICEF/WHO intervention for the prevention of mother to child transmission is six pronged (UNAIDS 1998): Early access to adequate antenatal care, voluntary and confidential counselling and HIV testing for women and their partners, a short course of antiretroviral treatment (AZT) given to HIV positive women in last weeks of pregnancy and during delivery, improved care during labour and delivery, counselling for HIV positive mothers who opt not to breast feed, counselling for HIV positive pregnant women on alternative feeding methods and monitoring and evaluation.

In the 1990's, UNAIDS, UNICEF and WHO initiated pilot projects in eleven African countries to provide HIV positive mothers with a short course of zidovudine during labour and delivery which has been found to be effective by studies in Thailand (Wade N et al 1998). Countries involved in these projects included Botswana, Rwanda, Zambia, Zimbabwe, and Cote d'Ivoire, Kenya, Tanzania and Uganda (Mercier E 1999). The projects promoted six components of PMTCT as outlined above. The projects were found to have low acceptance rates because they were implemented without community involvement (UNAIDS 1999). Certain cultural norms, values and beliefs may hinder the implementation of a PMTCT program. It is therefore important to understand the community and involve them in all program stages to avoid potential conflict. Such an understanding can come from doing an exploratory research, where community perception, knowledge and attitudes are assessed. The findings from such a research can then be used to formulate appropriate messages and strategies for the program



## **2.2 Community perception and awareness of mother to child transmission of HIV**

In order to determine what should be included in the PMTCT program, it is crucial to understand what the community knows about HIV/AIDS, signs and symptoms, modes of transmission and prevention. It is also equally important to gauge the community's perception of the magnitude of the HIV/AIDS problem. If the community doesn't perceive HIV/AIDS to be a problem among them, preventive messages are not likely to be received well. One has to know where they obtain their information on HIV, and their views. In a Zambian study, it was found that communities perceived HIV/AIDS to be a major problem and they showed a sense of hopelessness (Mukuka 2000). Messages geared towards inspiring hope were therefore included in the PMTCT programs. In Botswana, communities perceived HIV/AIDS not to be a real problem (Nyblade et al 2001). Messages in this setting therefore needed to focus on convincing the community that both MTCT and HIV/AIDS are really and growing concerns, which need to be addressed

The context within which women make decisions about MTCT prevention depends on the level of community knowledge about HIV/AIDS. Some communities blame the women for the spread of HIV, and this results in women being reluctant to take an HIV test (Temmerman et al 1995). Understanding community perception in this regard is therefore important so that appropriate messages countering such beliefs can be formulated.

Knowledge about perceived prevalence of mother to child transmission is also important. Unfortunately many studies have shown that the knowledge about mother to child transmission of HIV, including prevalence, points of transmission during pregnancy, delivery and breast-feeding is lacking (Michelle E 2003, Kayode CM et al 2002, Nyblade et al 2001). In these studies, participants could not specify the precise mechanism of infection and a few specified breastfeeding as a mode of transmission. For example in the Dominican Republic, a qualitative study by Michelle et al (2003) showed that women knew about heterosexual transmission and seldom mentioned vertical transmission especially breast feeding as a mode of transmission of HIV. In Nigeria, 70,6% of mothers of infants at a hospital believed that a mother can transmit HIV to her child while only 58% believed that a baby could be infected through breast milk (Kayode CM et al 2002). If communities do not understand the mechanism of MTCT, this might lead to scepticism about the effectiveness of the prevention programs, as was the case among the men in Botswana (Nyblade et al 2001). Education efforts will therefore be needed to correct such misunderstanding, which can jeopardize the success of a PMTCT program.

It is also important to understand the views of the community regarding antiretroviral prophylaxis in pregnancy. Perceived benefits and side effects might have an effect on the compliance with the drug regimen. In Botswana and Zambia, some community members thought that the women will become sicker once they stopped AZT (Nyblade et al 2001). Some were afraid of being discovered by their partners taking the medicine. In Tanzania women said

that their acceptance of prenatal VCT was contingent upon the provision of tangible benefits such as free antiretroviral drugs and infant feeding (De Paoli MM et al 2004). Knowledge of such views assist program managers in formulating appropriate information, education and communication materials to overcome potential barriers for taking ARV prophylaxis during pregnancy.

It is also important to understand the community's attitudes and views towards the PMTCT program. Attitudes towards PMTCT service elements such as access and availability (convenience, physical accessibility), structure of service (privacy, characteristics of venue, session and test, confidentiality etc) can have an impact on the uptake of prenatal VCT (Worthington C et al 2002). In South Africa and Cote D'Ivoire, it was found that women did not participate fully because of long waiting times, language barriers and lack of physical space for counselling (Doherty T, Besser M, Donohue S et al 2003, and Msellati P et al 2001). The counselling strategy also has an effect on uptake of VCT in South Africa. In provinces where women are given an option to receive individual pretest counselling, uptake rates are low as compared to the provinces where individual counselling is seen as an integral component of antenatal care where all women receive individual session with a counsellor (Doherty et al 2003). In other settings, it has been found that the terminology itself – mother to child transmission of HIV incites stigmatization as it solely blames the women for the infection of the child. The term parent to child transmission of HIV has been adopted under such circumstances (SEA-AIDS 2001). Program managers also need to understand how the community views the programs, their perceptions on effectiveness of intervention strategies and their suggestions on how the program could be run.

### **2.3 Voluntary counselling and testing: a vital tool for prevention of mother to child transmission of HIV**

Voluntary counselling and testing is a cornerstone of PMTCT. With the availability of antiretroviral prophylaxis in pregnancy, there was need and incentive for counselling and testing in pregnancy (MMWR 1995, MMWR 1998). Voluntary counselling and testing is a process by which an individual undergoes confidential counselling to enable the individual to make an informed choice about learning his or HIV status and to take appropriate action. As VCT services became widely available in Europe and North America, MTCT rates declined (Lindegren et al 1999, Mayaux M 1997).

Voluntary counselling and testing during and before pregnancy offers numerous advantages. Couples who wish to start or expand their families can weigh up risks and advantages of pregnancy; they make informed decisions about contraception and use of condoms. For those who are HIV negative, there is motivation to maintain safe behaviour to avoid infection and breast feed the baby for the greatest health of the infant. In a small study from Uganda, women attending VCT and MTCT and who were seronegative chose abstinence or condom use until their partners had been tested (Matovu et al 2000). For women who are HIV positive, VCT is an entry point to other HIV/AIDS services including prevention of mother to child transmission of HIV, prevention and management of HIV related illness and access to supportive groups that promote positive living (Carvalho-Neto 1989, Kaleeba N et al 1997). They can also make informed reproductive choices like avoiding unwanted pregnancies (Pugh et al, 1998)

Understanding what the communities, (both women and men) think about VCT provides a sense of how women might respond to the offer of testing during antenatal care. In Ndola Zambia, (Horizons 2003) when VCT services were introduced, people chose not to be tested as they

viewed HIV testing as a source of stress. However when the PMTCT intervention was introduced uptake of VCT services began to increase as women became aware of the benefits. Lack of tangible benefits had therefore initially hampered the VCT services. Other documented reasons for test refusal from a large scale study in antenatal clinics in Burkina Faso and Cote D'Ivoire were "to seek agreement of partner", "fear of AIDS" and the need to "make a decision later at home" (WHO 1997). In Botswana barriers for VCT included physical violence from partner (as women were considered to be the person who had brought the HIV to the family), fear of stigma and discrimination (Nyblade et al 2001). Programs should therefore not only target women, but reach all communities. One of the critical issues will be to involve men who have been found to be an oddity at most antenatal clinics in Africa. Baggaley et al 2000, report on the difficulty of including men in the antenatal VCT of many countries. In Zimbabwe 30 out of 600 women brought their partners (Baggaley et al 2000). In a Rwandan study of 1223 women screened for HIV, 70% wanted their partners to be tested but only 8% came. In Botswana uptake for VCT was less than 50% and this was due to lack of cooperation from men (Mazhani et al 2000). In PMCT programs in Zambia, it was found that involvement of male partners made a difference in women's uptake of services (Horizons 2003). Men were approached outside health centres through male community leaders. Uptake of VCT services improved. It was concluded that "providing men with information removes the onus of responsibility from women for bringing up discussion on PMTCT.

Access to VCT is directly determined by availability of health services, antenatal clinics, and it is an expression at the country level of the global inequities in wealth, skills and resources (Nicol A 1992). An evaluation of the PMTCT services in pilot sites in Zambia and Kenya (Horizons 2003) found that uptake of HIV counselling services was negatively affected by staff shortages and organisation of service delivery. A similar situation exists in South Africa where uptake ranges from 14% in some provinces to 92% in other provinces (Doherty T et al 2003). The differences

in uptake among provinces is thought to be likely to be due to differences in access to training by health staff, availability of lay counsellors and quality of counselling provided. Access to antenatal care services is one of the major deterrents to successful prenatal VCT. In developing countries access to antenatal services varies from country to country and can be as low as 20% as in Nigeria (UNAIDS 2001 ).

#### **2.4 Family planning, condom use in the context of prevention of mother to child transmission of HIV**

One of the strategies for reducing HIV infection in children is to assist women avoid unwanted pregnancies. Effective contraception with strong emphasis on condom use should be easily accessible to women and their partners. An exploration needs to be done to find out how HIV influences decisions around childbearing and contraceptive use. In Ndola, Zambia, it was found that in the absence of signs or symptoms of illness, HIV's impact on women's and men's childbearing and contraceptive use decisions is generally weak except for the observation of the burden of caring for children whose parents have died of AIDS. However, when signs and symptoms of the disease are present, both men and women are overwhelmingly against continued childbearing and support the use of condoms to prevent transmission of the disease to the spouse (Rutenberg et al 2000).

Women who are HIV positive may not always opt to stop childbearing. Studies that have explored the relationship between HIV positive status and subsequent fertility behaviour have found that known HIV status has little association with childbearing (Heyward W et al 1993, Temmerman et al 1990). In Cote d'Ivoire, most HIV positive women with children less than four were planning to be pregnant (Aka-Dago-Akribi H et al 1999). For many women with HIV childbearing may be their only means of improved self worth (Taylor 1989). Childbearing may therefore be of higher priority to them than the risk of perinatal HIV transmission to their

children. Health professionals therefore need to understand that HIV positive woman may not consider their HIV status in their decision making process about pregnancy, child bearing and contraception. Ignoring the woman's beliefs and values about motherhood may therefore alienate the woman from the very services which health professionals want to deliver. A study in New Jersey on reproductive decision making in mothers with HIV-1 found that mothers viewed motherhood as a source of joy and means of meeting their own needs and that HIV infection had a minor role in their lives (Wesley et al 2000). Women disliked providers who focused exclusively on their HIV status and not holistically on their lives. Understanding the community knowledge and practices regarding contraceptives and childbearing in the context of mother to child transmission of HIV assists in formulation of appropriate intervention strategies. If a couple knows that the baby will be at high risk of infection if infection occurs during pregnancy and lactation, motivation for condom use will be there. On the other hand those who opt to have children should have their wishes respected and offered help to reduce mother to child transmission of HIV.



