

**AN INVESTIGATION INTO KNOWLEDGE THAT HIV
POSITIVE WOMEN HAVE OF THE PREVENTION OF MOTHER
TO CHILD TRANSMISSION OF HIV**

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Assignment presented in partial fulfillment of the requirements for the degree of
Master of Philosophy (HIV/AIDS Management) at Stellenbosch University



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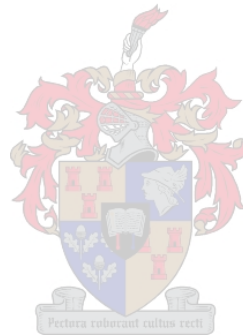
April 2006

DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously, in its entirety or in part, submitted it at any university for a degree.

Signature:

Date:



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ABSTRACT

One of the greatest challenges faced by modern society in the field of health is the devastation caused by the HIV/AIDS pandemic, which is decimating millions of people worldwide. Scientists and health care workers are busy adopting strategies to counter the pandemic. One of the key strategies that have been adopted by health organisations worldwide is the education of health professionals and people infected and affected by the HIV to understand the physiology and behaviour of this killer virus and hence to be able to manage it to prevent further infection.

This study is a small-scale study to investigate the effectiveness of education intervention and support programmes for HIV positive women who have small babies. The study was conducted through a questionnaire on a group of fifteen HIV positive women in Khayelitsha in the Western Cape. The study sought to find out what knowledge the women have of HIV/AIDS and the Prevention of Mother To Child Transmission Programme.

The findings of the study reveal that 97% of women have physiological knowledge of HIV, which is the knowledge of the virus and how it behaves in the body of the infected person. Seventy four percent of women have knowledge of the PMTCT programme and how the virus is transmitted from mother to baby and 73% of the women have knowledge of treatment against the disease. Whilst acknowledging that generally, women have this knowledge, this study has found that there are gaps that exist, which need to be addressed.

OPSOMMING

Die doel van die studie is om die doeltreffendheid van intervensies en ondersteuningsprogramme vir MIV positiewe moeders met klein babas te ondersoek. Die studie is binne Khayelitsha in die Wes Kaap onderneem.

Die studie bevind dat 'n redelike groot persentasie van moeders wel fisiologiese kennis van MIV het, maar dat 'n veel kleiner persentasie kennis het van die oordrag van moeder na kind. Voorstelle vir verbetering van hierdie situasie word voorgestel.

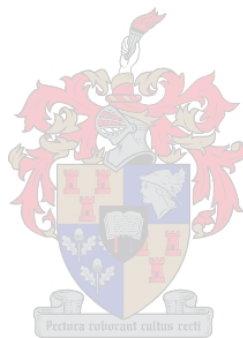


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CHAPTER 1

THE RESEARCH QUESTION AND OVERVIEW

1.1 INTRODUCTION

Humankind today is in the grip of the worst pandemic ever encountered in the world. A syndrome known as the Acquired Immunodeficiency Syndrome (AIDS) causes this pandemic (Whiteside & Sunter, 2000). A majority of scientists worldwide commonly agree that this syndrome is caused by a retro virus, which is highly adaptable and with a high degree of mutability, known as the Human Immunodeficiency Virus - HIV (Penn & Ahmed, 2003).

According to Whiteside & Sunter (2000) the first cases of this disease were reported in the United States of America (USA) by the Centre for Disease Control in 1981 amongst homosexual men. The disease was also noticed amongst haemophiliacs and recipients of blood transfusion. Whiteside & Sunter (2000) state that people with AIDS progressively develop a drastically weakened immune system as a consequence of which they became susceptible to the development of opportunistic infections like pneumonia, Kaposi's sarcoma, extra pulmonary tuberculosis and so on. An HIV infected person usually succumbs to one or more of these infections.