## **2.5 Community perception regarding infant feeding**

Communities' perception, attitudes and practices regarding infant feeding is important in the era of HIV/AIDS. Transmission of HIV in breast milk is well-established (Burman LG et al 1992) but public health approaches to its prevention in the developing world remain problematic. One in seven children born to HIV positive mother will be infected through breast milk (Bobat R et al 1997). It is important to understand how women who personally face choices about how to feed their infants view these issues. The choice involves an understanding of the risks and benefits of breast-feeding and its alternatives. The choice involve beliefs about mothering and nurturing, not only the beliefs of the woman but those of her partner and the community (Kreiss J 1997).

Where breastfeeding is the norm as in most African settings, women are pressurized to justify reasons for not breast-feeding. Legitimate reasons for not breastfeeding have been cited as: breast diseases, cancer, insufficient milk, work, pregnancy and HIV (Pool R, et al 2001).

Research is also needed on women's knowledge about breast feeding related HIV transmission to infants and about replacement feeding methods so as to determine the information required by pregnant women. In Zimbabwe for example, there was a successful breast feeding promotion campaign. Women who were discharged from the postnatal ward were therefore not counselled about feeding alternatives. A qualitative study done on HIV positive women on infant feeding discovered that women considered both breast feeding and prevention of HIV transmission to their babies important (Misihairabwi P et al 1997). They rejected the assumption that women in developing countries had no choice but to breast feed and felt that individual needs and circumstances had to be taken into consideration. However, they could not resist the pressure to breast feed because not doing so might lead to disclosure of actual or feared HIV status. On the other hand mothers who were HIV positive regretted that they had not bottle fed their babies thereby exposing them to infection. Public health workers will be in a better position to offer advice if they are prepared to learn from those who have to make and live with some of these difficult choices.

## **2.6 Disclosure of HIV test results**

Disclosure of HIV status especially to sexual partners is an important PMTCT prevention strategy promoted by WHO (UNAIDS 1997) and CDC (MMMR 2002) in their VCT protocols. Disclosure benefits both the individual and the public. To the individual, benefits include less anxiety, increased social support (Mathews et al 1999). It also leads to improved access to HIV prevention programs and treatment with HAART and opportunistic infections. Disclosure has also been found to create awareness of HIV risk to untested partners leading to improved VCT

uptake and high risk behaviour change (Allen S et al 1992, Allen S et al 1993). It allows couples to make informed reproductive health choices that may ultimately lead to reduction in number of unintended pregnancies among HIV positive woman.

Although disclosure of HIV test result has advantages, disclosure rates have been found to range from as low as 16,7% to 86% (Medley A et al 2004). Barriers to disclosure mentioned by participants in these studies included fear of rejection, abandonment, discrimination, violence and accusations of infidelity. However, what is encouraging is the fact that majority of studies have reported positive outcomes following disclosure of the HIV status. Women reported kindness, understanding and acceptance (Gaillard et al 2000, Keogh et al 1994, Mathews et al 1999). Most of the fears of disclosure were seldom realized in real life situations. Where negatives outcomes are reported, they can be severe. For example, in Kenya, Temmerman et al 1995 reports high levels of negative sequale following VCT. Of the 324 women tested only 66(27,2%) disclosed their results to their partners. Eleven seropositive women were chased away from their home or replaced by another wife. Seven were severely beaten up and one committed suicide.

Optimal participation in PMTCT programs is difficult for women whose partners are not aware of their HIV status. Women rarely make decisions concerning their own or children's health (Molyneux CS et al 2002, Guinan ME et al 1995, Manhart LE et al 2000). Unless ways of encouraging them to disclose their HIV test results and ways of minimizing partner violence following disclosure are found, participation in treatment and PMTCT program will remain suboptimal.

**Conclusion:**

Significant progress has been achieved in prevention of HIV MTCT in developed countries. In developing countries, progress has been hampered by shortage of staff, facilities, limited access to VCT, and lack of support for women by their partners and communities. The challenge is to increase VCT uptake during antenatal care. Listening to the voices of the individuals gives insight into how to design and deliver appropriate interventions that could be widely utilized. Its therefore important for messages to go beyond the ANC clinics so as to reach other important decision makers. Health services should continue to maintain dialogue with the community to keep them informed about the purpose and availability of program services and to monitor the acceptability and impact of the program within the community. It has been suggested that programs that have not yet begun to implement interventions should begin with participatory research to ascertain how community norms affect attitudes and behaviour regarding HIV/AIDS and mother to child transmission of HIV (Rutenberg et al 1997)



## CHAPTER 3: AIMS AND OBJECTIVES

3.0 **AIMS OF THE STUDY**: To assess community perceptions, knowledge and attitudes regarding mother to child transmission of HIV in Onandjokwe District, Northern Namibia.

### 3.1 SPECIFIC OBJECTIVES

- a. To determine what the communities know about mother to child transmission of HIV and whether they define it as a problem.
- b. To determine the attitudes of the community members regarding voluntary testing and counselling during pregnancy.
- c. To investigate the community perception regarding the government's PMTCT programs.
- d. To use the information gathered from the study in improving the effectiveness and acceptance of messages and services for the prevention of mother to child transmission of HIV program in the district.



## **CHAPTER 4: METHODOLOGY**

### **4.0 STUDY DESIGN**

The study was a descriptive qualitative study that utilized in-depth interviews and focus group discussions. Qualitative study methods were chosen because of their usefulness in exploration of people's knowledge views and experiences (Kitzinger J 1994). The findings from a qualitative study reveal patterns of feelings and emotions that underlie communities and women's otherwise quantifiable knowledge about HIV and mother to child transmission of HIV. The strategy elicits information about factors that may influence attitudes or behaviour. Sensitive topics such as sexuality are also easily discussed in qualitative methods which use focus group discussions because once the "ice is broken" by one participant, others will start to open up (Kitzinger J 1995). The other advantage of qualitative methods is that they can be participatory, democratic and empowering (Kitzinger J 1994). This may result in development of new perspectives and attitudes that are health promoting (Kitzinger J 1995). Use of open-ended questions in both in-depth interviews and group interviews allowed the participants to express themselves in their own vocabulary that would be difficult in close-ended questions characteristic of quantitative methods.

### **4.1 STUDY SETTING**

The study was conducted in Onandjokwe District, Northern Namibia. Onandjokwe district is a rural district with a population of about 150 000 inhabitants. There is one 450 bed district hospital which acts as a referral centre for 13 primary care clinics. At the time of the study nevirapine based PMCT program had been going on for six months at the district hospital with the aim of rolling over to clinics once the district's capacity improves. There are about 4000 deliveries per annum at the hospital and about more than 90 % of women attend antenatal care in the district ( MOHSS 2000).

## 4.2 DATA COLLECTION METHODS

A research team consisting of the principal investigator, HIV/AIDS counsellor and a primary health care nurse was assembled to conduct the study. Training on qualitative research was conducted for the two research assistants (both females). A semi-structured questionnaire for in-depth interviews was designed in English and translated to the local language, Oshiwambo.

In-depth interviews were conducted with key informants who included community leaders like church leaders and village headmen, people living with AIDS (PLWHA) and HIV positive mothers who had participated in the PMTCT program. Topics covered were: General awareness of HIV in children, HIV transmission in children and its prevention, and perceptions on VCT in pregnancy, awareness of government PMCT programs and perceptions and views on the program. Five in-depth interviews were conducted with mothers who had participated in the PMTCT program, three with church ministers, 3 with village headmen and three with people living with AIDS. The same interview guide was used with some modifications suitable for each particular group. In most instances interviews took place at the participants' homes at times convenient for them after advance booking. A brief explanation of the aim of the study and confidentiality related issues kicked off the interview. At the end of the interview, debriefing was carried out and some quotations were read back to the participants especially on some important points. Generally interviews were carried out in a harmonious, friendly and open atmosphere. Each interview lasted about one hour. During the interview, data was recorded by taking hand written notes and tape recorder.

### **Focus group discussions (FGD):**

Six focus group discussions were conducted: three for six week post-natal women and three for first visit antenatal women. Topics discussed were the same as the ones for in-depth interviews aided by relevant probing questions. Each focus group session began with a welcome, brief introduction of the research project and setting of the ground rules. Ground rules covered issues

of confidentiality of the discussion, the fact that the session was being recorded, and that there were no wrong or right answers and that all individual opinions were important and should be respected. It was emphasized that participation was voluntary and individuals had a right to terminate their participation at any time. After the introduction, the first question was posed and the discussion proceeded. Each participant was given an opportunity to speak until the information was saturated and no new ideas were emerging. One research assistant was acting as a moderator while the other was recording responses on the flip chart. The researcher was taking notes, observing the group interaction and atmosphere and operating the tape recorder. The discussions were held in vernacular language. A short questionnaire on age, educational level and parity was administered at the end of the discussions. A summary of the main views was made at the end. Each participant was given a 750g peanut butter as compensation for the time spent during the interview and this was appreciated by all the participants.



#### 4.3 SAMPLING METHODS

Sampling was purposeful so as to reach key informants who were able to provide information rich data.

**Antenatal and postnatal mothers:** Postnatal mothers were selected before they left the clinics. After the usual clinic routine, they were informed that a study was being conducted on HIV and those willing to spare an hour to participate in the interviews were welcome. This was done for three consecutive postnatal clinic days done twice a week at the district hospital. For antenatal mothers, the researchers were introduced by the clinic staff and we briefly explained our research to the mothers before they had gone for PMCT counselling as this would introduce bias to our results. We wanted to understand their perception of HIV transmission in children before they had been taught about it. Most of those who volunteered were included in the study. Since small numbers were found no attempt was made to homogenize the groups according to key demographic variables like age, educational or employment status.

## **In-depth interviews**

**Community leaders:** Three church leaders and 3 village headmen were randomly selected from villages near the hospital.

**Women who participated in PMTCT program and PLWHA:** Systematic sampling of women who had participated in the PMTCT program and people living with AIDS was done as they came for follow up at the paediatrics clinic and HIV clinic respectively. There is one day dedicated to the women who would have participated in the PMTCT program at the district hospital. On the two days of the study every third woman was chosen. Five women were interviewed. Three people with AIDS were interviewed at the hospital. The first three volunteers were chosen by the counsellors as they came for regular follow up at the VCT centre.

## **4.4 STRATEGIES TO ENSURE TRUSTWORTHINESS OF DATA**

To ensure that the data is trustworthy, issues relating to the soundness of data were addressed. Soundness of data was maintained through measures addressing the following: credibility, transferability, and confirmability of the data (Lincoln & Guba 1985)

**Credibility:** this refers to the degree to which the research conclusions are sound. This is provided through a detailed description of the research setting and methodology. Data was also stored on the tape recorder for further analysis. Credibility was also enhanced by using different data collection methods, (triangulation), which are: in-depth interviews and focus group discussions.

**Transferability or generalisability** relates to the extent the findings can be generalized to other settings. It is provided through detailed and rich descriptions of contexts (Smalling 1992). Clear statements of the theoretical basis of the research are also made so that other readers may determine the extent to which the results might apply to other settings.

**Dependability** is another criterion for soundness which is addressed. Dependability refers to the degree to which the reader can be convinced that the findings did indeed occur as the researcher

says they did. This is achieved through rich and detailed descriptions that show how certain actions and opinions are rooted and in and develop out of contextual interactions.

Confirmability: this refers to the extent to which the data confirm the general findings and not simply the products of the researcher's bias. This is achieved by comparing the findings and interpretations to the wider literature and was also done by giving feedback of the findings at the end of the interview to the participants and checking whether they agreed with them.

#### **4.5 DATA ANALYSIS**

Concurrent data collection and analysis was undertaken. This strategy enabled the researchers to go back and refine questions and pursue emerging avenues of inquiry in more depth, in the same or different settings. For example, one focus group of antenatal women complained that HIV positive pregnant women were being discriminated by labour ward staff. Subsequent postnatal focus groups and HIV positive women who had delivered were asked about this and refuted the claims. After the field study, the written and recorded materials were transcribed to English. The actual analysis began with reading through the transcribed interviews and listening to the audio records in order to get a good grasp of all the data. The key ideas and emerging themes were identified and colour highlighters were used for different themes. Themes from different groups were pooled together and integrated into common themes. This was then followed by generation of concepts that were used to organize the presentation of the results. The final write up consists of summaries, interpretations and textual excerpts which represent the common themes. The names of the participants are fictional due to the anonymous nature of the study.

#### **4.6 ETHICS**

Ethical clearance for the study was obtained from the Ethical Committee of the University of the Western Cape (UWC) and permission to conduct the study was granted by the Ministry of Health and Social Services (Namibia). The researchers understood the sensitive nature of the HIV problem and stigmatization which is heavily attached to the condition and as such, ensured confidentiality and anonymity by not divulging names of the participants in the report and also safe storage of field notes and tapes. Participation in the study was on an informed consent and voluntary basis and the right to withdraw from the study at any time was guaranteed. With the permission from the UWC, the findings and recommendations from the study will be presented to the Ministry of Health (Namibia) for possible implementation.



## **CHAPTER 5: RESULTS:**

### **5.0 Demographic characteristics**

Forty-four women participated in the six focus group discussions. Each focus group consisted of between six and eight women. The median age was 25 years, ranging from 18 to 46 years. The parity ranged from zero to eight with an average of three children. On the educational status, only two of the women had no formal education. Eight women (18,2%) had attained primary education, 34(77,3%) had attained secondary education and no woman had attained tertiary education. Most women came from poor socioeconomic backgrounds.

### **5.1 Community awareness of HIV/AIDS in children**

In order to get an insight into the community's understanding of HIV/AIDS, participants were asked to state what they understood by the term HIV/AIDS in their settings. The following is a list of local definitions of HIV/AIDS which were prominent in both FGD and in depth interviews.



#### **5.1.1 Local definitions of HIV/AIDS**

- Omukithi kaaguna epango - an incurable disease
- Omukithi hagu taandele pamilalo dhofanyama: - a sexually transmitted disease
- Omukithi omudhipangi, omuntu ha kanitha olutu - deadly disease
- Moving skeleton - represents the wasting syndrome
- Moving grave - also denotes a deadly and incurable disease.

The presence of such local definitions is an indication that HIV/AIDS is among the people. The prominent definitions for AIDS/HIV were that it was a sexually transmitted disease which is deadly and incurable. The participants were further asked whether they were aware of HIV/AIDS in children. In both focus group discussions and in depth interviews, participants were aware of

the presence of HIV/AIDS in children. HIV was viewed as a disease which is not restricted to any particular age group. Participants were witnessing many premature deaths, something which never used to happen before:

*If you open the death notices in the local newspaper, you see many deaths, children and the old. One would not expect so many deaths especially in children. AIDS is killing children, let's face it (female participant, antenatal FGD).*

The participants had also noted that there was an emerging pattern where parents were dying leaving children behind. Some of these children would die just after the deaths of their parents:

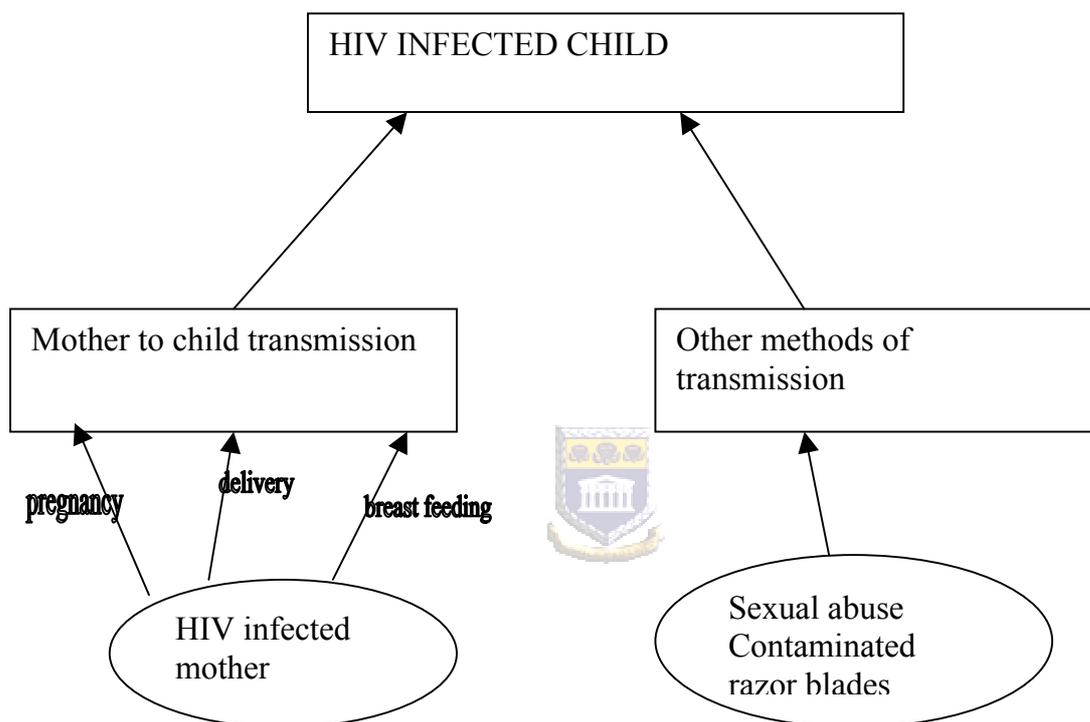
*First you hear that the mother has died. Within a short period of time the father follows, and then finally the child. This can only be this new disease AIDS. It's taking both young and old (35 year old pastor, in depth interview).*

Other participants had personal experience of having seen children with HIV/AIDS in their families, villages or at their church. Participants were then asked to mention some of the features of HIV/AIDS in children. Features mentioned included :poor weight gain or loss of weight, oral sores, recurrent illness, frequent hospitalisation, diarrhoea and vomiting, and skin changes. It was interesting to note that participants knew that although features like oral sores and diarrhoea were common in children, those with HIV infection were more likely to have recurrent or persistent diarrhoea and oral sores. Participants emphasized that despite the presence of physical signs, the only sure way of knowing whether the child had HIV infection was through a blood test.

## 5.2 Knowledge and perception on modes of HIV transmission in children

The diagram below illustrates the different modes of transmission as perceived by the participants:

Figure 1: Modes of HIV transmission in children



The participants generally understood the modes of HIV transmission in children. Most women who had participated in the postnatal FGD who had delivered at the hospital had obviously heard about MTCT during pregnancy. Most of them stated that they knew about it even before they came for antenatal care. The commonest source of information was the radio followed by health education at the clinics and the television. A few had read about HIV transmission in children in newspapers or had learnt about it at school. The participants also knew that besides mother to child transmission, HIV transmission would occur through cutting of skin with contaminated

razor blades by traditional healers. False modes of transmission like sharing food, kissing were not mentioned. Sexual abuse of children as a means of transmitting HIV to children was rarely mentioned in the focus group discussions.

When participants were asked to mention where most transmission occurred during mother to child transmission, breast feeding and pregnancy were the commonest. This was stated by both postnatal women FGD and antenatal FGD. The prevalence of mother to child transmission of HIV was perceived to be very high by the communities:

*It's difficult for an HIV positive mother to deliver an HIV negative baby. If ten HIV pregnant women deliver, all the ten babies will be HIV infected unless a miracle happens (70 year old headman, in depth interview).*

*When the baby is in the womb, he feeds from his mother. The blood of the mother goes with food to the baby. They say HIV is in blood. Therefore it will also be transported to the baby together with food. All babies of HIV infected mothers will be infected that way. (Female participant, antenatal FGD).*



Most of the participants shared the above sentiments. The risk of MTCT of HIV was estimated to be around 90% to 100%.

We further asked the participants to tell us what they thought could be done to prevent mother to child transmission of HIV. Common themes on prevention of mother to child transmission of HIV were: avoiding breast feeding, using condoms during pregnancy and breast feeding and testing pregnant women and offering them a drug which reduces transmission to the baby during labour. Most participants had heard about the drugs used in PMTCT through the radio:

*These days we hear through the radio that pregnant women should go to the hospital and get tested for HIV. They say there are medicines which are given to pregnant women to prevent the transmission of the virus to the baby. (65 year old headman, in depth interview).*

One PLWHA and most women who had participated in the PMTCT program who were interviewed individually strongly discouraged HIV positive people from childbearing as a means of preventing MTCT of HIV.

*Why should an HIV positive woman continue to have more children? It can be a source of burden. When a woman is pregnant again, she can become weaker again apart from having an HIV infected child. (28 year old single mother with HIV).*

The use of condoms during pregnancy and breast feeding and avoiding breast feeding as means of preventing mother to child transmission of HIV generated a lot of debate: We probed further on the issue of not breast feeding:

*Facilitator: Ruth mentioned avoiding breast feeding as a means of preventing HIV transmission to babies. What do the others feel?*

*Dinah: It's a difficult decision. The infant formula in the shops is expensive. A few people will afford and babies will die from lack of food. Its better to breast feed.*

*Sara: The government should try and assist poor people with lactogen (an infant formula). The family can also assist. Otherwise if the child is breast fed he can be infected again.*

*Dina: We are told by the nurses that one can breast feed up to 4 months. They say it can reduce infection. Those who are poor can try this method.*

*Ndeapo: If you don't breast feed, people start gossiping. It's a big problem. They will start saying that Mrs So and So is not breast feeding because she has AIDS. Some even accuse non breast feeding women as promiscuous.*

Participants were aware of the superiority of breast feeding over formula feeding. This included the bonding of mother and child and prevention of diarrhoea and other childhood illnesses. Not breast feeding was therefore a difficult decision to make. Women who had opted for formula feeding stated that at times they felt as if they had failed their children by not breast feeding them. According to them, breast feeding was a source of maternal joy which everywoman was supposed to experience.