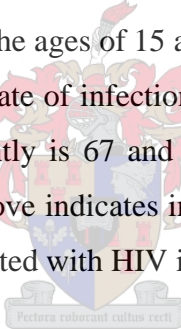
Penn & Ahmed (2003) argue that the HIV disease does have an adverse effect on pregnancy since it can lead to an increasing risk of miscarriage, stillbirth and infant mortality. The progression of the disease has sparked a huge interest amongst scientists and health care professionals. The debates amongst communities is further sparked by the reality that the virus is sexually transmissible and seems to have the potential to kill the infected person many years after the infection.

It is estimated that around 5 million people, including children became infected by HIV (Human Immunodeficiency Virus) and by the end of 2004, 39,4 million people were living with the virus worldwide.

The year 2004 saw the death of 3 million people (UNAIDS, 2004). This is in spite of the presence of ART therapy, which is readily available and effective in more developed countries as it saves many lives in those countries.

The UNAIDS report shows that, of all the people infected with HIV/AIDS worldwide, approximately 66% are from Africa. Of this percentage, 25,4% people from Sub-Saharan Africa live with the virus. The global statistics report demands that governments and organisations should see HIV/AIDS as a societal issue and Sub-Saharan Africa, in particular, needs urgent attention [[www.avert.org.worldstats.htm](http://www.avert.org/worldstats.htm)].

According to Haley & Stern (2003) it is estimated that 5.2 million South Africans are infected and this figure is growing by leaps and bounds. They say it is further estimated that 650 people die of AIDS related diseases and 1 500 are infected with HIV in South Africa every day. Prevalence studies indicate that the most infected age group with HIV/AIDS is between the ages of 15 and 19 years and between the ages of 20 and 29 years. The prevalence rate of infection in these groups is 17,5%. The life expectancy in South Africa currently is 67 and it is expected to drop below 40 by 2010. The statistics mentioned above indicates infection in 2003. It stands to reason that present number of people infected with HIV is far higher than 5.2 million.



The Western Cape Department of Health's HIV Antenatal survey results reveal that HIV infections increased from 8.6% in 2002 to 13.1% in 2003 in the Western Cape. The highest infection rates in the Western Cape are found in the black townships of Guguletu, Nyanga and Khayelitsha (Shaik & Abdullah, 2003). These statistics clearly emphasize the need for researchers to investigate the impact of HIV infection on pregnant women and their babies.

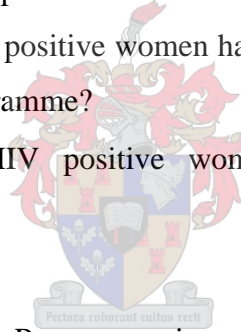
These statistics also impress on the need for researchers to make enquiries on the knowledge that women have about the Prevention of Mother To Child Transmission (PMTCT) program. The HIV/AIDS pandemic does not only affect those infected but also uproots communities and societies. HIV/AIDS threatens to deepen poverty in many nations, as an unstable diminishing labour base weakens the economy and traditional family networks dissolve (Shaik & Abdullah, 2003).

It is in the context of HIV infection in impoverished communities especially of women and their young ones that this study is undertaken, with special reference to the knowledge that women have of prevention programmes like the Prevention of Mothers to Child Transmission Programme (PMTCT).

1.2 STATEMENT OF THE PROBLEM

This study has assessed the knowledge that HIV positive women have of the PMTCT programme whilst participating or after participating in the support groups of the Mothers To Mothers To Be (M2M2B) Programme. The research questions, which this study has focused on, are the following:

- What knowledge do HIV positive women have of HIV and its transmission?
- What knowledge do HIV positive women have of the Prevention of Mother to Child Transmission Programme?
- What knowledge do HIV positive women have of the adherence to Antiretroviral therapy?



The Mothers To Mothers To Be Programme is an intervention programme to assist HIV positive pregnant women to cope with their HIV positive status and pregnancy. It also educates women about proper health management for themselves and their unborn babies and also their babies after birth. The programme was developed by Dr Mitch Besser, a specialist in obstetrics, and Elaine Maane, an HIV positive counsellor at the Maternity Centre of Grootte Schuur Hospital (GSH) South Africa in 1999. Together they observed that HIV positive pregnant women lacked support. Through their hard work the first (M2M2B) programme was launched in October of 2001 at Grootte Schuur Hospital. The second site opened in April at the Site B Maternity Obstetric Unit (MOU), one of the most disadvantaged community maternity clinics in Khayelitsha, working in conjunction with the Michael Mapongwana MOU, also in Khayelitsha.