Use of condoms in marriage is always a difficult issue in marriage in Sub Saharan Africa. We therefore probed further on the community perceptions regarding condom use:

*Facilitator: What do you think of condom use during pregnancy and breast feeding?*

*Hilma: If husband and wife were tested and are negative, it's difficult to convince the man to use a condom. He will simply say that you don't trust him (laughter).*

*Otilia: I will make sure that he uses condom. If i get HIV infection, it is my child and i who suffer. Men don't care.*

*Emma: Men move around a lot (have multiple partners) especially when the wife is pregnant. So even if you were negative during the start of the pregnancy you can end up getting infected. The only way out is to use a condom, whether he likes it or not.*

*Julia: Information must be provided to men also. You health workers only talk to us women. Go to the villages and convince men to use condoms if they can't stay at one place.*

It was clear that although women were aware of the effectiveness of condoms in preventing HIV transmission implementation was a problem because of lack of partner support. One pastor summarised this during an in depth interview:

*From the church's point of view, we support abstinence and faithfulness to preserve the sanctity of marriage. We therefore normally don't discuss issues of condoms. However, I think that couples should always discuss issues of HIV infection and consider whether to use condoms if there is mistrust. Men are the chief culprits and need to change their behaviour towards their wives. (55 year female pastor, in depth interview.)*

### **5.3 Voluntary testing and counselling:**

#### **5.3.1 Reasons for seeking an HIV test:**

We wanted to explore some of the reasons the communities thought were for having an HIV test. The common reasons cited by the participants were: knowing one's status, recommendation by the doctors and nurses when one was sick and when taking some insurance policies.

Most of the participants in both in depth interviews and focus group discussions cited knowing one's status as the most common reason why people were tested for HIV. We further asked the participants why it was important to know one's HIV status.

#### **5.3.2 Benefits of knowing one's HIV status:**

A question was raised as to whether testing for HIV was good. Most of the respondents were happy to be tested themselves and their fellow villagers:

*It is a good idea to test people. If I had the power I would test all the people in my village. This helps people to change their behaviour. The one who tests negative will wish to remain so by using condoms. One who is positive will also stop taking alcohol and smoking which are detrimental to health (66 year old headman, in depth interview).*

Numerous benefits of knowing one's status were mentioned during the FGDs. Participants emphasised that those who knew their status were free people. Those not knowing their status ran the risk of always viewing themselves as HIV positive even if they were negative. Other benefits are summarised by excerpts below:

*If you are HIV positive, you can get early treatment. These days we hear of medicines which can reduce the HIV in the body. We are told that when the virus is less in the body one can live a long time. It's therefore better to know your status. (40 year old female pastor, in depth interview).*

*Knowing one's status opens doors to many opportunities. You can also get support from friends and family if you are HIV positive. They will offer you food and counselling. You also get treated early from many other diseases like TB. (29 year old female living with HIV/AIDS, in depth interview).*

Participants therefore generally supported testing for HIV. We wanted to know whether there were some reasons why some people refused testing or whether there were disadvantages of getting tested for HIV.

### **5.3.3 Reasons for refusal of HIV testing/ disadvantages of getting tested for HIV.**

One of the commonest reasons cited for refusal of HIV testing was the fear of the positive result. The participants felt that a lot of people had difficulties in accepting a positive result. These people viewed a positive result as the end of their world.

*Some people fear to get the positive result. To them that's the end of the world. They say that if they know that they are positive; they will die early because they will start to think a lot. They can't stand the thought of being seen with symptoms of HIV (female participant, postnatal FGD).*

Those people who viewed an HIV positive result as the end of the world ended up committing suicide. Most of the participants knew or had heard of somebody who had committed suicide after testing HIV positive.



We therefore probed further on the issue of suicide:

*Facilitator: Why do you think that people commit suicide after learning that they are HIV positive?*

*Negonga: They get confused. They wonder how they got it and just can not stand it.*

*Aune: They become ashamed. They are afraid of what people will say, especially about how they got the virus. They also fear to be seen going down with signs of AIDS. For them its better to die before people can see.*

*Rauna: AIDS is not like any other disease. It's sexually transmitted and so people are afraid that they will be called promiscuous.*

*Alice: Some people fear to be rejected by their family and friends. So before this happens, they would rather die.*

The participants also argued that while other people would change their behaviour for the better after knowing their HIV status, others changed for the worse by deliberately spreading the virus so that they would not die alone:

*At times it can be bad to know your HIV status. There is this lady who was my classmate who tested HIV positive. She told me that she was going to retaliate by not using condoms during sex. She says she will not die alone. I don't agree with such ideas. (28 year old female HIV positive, in depth interview)*

*When some people discover that they are HIV positive, they become reckless with their lives. They just take any men/woman they come across. This is very dangerous. (female participant, antenatal FGD)*

It was established from both FGD and in depth interviews that refusal for HIV testing was mainly due fear of an HIV positive result, shame and guilt for having acquired the virus, fear of rejection and abandonment. The participants themselves did not condone the suicidal acts. They would not do so if they were HIV positive. They would rather seek counselling, go to the hospital, get treated early and eat good food so as to lead a normal life.

*Why commit suicide nowadays? We are told HIV is now like high blood pressure. One can live long by eating good food and going to the hospital when ill (70 year old headman).*



Once an individual has overcome the barriers for getting an HIV test, an uphill task remains of disclosing the HIV status to partners and significant others. Respondents were asked about their views on disclosure of an HIV test result:

*Magdalena: for a negative result, it is easy, but for a positive result this is difficult. You tell one person they tell the whole world and everyone starts talking about you.*

*Monica: AIDS is not like any other disease; you can't just tell anybody even your partner. He will start blaming you for bringing the disease. He will simply not come back to you from the South (most men in Namibia are employed in the southern part of the country which is more industrialized than the north)*

Disclosure of the HIV test result especially to partners was a big problem. Only one woman in the in depth interview had disclosed the HIV positive status to her partner. However it was easy to disclose to relatives like sisters, brothers and mothers. Failure of disclosure of HIV test result was related to fear of partner violence, rejection and abandonment. They were afraid to be cast as social pariahs accused of illegal sexual behaviour:

*You know if I tell people about my HIV positive result, they will see me as a dog. A person who was sleeping around. They will go on to say many bad things about me which might disturb me. So I have to tell only those that I know truly love me (HIV positive female participant, in depth interview)*

Two participants who were living with AIDS and had disclosed their HIV results had other views:

*It is good. You feel you have removed a huge burden from your shoulders. It's painful to keep a secret. After I disclosed my result, I felt free. More people understand now. I got lots of support and love from relatives and friends. (29 year old male Living with HIV/AIDS, in depth interview).*

We asked him why he had kept it a secret for 6 months:

*I can call it fear of the unknown. First you fear how the other person would respond. You also wonder whether people would accept you or help you when you are sick. So I was afraid until the counsellor encouraged me to share with close friends.*

The other participant noted the societal benefits of disclosure:

*Disclosing my HIV result has helped me to do something for the society. At first people couldn't believe me. I am happy. I can now give health education from a PLWHA perspective; I think it makes a difference. (Female participant, in depth interview).*

In both in depth interviews and focus group discussions participants noted that although people feared to be rejected or abandoned after disclosing their HIV status, it was a rare occurrence. All the participants said that they would not abandon their relatives but would assist where they can.

Participants also put the blame on HIV positive people for isolating themselves at times:

*At times HIV positive people just isolate themselves. Instead of telling you the truth they lie. They always think that people are gossiping about them. This is not true. How can we help if we don't know what the problem is? (Female participant, postnatal IFGD)*

### 5.3.4 Attitudes towards routine testing of pregnant women

One of the objectives of the current PMTCT program is to counsel all pregnant women for HIV testing. Those who want the test are then offered. There is no routine HIV testing without the consent of the woman. We wanted to establish what the participants thought about routine testing of pregnant woman:

*This is a good idea. If the mother is HIV positive then she will get help to reduce transmission of HIV to the baby (female participant, postnatal FGD).*

*I would personally support even testing before pregnancy. For us to have a generation free of HIV everyone has to be tested before pregnancy. If it was not done, then during pregnancy it is good. The mother will be assisted by health workers so that transmission to the baby will be reduced (male pastor, in depth interview)*

Most participants in the focus group discussion were also aware that apart from prevention of mother to child transmission of HIV other benefits of being tested were that the mother would also get treatment for the HIV and other infections. The consensus was that the best approach would be to make HIV testing a normal test done to pregnant women just like other tests. A few were worried that such an approach would result in women avoiding the antenatal care for fear of being tested for HIV.

During an in-depth interview one headman strongly supported the idea of testing all pregnant women after counselling them. He said,

*HIV is an aggressive disease, if we are to conquer it we have to be aggressive as well. Testing everyone including pregnant woman is a starting point.*

Most participants supported the idea of testing of pregnant women routinely as long as there was adequate counselling. No attempt was made in the FGD with postnatal women to find out whether they had been tested because of the anonymous nature of the study. For the antenatal women, most of them accepted the HIV test after the discussion.

We also asked the woman whether they would consult their partners before taking the HIV test. Most married women would do although there was a general feeling that men were not always

supportive of the idea of an HIV test. Women would therefore get tested without telling their partners. Only one woman out of the five interviewed in the individual interview sessions had consulted their partners or told them of the HIV test result.

#### **5.4 Voluntary Counselling and testing services at the hospital**

Most participants bemoaned the lack of adequate testing centres in the district. The availability of testing facilities only at the hospital made it difficult for people from remote places to have access to counselling and testing facilities. As one female participant in an antenatal FGD put it:

*I was fortunate that I was referred here for antenatal care because my previous pregnancy had problems, otherwise I would not have had access to this HIV counselling and testing. It's better to have mobile testing centres just like the immunisation.*

Participants who had been counselled and tested at the hospital expressed satisfaction with the location of the counselling offices. There was also privacy. However of major concern was the size of the counselling rooms which was felt to be very small. We asked the participants what they thought of the quality of the counselling that they had received. The quality of counselling was perceived to be of high standard. Counsellors were described as highly knowledgeable and compassionate.

*The counsellor was very nice to me. She helped me a lot. After telling me that I was HIV positive, she reassured me politely and was able to answer all my questions. She also treated me with dignity and respect. I never got depressed. (Female participant, in depth interview).*

A few participants had experienced difficulties like waiting a long time before they saw the counsellor and language problems. Participants could not agree on the best method of counselling between group and individual counselling:

*I like the fact that we were three people counselled at the same time. If one ran out of questions the others would ask. We were learning from each other. (Female participant, focus group discussion).*

*I didn't like that idea of being counselled in groups. I wanted to ask more questions but was afraid that if I kept on asking, the other ladies would suspect that I had HIV. (Female participant, focus group discussion).*

#### **5.4.1 Confidentiality:**

We asked the participants whether they had faith in the counsellors in terms of confidentiality:

*Ndeapo: They are trained people; it would be unlikely that they would do that.*

*Josephine: I think it is difficult for them to remember everyone they see unless if they are related or come from the same village.*

*Ndapandula: If they were divulging people's HIV status, people would have complained through the open line (open line is a radio program where the community air their complaints about any issue in Namibia). I think they keep the information to themselves.*

It was clear that the participants were satisfied that the counsellors would not divulge their HIV status to other community members.



#### **5.4.2 Waiting period for the test result.**

The HIV test result takes about one to two weeks to be processed in this setting. This is because there are no facilities to do the test at the district hospital. Blood specimens are therefore sent overnight to be processed at the central laboratory which is about 700 km away. We therefore wanted to get the participants' preferences regarding the duration of the waiting period for the result. The following excerpts are some of the typically responses:

*I prefer the same day result because I come from very far. It's expensive for me to come back (female participant, antenatal FGD).*

*Same day result is good. Waiting for a long time for the results can lead to numerous nightmares. Some people end up committing suicide because of the long waiting period. I would support the idea of getting the results the same day (female participant, antenatal FGD).*

*I would prefer to wait for a long time before I get the result. This gives me enough time to prepare myself, especially if I am positive. (Female participant, postnatal FGD).*

It was clear that participants were divided over the duration of the waiting period for the test result. All the participants who had been post test counselled were happy with the one week waiting period. They viewed the waiting period for the results as a time for reflection, giving pretest counselling a greater impact and allowing individuals to cope better with a positive result.

#### **5.4.4 Perception on treatment by maternity staff in labour ward and post natal ward:**

We wanted to get the views of the women on maternity staff members towards women in the PMTCT program. One HIV positive woman who had participated in the program had this to say:

*In the labour ward there was no problem. The problem was in the postnatal ward. The nurse just came and stood at the door shouting “are there any of you who are in the PMTCT program, I want to give nevirapine to your babies?” Obviously the other women in the room ended up knowing that we were HIV positive.*

One FGD of antenatal women spoke very bitterly about the attitudes of the maternity staff towards HIV positive woman in labour:



*Facilitator: What do you think about the way the maternity staff treats woman in the labour ward and postnatal ward?*

*Ruth: Some midwives become rude to you and don't assist you once they discover that you are HIV positive.*

*Johanna: They don't want to assist you because they fear to get infection. But they have gloves, so I don't understand it.*

*Alice: Some shout at you accusing you of all sorts of things, including being promiscuous. It's not good. I think you can help us by talking to them so that they may change*

After the above complaints were raised, we centred our subsequent in depth interviews with women who were HIV positive on the subject of discrimination by the maternity staff. None of the four HIV positive women we interviewed had experienced such problems. One postnatal FGD which we conducted on the subject felt that the staff was not discriminatory.

#### 5.4.5 The Future:

We finally wanted to know what the participants thought about the future in terms of combating HIV especially in children. Once that question was asked, the atmosphere in room became gloomy:

*Facilitator: How do you see our country in the next 10 years? Do you think that we will conquer the virus especially transmission to children?*

*Ndeapo: Unless people change their behaviour, we will all perish.*

*Juliana: People should be tested, when you know your result, change your ways, that way we will win.*

*Sara: Let's be aggressive. Testing all pregnant women and assisting them so that their babies are born without infection. Otherwise we will lose the battle.*

*Helena: Without God's intervention, I don't see us winning. Lots of information is being given, through the radio, the TV, newspapers, everywhere but people are not changing. There is no hope.*



## CHAPTER 6: DISCUSSION

This study was designed to determine whether the community is aware of mother to child transmission of HIV, their perceptions towards voluntary counselling and testing for HIV infection, attitudes towards perinatal HIV testing and the newly commissioned government PMTCT program. Such information is important in designing appropriate intervention messages for the PMTCT program.

For the community to actively participate in health promotion programs, it is important to know whether they view a targeted health problem as a threat to them. It is against this background that we wanted to assess whether the communities were aware of HIV infection in children. There were many local definitions of HIV/AIDS. These included an incurable disease, a deadly disease and other derogatory stigmatizing names like moving skeleton and moving grave both of which represent a deadly disease. The fact that AIDS/HIV has local definitions shows that disease is among the people.



All the participants regarded HIV as a problem in children in their localities. Prominent features of HIV in children which the participants cited were poor weight gain, loss of weight, diarrhoea and vomiting, oral sores, recurrent hospitalisation, frequent sickness, skin and hair changes. In clinical paediatric practice, these clinical features also predominate. The participants were able to distinguish ordinary diarrhoea from HIV related diarrhoea which they correctly referred to as non-stop diarrhoea. The fact that the participants were highly knowledgeable about the symptomatology of HIV in children may mirror the high prevalence of the disease in the community.

After making sure that the participants were aware of the presence of HIV in children, it was necessary to get their views on the possible modes of transmission. The level of community

knowledge about HIV influences the context within which couples make decisions about the prevention of mother to child transmission of HIV. Health promoters should harness that knowledge and incorporate it into the health promotion programs. The participants in this study showed a high level of knowledge about the modes of transmission of HIV in children. Most participants correctly mentioned mother to child transmission as the primary route through which children acquire HIV infection. However, the knowledge about the relative contribution of the three points: pregnancy, delivery and breast feeding to MTCT was lacking. Participants in this study cited that HIV transmission was commonest during pregnancy and breast feeding. The most transmission of HIV has been found to occur during the intrapartum period. The findings in this study are similar to those of Mukuka (2000) and Nyblade et al (2001) in Zambia and Botswana respectively. In both studies, communities thought that most transmission occurred during pregnancy. There is therefore need to improve the knowledge of the counsellors so that they can correctly inform the community about the timing of MTCT of HIV. Women will be motivated to take nevirapine or other drugs when labour starts if they are aware that most transmission of HIV occurs during this period.

Other modes of HIV transmission in children cited by the participants include use of contaminated razor blades by traditional healers. Surprisingly sexual abuse of children was rarely mentioned spontaneously in a society where this is highly rampant. It was encouraging to note that participants were aware that HIV can not be transmitted by shaking hands, kissing, sharing food or staying in the same house with the infected person. This may be a result of successful awareness campaigns through the media, health education at clinics and other channels of information dissemination. Such knowledge can also be used to counter stigma and discrimination.

The participants overestimated the risk of mother to child transmission of HIV. Vertical transmission rates in Africa are estimated to be around 15-30% during pregnancy and labour, when infants are breastfed an additional 10-20% risk of infection occurs (Kreiss 1997, Nduati et al 2000). Participants in this study estimated the rate to be anything from 90 to 100%. Hentgen V et al (2002) found that even health workers overestimated the risk of vertical transmission of HIV. In their study, 73% of health staff (who included physicians, midwives, nurses, medical students and nursing auxiliaries) believed that a child born of an HIV positive woman would systematically be infected. Whether such an overestimation by our participants will motivate the community to participate in PMTCT programs remains to be seen. Counselling programs also need to correct this misconception.

Participants were aware of the methods of prevention of mother to child transmission of HIV. They were aware of the intrapartum antiretroviral prophylaxis. They had heard about this mainly through the radio. Other methods cited were: avoiding breast feeding and use of condoms during pregnancy and lactation. None of the participants mentioned the role of obstetric interventions in PMTCT.

Avoiding breast feeding and using infant formula was one of the most favoured methods for prevention of HIV transmission. Participants acknowledged that this was a difficult choice. Barriers to use of infant formula cited were: poverty, therefore unable to buy formula, fear of being labelled as being HIV positive, being accused of showing off and promiscuous. Nyblade et al 2001 found similar findings in Zambia and Botswana. In their study, participants noted that non breast feeding women are closely scrutinised by family members and community residents and are often pressurised to justify reasons for not breast feeding. Health workers therefore need to understand the difficulties which women who opt not to breast feed face in order to develop appropriate messages to the community.

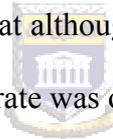
Condoms use during pregnancy and lactation was also mentioned as one of the PMTCT methods. None of the postnatal women interviewed during in depth interviews were using condoms or family planning as they said they were not sexual active and they had been with their partners since delivery (they were interviewed at six weeks). In the FGD we didn't try to establish this due to the sensitive nature of such issues. The general consensus was that while a decision to use condoms during pregnancy and lactation was a noble one, men were not always cooperative. In a study in Zimbabwe, Mbizvo et al (2001) found that among 372 HIV negative pregnant women who were enrolled, 66(17,7%) seroconverted during follow up. Those who seroconverted were more likely to be married and those who didn't seroconvert were significantly more likely to have used condoms with their partners. In Sub-Saharan Africa patriarchal structures dominate and relationships are characterized by gender inequality. Men have a final say in making family decisions, including whether or not condoms are used. Health promotion messages need to be designed in such a way that they move away from the clinic setting where men are a rarity.



Most participants were aware of the availability of HIV counselling and testing services at the hospital. The main reason for seeking an HIV test was cited as knowing one's status. The advantages of knowing one's status included sexual behaviour change by consistently using condoms and desisting from having multiple sexual partners, getting counselling and other support services including early treatment with antiretroviral therapy if one was HIV positive. It has been found that there are compelling arguments made for the importance of providing HIV VCT services, Dezoysa et al (1990). A recent multi-country study on the efficacy of HIV VCT demonstrates the important role of VCT as an HIV preventive strategy (Gregorich et al (1999), Voluntary Counselling and Testing Study Group (2000). In these studies, there was increased condom use and fidelity to one partner following VCT. It is encouraging to note that the participants were aware of the benefits of VCT. The recent introduction of antiretroviral drugs

into the armoury of HIV management may explain why most participants were supportive of VCT. The goal of combating AIDS might be achieved if the knowledge is translated into action.

Antenatal and perinatal HIV testing was considered as a good initiative by most participants. Perceived benefits included enrolment into the PMTCT program and access to HAART for pregnant women. A comparison of 13 studies in urban areas mainly in Africa showed that VCT is acceptable to pregnant women who want to reduce the risk of transmitting HIV to their children (Cartoux et al, 1998). Other studies have also linked knowledge, (Messiah A et al 1999) specifically knowledge of a medicine to reduce perinatal transmission (Curusi D et al 1998) to HIV acceptance during pregnancy. During the first six months of the PMCT program in our setting the acceptance rate has been increasing as more people are becoming aware of the program and more information is being disseminated about the benefits of perinatal VCT. Elsewhere, Simpson et al (1998) showed that although most women (88%) thought that the offer of HIV testing was a good idea, the uptake rate was only 35%.