The main objective of the M2M2B programme is to support HIV positive women against stigma and discrimination, and empower them with life skills to become independent and to manage their health during pregnancy and after giving birth. Although the program is functioning positively and rendering the support that women need, the revelation to the health care team is that these women still do not comply with the prevention strategies against HIV infection, according to a health care specialist. Hence the need to investigate the knowledge that women have about the PMTCT programme becomes an important one for investigation. This is motivated by the understanding that if HIV positive women fail to attend post natal clinics due to lack of knowledge about the importance of bringing the infant for further follow up in the PMTCT program, then the problem of high infant mortality in the country will be compounded.

The high rate of HIV infection in South Africa and the high numbers of AIDS deaths amongst adults create a very huge problem for the health care system to manage. There are long lists of patients who are infected with the virus in need of antiretroviral therapy to manage the disease and the department of health has not made a dent in providing for these patients. The statistics in South Africa show an increase in the number of orphans and child headed household as more and more people succumb to the disease. It is believed that as many as 30% of all children aged between 15 and 17 years will have lost their mothers and a total of over 5 million will lose one or both parents by 2015 (Shisana & Simbayi :2002). Assumptions are made that the increase in mortality rates due to HIV infection may be the result of people not receiving treatment or because they default in following a treatment regimen. Defaulting in treatment or following recommended health strategies could be due to the existence of language barriers between HIV positive mothers and health professionals or lay counsellors.

1.3 MOTIVATION FOR THE RESEARCH

The researcher is a social worker and presently an assistant director in the Department of Social Services and Poverty Alleviation. In her capacity as assistant director she has overall responsibility for developing HIV/AIDS alleviation programmes for orphans and vulnerable children and their families.

The researcher was also a Senior Training Officer of lay counsellors in the field of HIV/AIDS, STI and TB at the Aids Training Information and Counselling Centre (ATICC) in the Western Cape Province of South Africa for a number of years. During the researcher's interaction with lay counsellors, it emerged that although women in the M2M2B support group programme have been trained about the PMTCT, they still failed to adhere to the protocol of the PMTCT. The problem of lack of adherence is further complicated by the failure of women to attend the Well Baby clinic after giving birth. This further compounds the problem of HIV infection.

The researcher consequently felt that there was a need to investigate why women lack knowledge of PMTCT, which is crucial in minimising infant mortality and the spread of HIV amongst women. An evaluation study by Chopra et al (2004) was conducted on the quality of counselling of women on the PMTCT programme. The study by Chopra et al (2004) had as its target group the lay counsellors who were doing the counselling and focussed on the quality of the counselling whilst this research had as the target group HIV positive pregnant women and those who had already given birth but have participated in the PMTCT program.

The results of their study showed that women who received proper counselling of Voluntary Counselling Therapy (VCT) and proper PMTCT understood the importance of the postnatal attendance (Chopra et al, 2004). This study has some relevance to the previous study because it is also checking the understanding of HIV positive women whilst the Chopra study only focussed on the role of lay counsellors in providing information to the women, this study has directly interacted the HIV positive women and has investigated their understanding of the PMTCT.

1.4 LITERATURE STUDY

1.4.1 CONTRACTION AND TRANSMISSION OF HIV

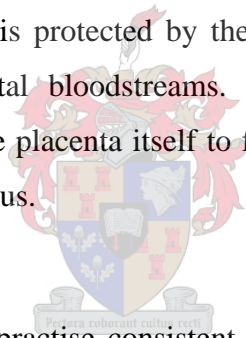
Whiteside & Sunter (2000) state that the predominant mode of contracting the virus in adults is through the transmission of infected bodily fluids (semen, vaginal fluid and infected blood) that enter the bloodstream primarily through unprotected sexual intercourse. Secondly, adults can contract the virus through contact with infected

blood such as inadequately screened blood transfusion. They also state that untreated sexually transmitted infections increase the risks of HIV transmission.

UNAIDS (2002) reports that, of the people infected with the HI virus worldwide, half are women, who in turn, tend to infect their children.

Children primarily contract the virus via the mother during pregnancy, through blood exposure across the placental wall or in the birth canal during the birth process. As many as one million African children are infected this way. This is known as the Mother To Child Transmission (MTCT) or vertical transmission. Meldrum (2003) defines vertical transmission as the transmission of the virus to the foetus through the placenta.

Penn & Ahmed (2003) explain that vertical transmission occurs in various ways. While in the womb, the foetus is protected by the placenta, which forms a barrier between the maternal and foetal bloodstreams. For infection to occur during pregnancy, it is necessary for the placenta itself to firstly become infected before the virus can be passed on to the foetus.



However if the mother fails to practise consistent correct use of condoms with her partner, the virus can be passed on to the foetus. Infection is also possible during labour and delivery, when a large amount of the mother's blood is exposed to the foetus during birth.

Breastfeeding is reported to carry a lower transmission risk especially if the HIV positive woman correctly and consistently practises safer sex to ensure that her viral load remains low (Whiteside & Sunter, 2000).

Penn & Ahmed (2003) concur with this view and state that women exposed to the PMTCT programme usually obtain the knowledge and skills to take care of themselves and the unborn. The Prevention of Mother to Child Transmission

(PMTCT) is a programme whereby women are educated about proper ways of preventing infection by the HI virus from the mother to the baby.

Such interventions, which focus on the antenatal administration of antiretroviral drugs have an implicit programme of reducing the number of children born with HIV and at the same time render appropriate health management to women whilst pregnant and after care when the baby is born (SAFAIDS, 2004). Antiretroviral drugs are drugs, which are used to reduce the number of viruses in the body by boosting the immune system. (Whiteside & Sunter, 2000)

The (UNAIDS, 2002) report highlights that, in developing countries, the average risk of HIV infection in the absence of any intervention is 20 to 40 percent. It further states that mothers with a high viral load in their blood have an increased risk of transmitting the virus to their babies. Meldrum (2003) also states that the lower the CD4 cell count and the higher the viral load, the higher the chances of the foetus being infected prenatally.

According to Chopra, Jackson, Ashworth and Doherty (2004) researchers cannot quantify the risk of HIV transmission during pregnancy or childbirth. They state, however, that the Grootte Schuur laboratory to the PMTCT program reveals that the foetuses of women with CD4 counts that are below 200 stand a very high probability of infection by HIV if proper interventions are not in place.

Between December 2003 and February 2004, a survey of CD4 cell counts of pregnant HIV positive women was done in maternity obstetric units (MOU) of Khayelitsha, Guguletu and Vanguard clinics.

It was found that 15% of the Khayelitsha women, 20% of the Guguletu women and 12% of the Vanguard women had their CD4 cell counts below 200. This is an issue, which raises concern about the possibility of HIV infection rates amongst children (Shaik & Abdullah, 2004). Women who are at early and later stages of HIV infection are at higher risk of transmitting the virus to their babies.

Penn & Ahmed (2003) report that HIV disease does have an adverse effect on pregnancy, increasing the risk of miscarriage, stillbirth, foetal abnormality, neonatal death, infant mortality, intra-uterine growth restriction, low birth weight and pre-term delivery. They further note that a percentage of children born to HIV-infected mothers escape HIV infection when their mothers are introduced to HIV treatment. For this reason, women are firstly exposed to Voluntary Counselling and Testing and when they plan to get pregnant; they can go for an HIV test so that they can make an informed decision. Those who are already pregnant get tested as part of the prenatal health care. Commencement of antiretroviral treatment during pregnancy is viewed as the most effective way of reducing PMTCT of HIV.

Kalichman (2003) notes that most countries have adopted a proactive approach in attempting to educate pregnant women about the HIV virus and the potential benefits of participating in the MTCT program and starting antiretroviral treatment regimens during pregnancy and immediately during the postnatal period. This has resulted in widespread public health approaches targeting the prophylactic compliance with antiretroviral medications of prenatal clinic attendees.