Most participants in our study were supportive of routine prenatal HIV testing as long as there was adequate pretest and post test counselling. Simpson et al (2003) found similar findings in the United Kingdom. In their study, most women found HIV testing to be acceptable as a routine test. This has resulted in some health authorities adopting this “opt out” approach to prenatal testing (Jayaraman G et al 2003). Under this approach, HIV testing is routinely done for all pregnant women seeking prenatal care unless they specifically choose not to be tested (Jayaraman G et al 2003) as opposed to the “opt in” approach where women actively choose to be tested themselves. When the “opt out” approach was introduced in Alberta, Canada, there was a dramatic and sustained increase (28%) in rates of prenatal HIV testing (Jayaraman G et al 2003). Similar trends have been reported in the United Kingdom and United States (Stringer E et al 2001, Simpson et al 1999, Blott et al 1999). In these countries the

proportion of women tested for HIV infection increased from 33-74% under opt in policy to 81-88% under the opt out policy. In these studies and ours, women might not accept HIV testing in the “opt in” approach as they might fear to be considered as high risk and therefore more likely to be HIV positive. This therefore leaves room for introduction of routine mandatory voluntary testing and counselling in our setting.

It is important for health workers to understand some of the reasons why women might not seek HIV testing in pregnancy in spite of being aware of the advantages. Themes which emerged in this study about the reasons for refusal of HIV testing included fear of stigma, rejection and fear of the psychological stressful situation of accepting an HIV positive result. Such fears also led some people to commit suicide or conceal their HIV positive status to their partners and relatives. It was noted that even though the fears of rejection and discrimination were mentioned none of the participants who had disclosed their HIV status to their relatives had experienced them. Our findings concur with those found by Keogh et al (1994), Gielen et al (1995), and Heyward et al (1993). In these studies the majority of women were found to experience support and understanding from their partners upon disclosure of their HIV test result. Of major concern in our study was the lack of disclosure by HIV positive women to their partners except for one woman. The other four had only disclosed to their relatives. Reasons for not disclosing were fear of violence and rejection by the partner. Such lack of disclosure to partners is a potential deterrent to PMTCT efforts. A partner not aware of his HIV status is unlikely to cooperate in risk reduction behaviour, use of condom during pregnancy and other PMTCT components. A large study needs to be done in our setting to ascertain the real level of partner violence following disclosure so as to design strategies to counter it.

Concerns about negative social consequences of getting an HIV test and disclosing it if positive can be real. Temmerman et al (1995), Maman S (2002) found that a significant proportion

(prevalence of 5,9% and odds of physical violence HIV positive was 2,6 ;95% CI 1,23; 5,63 respectively) of their interviewees had suffered physical violence upon disclosure of their HIV status. Such concerns need to be addressed by reassuring the community that although discrimination and rejection exist, they are rare while efforts are being made to destigmatise the disease.

The commonest reason for refusal of HIV testing cited by our participants was the fear of an HIV positive result which was seen as depressing and shameful to the recipient. Similar results were found in Nigeria where 75% of those who opposed routine HIV testing cited the fear of a positive result as the major reason (Orji E et al 2001). In our study participants cited that people could not easily accept an HIV positive result as they feared to think of undergoing the suffering which they had seen HIV positive people experiencing. This calls for measures to be put in place to mitigate against the impact of the suffering which AIDS patients go through, like strengthening hospice services and provision of highly active antiretroviral drugs. It is hoped that as many people's health condition improves on HAART then more people will be more willing to accept the HIV positive result and hence come forward for testing.

We also investigated the participant's views of HIV testing services to determine the elements of testing services of concern to the test recipients in order to generate recommendations for improvement of service delivery. In recent years, the explicit incorporation of consumer views into program design and enhancement has been advocated (Dehar M et al 1993, Temmer M 1994). One of the major concerns raised by the participants was the lack of counselling services at sites other than the hospital. The service was therefore benefiting only residents staying within the vicinity of the hospital. There is therefore need to build the district's capacity to handle the ever increasing demand for VCT services.

The participants who had used the VCT service were generally happy with the location of VCT offices at the hospital, knowledge of the counsellors on HIV issues and the duration of the counselling sessions. Participants also had confidence that the counsellors and maternity staff maintained strict confidentiality and would not divulge their HIV status to the community. In a study by Pool et al (2000) in Uganda participants were worried that counsellors and maternity staff would inform other people about their HIV status. Where such concerns exist the community will have to be assured and convinced that confidentiality is always respected. If the community is concerned about confidentiality issues, uptake of VCT services will remain low.

There were individualised care concerns which were raised by the participants. The range of opinions differed on issues of individual versus group counselling, waiting period for HIV test results and the preferred age group for counsellors. The participants were giving valid reasons for their preferences as presented in the results. This shows that there is no service that is “one size fits all”. Each of the participants wanted their individual needs to be met. It is therefore important for service providers to have choices available to meet the different needs of recipients rather than having a standardized and rigid process. Accommodating individual needs may increase acceptance of VCT services.

### **Limitations of the study:**

Voluntary participation in the focus group discussions may have introduced some selection bias. The common reason for not participating in the FGD was that the participants were coming from very far hence were afraid of missing their transport back home. This could therefore have resulted in inclusion of women staying near the hospital and who are possibly more informed about health issues than those from remote areas. The study also did not include working women as it was carried during work hours. Views presented may therefore not be representative of that group.

Although the focus group discussions were able to examine a spectrum of values, norms and meanings revealed in the discussions by the woman, the group dynamics could have had a more pronounced effect on some individuals than on others. This could have led some participants into providing “desirable” responses (Basch, 1987). One of the assistant researchers is a nurse who works in the Primary Health Care and this could have resulted in those participants who recognised her not opening up during the discussions.

One of the strengths of the study was the inclusion of community leaders like church leaders and headman. These are influential people in their communities and incorporation of their views and opinions in health promotion messages may lead to greater PMTCT acceptance.



## CHAPTER 7: CONCLUSION AND RECOMMENDATIONS

Participants in our study were highly knowledgeable about mother to child transmission of HIV. Prenatal HIV testing was considered as a good initiative. Perceived benefits were: enrolment into the PMTCT program if the mother was HIV positive and getting early antiretroviral therapy. Knowing one's HIV status was seen as the most important reason for VCT as such knowledge would help reduce HIV risk behaviour. Barriers to VCT were cited as fear of a positive result, fear of rejection, abandonment and psychological distress leading to suicide. However those negative consequences were rarely experienced by those who had disclosed their HIV status. The following recommendations can be made based on the findings in this study:

- Counsellors should emphasize that most transmission of HIV occurs during delivery and not pregnancy and breast feeding.
- There is need to make VCT services more accessible to the wider population. This can be made though training more lay counsellors and stationing them at the clinics so that counselling services and blood collection can be available there instead of clients travelling to the hospital. Integrating VCT services into the current mobile clinic services also needs to be explored.
- Prenatal VCT services need to involve more partners. In this study it was obvious that men are difficult to reach. Attempts should be made to reach men where they are for example : in villages through community health workers, work places , other departments at the hospital/ clinic
- Health education efforts should develop communication strategies that focus on both women's and men's rights and responsibilities to protect their health and to insist on condom use or deny sex to a partner who refuse condom when requested
- Most participants in this study knew of somebody who had committed suicide following receipt of an HIV positive result. This was attributed to depression, shame and fear of

rejection. There is therefore need to have community based supportive structures for people who are both HIV positive and negative. Ways of destigmatising the disease also need to be sought as stigma attached to HIV is one of the reasons for committing suicide. Awareness campaigns need to desist from using negative terminology like “AIDS kills”, “AIDS is incurable”. This can only help to fuel hopelessness and stigma.

- Community structures need to be harnessed for information dissemination. Most people had heard about PMCT through radios. This could leave some disadvantaged people out. Community volunteers, community leadership need to be involved in PMTCT prevention efforts.
- Counselling strategies should not be rigid but flexible to accommodate individual client needs. Some participants in this study had received group counselling which they didn't like. Providing choices will make VCT more acceptable.
- Since most participants were highly supportive of prenatal HIV testing, introducing an opt out approach in our setting might be worth trying as soon as possible so as to increase the VCT uptake.
- The programs managers need to devise ways of constantly receiving feedback from the clients so as to improve the running of the program. Some clients may have some negative views about the program which might lead to poor VCT uptake. Unless mechanisms are put in place to receive those views, effective program functioning can be compromised.

## REFERENCES

- H. Aka-Dago-Akribi, A. Desgrées Du Loû, Philippe Msellati, R. Dossou and C. Welffens-Ekra (1999). Issues surrounding reproductive choice for women living with HIV in Abidjan, Cote d'Ivoire. *Reproductive Health Matters*; 7(13):20-29.
- Allen S, Tice J, Van de Pierre P et al (1992). Effect of serotesting with counselling on condom use and seroconversion among discordant couples in Africa. *BMJ*; 304:1605-9.
- Allen S, Serupilira A, Gruber V et al (1993). Pregnancy and contraceptive use among urban Rwandan women after HIV counselling and testing. *American Journal of Public Health*; 83:705-10.
- Baggaley R, Sixaxhe T, Gaillard (2000). Involvement of men in MTCT intervention. *AIDS care*; 17(10):413-20
- Basch CE, (1987). Focus group interview: an underutilised research technique for improving theory and practice in health education. *Health Education Quarterly*, 14:411-448.
- Blott M, Yearwood J, Gerval M et al (1999). Routine antenatal testing is acceptable to women. *BMJ*;319:1069-70.
- Bobat R, Moodley D, Coutsooudis A et al (1997). Breast-feeding by HIV-1 infected women and the outcome of their infants. A cohort study from Durban, South Africa. *AIDS*; 11:1627-1633
- Burman LG, Christensen P, Christensen K et al (1992). Prevention of excess neonatal morbidity associated with group B streptococci by vaginal chlorhexidine disinfection during labour. *Lancet*; 340:65-69
- Busza J (1999). Challenging HIV related stigma and discrimination in South East Asia: past successes and future priorities. New York, Population Council Horizons.
- Bulterys M, Fowler M. (2000). Prevention of HIV infection in children. *Paediatric Clin North Am*; 47:241-60.
- Cartoux M, Meda N, Van de Pierre P et al (1998). Acceptability of voluntary testing by pregnant women in developing countries: an international survey. *AIDS*; 12:2489-93.
- Carvaho-Neto LD et al. (1989). Effectiveness of preventive and educational aspects in a multidisciplinary study group with HIV infected patients' family member group, Brazil. Second International Symposium on AIDS Information and Education, Cameroon, Abstract 2.4-5.
- Connor E, Sperling R, Gebler R et al (1994). Reduction of maternal infant transmission of human immunodeficiency virus type 1 with Zidovudine treatment. *N Engl J Med*; 331:1173-80
- Curusi D, Learman, LA, Posner SF. (1998). Human immunodeficiency virus test refusal in pregnancy: a challenge to voluntary testing. *Obstetrics Gynaecology*: 91:540-5.
- Dabis F, Leroy V, Castetbon K et al.(2001). Preventing mother to child transmission of HIV-1 in Africa the year 2000. *AIDS* 14:1017-26.

Deher M, Caswell S, Duidnan P. Formative and process evaluation of health promotion and disease preventive programs. *Eval Rev* 17:204-20.

De Paoli MM, Manongi R, Kleep KI (2004). Factors influencing acceptability of voluntary counselling and HIV testing among pregnant women in Northern Tanzania. *AIDS care*; 16(4):411-25.

Dezoysa I, Philips KA, Kamenya MC et al (1995). Role of HIV counselling and testing in changing risk behaviour in developing countries. *AIDS*; 9 (supp A), S95-S101.

Doherty T, Besser M, Donoue S et al (2003). An evaluation of the Prevention of Mother to Child Transmission of HIV Initiative in South Africa: Lessons and Key recommendations. Health Systems Trust, September, Durban 2003.

Dunn DT, Newell ML, Ades AE et al (1992). Risk of HIV-1 transmission through breast feeding. *Lancet* 340; 585-88.

Gaillard P, Melis R, Mwanyumba F et al (2000). Consequences of announcing HIV seropositivity to women in an African setting: Lessons for the implementation of HIV testing and interventions to reduce mother to child transmission. The 12<sup>th</sup> International Conference on HIV/AIDS, July, Durban South Africa, pp 334.

Gielen AC, O'campo P, Faden R et al (1997). Women's disclosure of HIV status: experience of mistreatment and violence in an urban setting. *Women Health*; 25(3):19-31.

Gregorich S, Kamenga C, Sangiwa G. (1998). Impact of HIV counselling and testing on married couples in three developing countries: results from the voluntary counselling and testing study. Paper presented at the 12<sup>th</sup> World AIDS conference, Geneva.

Guinan ME, Leviton L. Prevention (1995). Prevention of HIV infection in Women: overcoming barriers. *Journal of the American Medical Women's Association*; 50:74-7.

Hentgen V, Jaureguiberry S, Ramiliarisoa A et al (2002). Knowledge, attitude and practices of health personnel with regard to HIV/AIDS in Tamatave, Madagascar. *Bull Soc Pathol Exot*;95(2):103-8.

Heyward W, Batter V, Malulu M et al (1993). Impact of HIV counselling and testing among childbearing women in Kinshasa, Zaire. *AIDS*; 7:1633-37.

Horizons (2003). HIV Voluntary Counselling and Testing: An essential component in preventing mother to child transmission of HIV. [www.popcouncil.org/horizons/horizonsreports.html](http://www.popcouncil.org/horizons/horizonsreports.html)

Jayaraman G, Preiksaitis J, Larke B (2003). Mandatory reporting of HIV infection and out out prenatal screening for HIV infection: effect on testing rates. *CAMJ* ;168(6): 679-82

Kaleeba N, Kalibala S (1997). Participatory evaluation of counselling, medical and social services of the AIDS Support Organisation (TASO) in Uganda. *AIDS care*;9(1):13-26.

Kayode CM, Adeyemo AA; Omotade OO (2002). Beliefs and perceptions about HIV infection and AIDS among mothers of infants in Ibadan, Nigeria; *West Afr J Med* 21(1):43-7.

Kreiss, J (1997). Breastfeeding and vertical transmission of HIV-1 infection. *Acta Paediatrica (suppl)* 421:113-117.

Keogh P, Allen S, Almedal C, et al (1994). The social impact of HIV infection on Women in Kigali Rwanda.: a prospective study. *Social Science and Medicine*, 38(8):1047-53.

Kitzinger J (1994). The methodology of focus groups: the importance of interactions between research participants. *Sociology of Health and Illness*; 16:103-21

Kitzinger J (1995). Introducing focus groups. *BMJ*; 311:299-302.

Kreiss J (1997). Breast feeding and vertical transmission of HIV-1. *Acta Paediatrica*, 421: 113-117.

Lambouray J L (2000). HIV and Health Care Reform in Phayao. From crisis to opportunity. UNAIDS Best Practice Collection, Geneva, Switzerland

Lincoln Y S, Guba EG. (1985). *Naturalistic inquiry*. Beverly Hills: Sage

Lindgren M, Byers R Jr, Thomas P et al (1999). Trends in perinatal transmission of HIV/AIDS in the United States. *JAMA*; 282:531-8.



Maman S, Mbwambo JK, Hogan NM et al (2002). HIV positive women report more life partner violence: findings from a voluntary counselling and testing clinic in Dar es Salaam, Tanzania; *92(8):1331-7*.

Manhart LE, Dialmy A, Ryan CA, et Al (2000). Sexually transmitted diseases in Morocco : gender influences on prevention and health care seeking behaviour. *Social Science and Medicine* ;50:1369-83.

Mathews C, Kuhn L, Fransman D, Hussey G et al (1999). Disclosure of HIV status and its consequences. *South African Medical Journal*;89:1238

Matovu S, Ekideit H, Chimulwa T (2000). AIDS counselling as strategy to prevent HIV vertical transmission. Presented at the 13<sup>th</sup> International Conference of AIDS, Durban, South Africa. Abstract C5295.

Mayaux M, Teglas J, Mandelbrot L et al (1997). Acceptability and impact of zidovudine prevention on mother to child HIV-1 transmission in France. *J Paediatr*; 131:857-62

Mazhani L, Sekgoma B, Mokopakgosi O et al (2000). Report of midterm review of the prevention of MTCT program of Botswana. Botswana Ministry of Health and UNICEF

Mbizvo MT, Kasule J, Mahomed K, Nathoo K (2001). HIV-1 seroconversion incidence following pregnancy and delivery among women seronegative at recruitment in Harare, Zimbabwe. *Cent Afr J Med*;47(5):115-8.

Medley a, Garcia-Moreno C, McGill S, Maman S (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother to child transmission programs, *Bulletin of the World Health Organisation*;82:299-302.

Mercier E 1999. Status of implementation of the pilot projects for PMTCT. Second Global Strategies for the Prevention of HIV transmission from mother to Infants. Montreal, September

Messiah A, Rey D, Obadiah Y et al (1998). HIV testing knowledge, attitudes, beliefs and practices among minorities : pregnant women of North African origin in South Eastern France. *J Natl Med Association*: 90:87-92.

Michelle E, (2003). Women's Knowledge and attitudes regarding HIV/STDs and Contraception in Portsmouth, Dominica: A Qualitative Study of Women and their Sexual decision-making. *Journal of Health and Population In Developing Countries* 3(2):1-11

Misihairabwi P et al (1997). HIV and breastfeeding: individual and policy dilemmas. *SafAIDS news*;5(3):14



MMWR 1995. US Public Health Service recommendation for human immunodeficiency virus counseling and voluntary testing for pregnant women. *MMWR*; 44:1-14

MMWR 1998. Public health taskforce recommendations for the use of antiretroviral drugs in pregnant women infected with HIV-1 for maternal health and for reducing perinatal transmission in the United States. *MMWR*; 47:1-30

MMWR (1998). Revised guidelines for HIV counselling, testing and referral; 50:1-57.

MOHSS (2000). Namibia Demographic and Health Survey.

Molyneux CS, Murira G, Masha J et al (2002). Intra-household relations and treatment decision making for childhood illness. A Kenyan case study. *Journal of Biological Science*;34:109-31

Mukuka C (1999). Mother to Child Transmission Intervention: a report on formative research conducted in Chipata Health Centre and its catchment area. Ministry of Health, Zambia.

Msellati P, Hingst G, Kaba F et al (2001). Operational issues in preventing mother to child transmission of HIV-1 in Abidjan, Cote d'Ivoire, 1998-99. *Bulletin of the World Health Organisation*; 79(7):641-47.

Nduati R, John G, Mhori-Ngacha D, et al (2000). Effect of breast feeding and formula feeding on transmission of HIV-1. A randomized clinical trial. *Journal of American Medical Association*; 283:1167-74.

Nicoll A (1992). Infant feeding policy and practice in the presence of HIV-1 infection. *AIDS & Public Policy*; Spring: 18-27.

Nyblade L, Field ML (2001). Women, communities and Prevention of Mother to Child Transmission of HIV: Issues and findings from community research in Botswana and Zambia. International Council for Research on Women, Population Council, June.

Orji EO, Sotiloye D, Fawole AO et al (2001). Attitude of Abeokuta pregnant women to routine human immunodeficiency virus screening. *Nigerian Journal Med*; 10(4):173-6

Peckham C, Gibb, D (1995). Mother to child transmission of human immunodeficiency virus infection. *N Engl J Med*; 333:2.

Pool R, Nyanzi S, Withworth JAG (2001). Attitudes to voluntary counselling and testing for HIV among pregnant women in rural South West Uganda. *AIDS care*; 13(15):605-15.

Pool R, Nyanzi S, Whitworth JA (2001). Breast feeding practices and attitudes relevant to the vertical transmission of HIV in rural South West Uganda. *Ann Trop Paediatr*; 21(2):119-25.

Pugh G, Narciso S (1998). Reproductive health counseling among PHLAs. Presented at the 12<sup>th</sup> International Conference on HIV/AIDS, Geneva, Switzerland, Abstract 60711.

Rothernberg K, Paskey S, Reuland M et al (1995). Domestic violence and partner notification: implication for treatment and counselling of women with HIV. *Journal of American Medical Women's association*, 50:87-93.

Rutenberg N, Field ML, Nyblade L (2002). Community Involvement in the Prevention of Mother to Child transmission of HIV: Insights and Recommendations. International Council for Research on Women, Population Council, June.

Rutenberg N, Biddlecom AE, Kaona FAD 2000. Reproductive decision making in the context of HIV/AIDS: a qualitative study in Ndola, Zambia. In *International Family Planning Perspectives*; 6(3): 124-130

Scarlati G 1991. Pediatric HIV infection. *Lancet*; 348:863-868

SEA-AIDS 2001. Stigma and discrimination: Barriers to All Our Work. 6<sup>th</sup> ICAPP 5-10 October 2001. Melbourne, Australia. Copyright SEA-AIDS 2001.

Simpson WM, Johnstone F, Boyd F et al (1996). Uptake and acceptability of HIV testing: a randomised controlled trial of different methods of offering the test. *BMJ*; 316:262-67.