Other African countries also have PMTCT programmes and in these countries problems of adherence have been experienced. For example, a study was conducted for four years in Kenya amongst 1 300 women at Karatina and 800 women at Homa Bay as well as 1 002 women at the Chipata Clinic in Zambia (SAFAIDS, 2004). These women were tracked and interviewed about their experiences of the PMTCT and their satisfaction with the services through their postpartum consultations at 12 or 18 months after birth

The results of the study show that the number of women returning for further consultation and treatment was declining at each step of the PMTCT process. Dr Naomi Retenberg of Horizons/Population Council and a principal investigator for the study notes:

“Attendance of women in the clinics is influenced by both supply and demand, including lack of sufficient staff to handle client load, accessibility issues, fear of

stigma and where there are low levels of male involvement, opposition of men to use the services by their female partners” (SAFAIDS News, 2004:11)

At most of the sites, despite considerable efforts to promote antiretrovirals to HIV positive women at the later stage of pregnancy, the number of clients who ultimately obtained treatment was lower than expected (SAFAIDS, 2004). The aforementioned results reinforce the importance of investigating the knowledge that women should have about the PMTCT program. As has already been stated, the reasons for not adhering to the PMTCT protocol are many and varied. Consequently we need to explore the women’s level of understanding as well.

A study conducted in three PMTCT sites across South Africa by Chopra, Jackson, Ashworth & Doherty (2004) evaluating the quality of counselling provided to women in three shows that the general quality of communication skills was very good. 73% of HIV negative mothers were informed of the advantages of exclusive breastfeeding (EBF).

However, only one of the thirty-four HIV positive mothers were informed about the possible side effects of Nevirapine, an antiretroviral tablet, which reduces the viral load in the immune system of the pregnant woman. No one was told what to do when side effects occurred. Only two HIV positive mothers were told about essential conditions for safe formula feeding before a decision about an infant feeding option was made. None of the twelve mothers on the study choosing to breastfeed was shown how to position the baby correctly on the breast or asked whether they thought exclusive breastfeeding (EBF) was feasible. Very few of the mothers expressed confidence in performing the actions required and 85% could not define the term EBF. The results further showed that sites, which had received more training and supervised support, performed the best.

In the African context, a recent study of Kenyan and Zambian Prevention of Mother to Child Transmission of HIV (PMTCT) services found that infant-feeding counsellors explored some but not all the key issues with clients.

Many counsellors were biased about infant feeding choices for HIV positive women and most of the PMTCT programmes had mixed success in improving infant feeding practices except in sites with intensive counselling and where support groups were organised. Community-based education and mobilization of community were seen to be positive steps in encouraging women to learn properly about proper feeding of babies (SAFAIDS, 2004).

In a study conducted in Khayelitsha since 2001, Chopra, Jackson, Ashworth and Doherty (2004) report that rapid assessment examined the impact of the urban Khayelitsha PMTCT Programme on infant care practices amongst programme participants and the local population. The study revealed the mothers had a good knowledge of the spread and prevention of HIV. Most knew that breastfeeding can transmit HIV but 90% stated that this did not affect their feeding decision. Over 50% had introduced non-human milk in addition to breast milk before one month of age and 82% reported that they stopped breastfeeding exclusively before their infants were 3 months. All respondents felt that being diagnosed HIV positive would result in serious social and domestic consequences. None of the health workers could correctly estimate the risk of acquiring HIV through breastfeeding and many of them reported feeling confused about what they should say to mothers. All the participants also had knowledge about exclusive formula feeding but they reported that they experienced serious problems with its preparation.

Nearly all reported running out of milk before being able to fetch new supplies. To conserve formula supplies they resorted to giving the baby sugar and water or sweetened fruit juice in between feeds.

Participants felt good about the PMTCT programme but the reality still prevailed that they were not adhering to the principles of the protocol which is to exclusively formula feed or exclusively breastfeed their infants.

1.4.2 THE IMPORTANCE OF SUPPORT GROUPS IN THE PMTCT

According to Van Dyk (2001) in Blom & Bremridge (2002) support and self-help groups have been proposed as a key intervention for people living with illness.

Support groups are described as structures where people meet on a regular basis to talk about their difficulties or simply to relax and enjoy one another's company.

The research done by the Voices and Choices, a project developed by the International Community of Women (ICW) in 2002 showed that support groups are effective in providing emotional support for group members to come to terms with an HIV diagnosis by giving each other adequate information and sharing their experiences (SAFAIDS, 2004). The members of the group give a sense of identity and collective strength. According to Haley & Stern (2003), The Mothers to Mothers to Be (M2M2B) support group program assists HIV positive women to share an identity with people of similar status. The support group helps these women to be aware and more assertive about their rights. It further empowers the women on how to cope with stigma and discrimination within their homes; at work and the challenges they face with their mothers-in-laws.

Corey & Corey (1997) posit that support groups have very important principles to adhere to. The facilitator of the group has to ensure that the group rules are clearly defined to determine whether it should be a closed or open group. According to them, issues of confidentiality must be discussed to create a trusting environment. They define the closed group as a group in which members join for a stipulated time, which could be between six and eight sessions. No new members are allowed to join the group.

In the experience of this researcher as group facilitator in the M2M2B support group programme, it is no easy task to work in a closed group with HIV positive women because they first need time to deal with the knowledge of their HIV status. They also fear that if they expose themselves to new members, their status would be known. Their closed status stultifies the growth of the group and the possibility of gaining new knowledge through interaction with other people. It also defeats the purpose of the programme of disclosure.

Corey & Corey (1997) define open groups as groups in which membership is ongoing and growth of the group is not restricted.

Group members are allowed to join and leave at anytime. They further state that open groups are useful for people requiring immediate support.

A woman who is informed of her HIV positive status needs emotional support most of the time and hence a support groups gives her the opportunity to learn about herself through the experience of other members. The same principles that guide the closed group apply to the open group.

This researcher has the experience of working with support groups of HIV positive women in the M2M2B programme. They experience challenges as African women because they are culturally expected to breast feed their babies and they cannot take a decision not to breastfeed their babies. They not only get pressure from their mothers –in- law to breast feed their babies until the age of two years but the mothers in law may also mix feed the babies whilst their mothers are absent from home.

Some women stated that disclosure is a thorny area for them. They fear rejection by their families if their HIV status is known and pressure is exerted by partners not to disclose. Women in the M2M2B programme fear stigmatisation and the discrimination from their society that would arise out of the disclosure of their HIV positive status. Lastly, these women are powerless to refuse the sexual advances of their partners who demand sex without condoms.

The pressure is from the fact that these partners, most of the time, are breadwinners and they use this status as a lever to enforce their demands on their helpless woman-partners.

1.4.3 THEORY OF CHANGE IN THE MOTHERS TO MOTHERS TO BE (M2M2B) SUPPORT GROUP PROGRAMME

According to Haley & Stern (2003), the mission of this program is the empowerment of disadvantaged, HIV positive women. The program defines an empowered woman as one who views life positively, feels in control of her life, and proactively makes the best possible choices for herself and her family within the context of the society in

which she lives. The program plays a powerful role in a woman's transformation because of three key elements.

1) **Entry Point**

Entry point means the time when an HIV positive woman joins a support group. The time of joining the support group is critical because intervention dramatically alters the direction of a woman's life and set her on a path towards empowerment. The M2M2B believes that the discovery that one is HIV positive and pregnant opens the door for such a life-transforming event.

2) **Pathway to empowerment**

By pathway to empowerment is meant the process of empowerment of the HIV positive woman through the provision of life skills and the knowledge to cope with her HIV positive status. The program facilitates a life transforming experience for the women in need by affecting change in the most important aspects of their lives. Through education on the prevention of Mother-to-child-transmission of HIV the women are becoming knowledgeable of ways to take care of their unborn and themselves and improve their social, emotional and physical health. Women are empowered in the program to increase economic independence and the HIV status partially destigmatised within family and community.