Simpson WM, Johnstone ED, Goldbert DJ et al (1999). Antenatal HIV testing: assessment of a routine voluntary approach. *BMJ*; 318:1660-61

Smalling A (1992). Varieties of methodological intersubjectivity- the relations with qualitative and quantitative research, and objectivity. *Quality and Quantity*, 26; 169-180.

Stringer EM, Stringer JS, Cliver SP et al (2001). Evaluation of a new testing policy for human immunodeficiency virus to improve screening rates. *Obstet Gynecol*; 98(6):1104-8.

Taylor, P. K (1989). The impact of AIDS on women's lives and implications for nurse-midwifery practice. *Journal of Nurse –Midwifery*, 35(5):273-75.

Temmerman M, Moses, S (1990). Impact of single session post-partum counselling of HIV infected women on their subsequent reproductive behaviour, *AIDS Care*; 2(3):247-52

Temmerman M, Ndinya-achola J, Ambani J, Piot P, (1995). The right not to know HIV test results. *The Lancet*, 345: 969-70.

Temmer M (1994). Formative evaluation alternatives. *Performance improvement Q*; 7:3-18.

The Breastfeeding and HIV International Transmission Study Group (2004). Late Postnatal Transmission of HIV-1 in Breast-fed Children: An individual Patient Data Meta-Analysis. *The Journal of Infectious Diseases*; 189: 2154-66.



UNAIDS (1997). *Counselling and HIV/AIDS*. Geneva, Switzerland. UNAIDS Best Practice Collection

(UNAIDS 1998). New initiative to reduce HIV transmission from mother to child in low income countries . June 29, Geneva, Switzerland.

UNAIDS(1999). *HIV in pregnancy: A review*. Geneva. Switzerland .

UNAIDS (2000). *AIDS epidemic update*. December 2000, Geneva, Switzerland.

UNAIDS (2001). *The Impact of Voluntary Counselling and Testing: A Global Review of Benefits and Challenges*, Key Material, Geneva: UNAIDS Best Practice Collection.

UNAIDS (2001). *AIDS epidemic update*. December 2001, Geneva, Switzerland.

UNAIDS (2002). *AIDS epidemic update*. December 2002, Geneva, Switzerland.

UNAIDS (2003). *AIDS epidemic update*. December 2003, Geneva, Switzerland.

Voluntary HIV-1 Counselling and testing efficacy group (2000). Efficacy of Voluntary HIV-1 counselling and testing in individuals in Kenya, Tanzania and Trinidad: a randomised trial. *The Lancet*, 356:103-112.

Wade N, Birkhead G, Warren B et al (1998). Abbreviated regimens of Zidovudine prophylaxis and perinatal transmission of human immunodeficiency virus infection. *N Engl J Med*; 339:1409-14.

Wesley Y, Smelter S, Walker S et al (2000). Reproductive decision making in mothers with HIV-1. *Health Care for International Women*;21(4):291-301.

WHO (1997). Coverage of maternal care. A listing of available information 4<sup>th</sup> Edition. WHO Geneva.

Worthington C, Myers T (2002). Desired elements of HIV testing services: Test Recipient Perspectives, *AIDS Patient Care and STDs*; 16(11):537-48.



## **APPENDIX 1: FOCUS GROUP DISCUSSION GUIDE**

### **FOCUS GROUP DISCUSSION GUIDE;**

#### **The HIV problem**

. What is HIV/AIDS?

Is it a problem in children in our community?

How is it recognized in children?

#### **Mother to child transmission**

How do children acquire HIV infection?

What factors increase the risk of transmission to children?

How can the community prevent HIV transmission in children?

#### **Voluntary testing and counselling for HIV**

How can people know of their HIV status?

Where are testing centres in your district?

What are the advantages and disadvantages of being tested for HIV? What generally would be better?

Do you think that knowing HIV status can help prevent transmission?

Why do some people refuse HIV testing?

What should be done to get more people tested in our district?

Should all pregnant women be tested for HIV? Explain? Who should they consult before testing? Should their partners be tested also?

Should people disclose their HIV status? Why or why not?

*For pregnant women: How may want to be tested? Why not for those who don't want?*

*For postnatal women: how many tested? Why not for those not tested?*

#### **VCT service delivery:**

What do you think about counselling services at Onandjokwe? Bad things? Good things

Do you think that nurses and doctors / counsellors maintain confidentiality?

What can be done here so that many people get tested?

Would it be good to have a test result the same day? Explain.

**Awareness of the PMTCT program**

Have you heard of the GVT PMTCT program? From where?

What is involved?

What do you think of such programs?

Give suggestions on how the program is run?

If you were in the program here, were you satisfied?



## **APPENDIX 2: INDEPTH INTERVIEWS: MOTHERS WHO PARTICIPATED IN THE PMTCT PROGRAM**

### **A: GENERAL INFORMATION ON HIV/AIDS**

1. What is HIV/AIDS?
2. Is it a problem in children in this community?

### **B: MOTHER TO CHILD TRANSMISSION OF HIV**

1. How can small babies become infected with HIV?
2. When did you first hear about MTCT? During this pregnancy? Or before?
3. Where did you get the information?

### **C: VOLUNTARY COUNSELING AND TESTING FOR HIV**

1. How can people know whether they are HIV infected?
2. When did you learn about your HIV status? Before or during pregnancy?
3. What made you decide to take an HIV test?
4. Who did you consult before taking the HIV test?
5. How long did it take you to get the result?
6. How did you feel after getting the result?
7. Who did you inform about your result?
8. How did the above react?
9. Did you inform anyone before you enrolled in the PMTCT?
10. Why do some people refuse testing in pregnancy?
11. What do you think should be done to get more people tested?
12. Do you think that all pregnant women should be mandatory tested?

#### **D: COMMUNITY ATTITUDES TOWARDS PLWHA**

1. How did your family members respond when you told them about your HIV status?
2. Who has been supportive to you?
3. Do you think that the HIV status of an individual should be made public? Why and why not?
4. What does the community think about people who are HIV infected?
5. Does the community assist people who are HIV infected?

**THANK YOU FOR YOUR TIME.. WE HOPE THE INFORMATION YOU HAVE PROVIDED WILL ASSIST IN FUTURE PMTCT PROGRAMS.**

#### **APPENDIX 3: IN-DEPTH INTERVIEW: PLWHA:**



##### **A: GENERAL INFORMATION ON HIV/AIDS**

1. What is HIV/AIDS?
2. Is it a problem in children in this community?

##### **B: MOTHER TO CHILD TRANSMISSION OF HIV**

1. Can HIV infect babies?
2. How do children get HIV infection?
3. **Check during pregnancy, labour, and breast-feeding?**
4. Do all HIV positive women infect their babies?
5. If the woman is HIV positive can the husband also be positive?
6. **Is mother to child transmission of HIV a problem in this community? How does the community know about this if yes?**
7. What can women and couples do to prevent HIV infection in their babies?

### **C: VOLUNTARY COUNSELING AND TESTING FOR HIV**

1. How can people know whether they have HIV infection?
2. When did you learn about your HIV status?
3. What made you decide to take an HIV test?
4. Who did you consult before taking the HIV test?
5. How long did it take you to get the result?
6. How did you feel after getting the result?
7. Who did you inform about your result?
8. How did the above react?
9. Do you think that all pregnant women should be tested for HIV? WHY AND WHY NOT?
10. What are some of the reasons for people not wanting to get tested?
11. What do you think should be done to get more people tested?



### **D: COMMUNITY ATTITUDES TOWARDS PLWHA**

1. How did your family members respond when you told them about your HIV status?
2. Who has been supportive to you?
3. Do you think that the HIV status of an individual should be made public? Why and why not?
4. What does the community think about people who are HIV infected?
5. Does the community assist people who are HIV infected?
6. What do you think can be done to reduce negative attitudes towards to PLWHA?

**E: AWARENESS OF THE PMTCT PROGRAM:**

1. Have you heard about the government's programs for prevention of mother to child transmission of HIV?
2. May you describe what is involved?
3. Do you think that the drugs given are effective?
4. Are there side effects of the drugs that you have heard?
5. Do you think that all HIV positive pregnant women should be offered that drug?
6. Would you participate in the program if you were pregnant?
7. What are some reasons people would give for not wanting to participate in the program?
8. **What are your suggestions on how the program should be run?**

**THANK YOU FOR YOUR TIME. WE HOPE THE INFORMATION YOU HAVE PROVIDED WILL ASSIST IN FUTURE PMTCT PROGRAMS.**



## **APPENDIX 4:IN-DEPTH INTERVIEWS: COMMUNITY LEADERS**

### **A: GENERAL INFORMATION ON HIV/AIDS**

1. What is HIV/AIDS?
2. Is it a problem in children in this community?

### **B: MOTHER TO CHILD TRANSMISSION OF HIV**

1. Can HIV infect babies?
2. How do children get HIV infection?
3. **Check during pregnancy, labour, and breast-feeding?**
4. Do all HIV positive women infect their babies?
5. If the woman is HIV positive can the husband also be positive?
6. **Is mother to child transmission of HIV a problem in this community? How does the community know about this if yes?**
7. What can women and couples do to prevent HIV infection in their babies
8. Have you heard of any programs in this community which are helping prevention of MTCT of HIV

### **C: VOLUNTARY COUNSELING AND TESTING FOR HIV IN PREGNANCY**

1. How can people know whether they are infected with HIV?
2. Are there ant HIV testing facilities in this area? Where?
3. Would have an HIV test if offered to you? Why and why not?
4. Who would you consult before being tested? Why?
5. When would you consider having any HIV test?
6. Would you come back for the result if tested? Why and why not?
7. If the result is positive who would you inform and why?
8. **If you had a young baby would you continue breast feeding if HIV positive**
9. Do you think that it is a good idea to be tested during pregnancy ? Give reasons.

10. Do you think that all pregnant women should be legally be required to get tested during pregnancy? And their partners?
11. Do you think that people in this community generally want to be tested for HIV? What are some of the reasons for not wanting to be tested?
12. What can be done to improve testing?

#### **D: COMMUNITY ATTITUDES/PERCEPTIONS TOWARDS PLWHA**

1. How do families react when one of their members has HIV/AIDS?
2. How does the community react and think of HIV/AIDS positive people?
3. Do you think that one's HIV status should be made public in the community? Why and why not?
4. Where do people with AIDS get most of their support?



#### **E: AWARENESS OF THE PMTCT PROGRAM:**

1. Have you heard about the government's programs for prevention of mother to child transmission of HIV?
2. May you describe what is involved?
3. Do you think that the drugs given are effective?
4. Are there side effects of the drugs that you have heard?
5. Do you think that all HIV positive pregnant women should be offered that drug?
6. Would you participate in the program if you were pregnant?
7. What are some reasons people would give for not wanting to participate in the program?
8. What are your suggestions on how the program should be run?