3) **Self -Empowerment**

Having been empowered themselves, these women transfer their own skills to other women like themselves.

The program further employs women who are HIV positive and empower them with skills so that they can be able to help other women along the journey. The theory of change applied by the program is firstly based on support groups and on the assertion that mothers can best empower other mothers about living positively with the disease. (Haley & Stern, 2003: 6)

The theory of change is based on women working in a support group, firstly learning about the HIV/AIDS and how the virus can infect the foetus.

The women are empowered to understand voluntary counselling and testing (VCT) and the Prevention of Mother To Child Transmission (PMTCT). All the elements of the program are taught in support groups that create an environment which is non-threatening to the HIV positive woman (Haley & Stern, 2003).

1.4.4 THE PMTCT PROGRAMME

The Prevention of Mothers to Child Transmission Programme is a programme attended by pregnant HIV positive women within Maternity Obstetric Units. The women are encouraged to join the PMTCT programme after receiving an HIV positive result from Voluntary Counselling and Testing (VCT).

If a woman agrees to participate in the programme, she is counselled about having a CD4 cell count to determine her immunity level so that she can be in a position to receive appropriate treatment. A woman who has been found to be living with a CD4 cell count, which is below 200, will be referred to the Highly Active Antiretroviral Therapy (HAART). A woman with a CD4 cell count above 200 will receive a double therapy regimen of AZT at 34 weeks to be taken twice daily until labour.

During labour she receives AZT tablets every three hours with a once-off dose of Nevirapine. The aim of giving the woman these medicines is to reduce viral load. Women are also encouraged to come to the MOUs immediately they are in labour. If the woman comes late to the MOU, this would be to the detriment of the foetus.

The Department of Health protocol on the Prevention of Mother to Child Transmission (PMTCT) (2004) guides the HIV positive pregnant woman to exclusively breastfeed or exclusively formula feed the infant for six months. This

means that the infant will only be breastfed without any introduction to other solid foods and juices for six months and this also applies to the formula milk, which is Perlagon, which the woman will receive free of charge for six months. If the woman does not adhere to the guidelines of the program and begins to mix feed the infant, the baby will have stomach cramps due to mix feeding and the breast fed infant will be exposed to HIV infection because the stomach lining would have lesions due to the diarrhoea the infant would have suffered. The woman is also educated to ensure that the infant receives doses of Nevirapine and zidovudine (AZT) syrup before she leaves the Maternity Obstetric Unit (MOU) (Western Cape Province: PMTCT Protocol Revised, 2004).

The woman also needs to ensure that she gives the infant the zidovudine (AZT) at home for 7 days. She also must follow up with the baby clinic at 6 weeks to collect bactrim, which she needs to give to the infant three times a week. Bactrim is a syrup, which protects the infant from infections until the infant is tested at 14 weeks. Once the Polymerase Chain Reaction (PCR) test has been done on the infant and the result show that the infant has not been infected with the virus [negative result], the woman will be re-counselled about breastfeeding options.

If she decides to continue with breastfeeding although the infant is HIV negative then the test will be repeated at 4 weeks after the infant has been weaned (Western Cape Province: PMTCT Protocol Revised, 2004).

1.5 CONCLUSION

This chapter discusses the background to the study, the research question and motivation for the study.

It also describes the programmes in which the target groups receive the necessary emotional and professional support. The following chapter discusses the methodology for the study.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

Issues of methodology regarding this study are addressed in this chapter. The chapter describes the target group of study, and methods of data gathering.

2.2 THE RESEARCH APPROACH

The methodological paradigm that is followed in this study is qualitative research. In a qualitative inquiry, the researcher becomes involved personally by participating in the subject of inquiry or through observing participants in action. McMillan & Schumacher (1993) define qualitative research as a naturalistic inquiry, which does not interfere in the natural flow of events but rather observes and interprets things as they happen in a natural setting.

What this means is that qualitative research occurs in a natural setting and what the researcher has to do is to observe and interpret what is happening in this natural setting. According to Hitchcock & Hughes (1995) what researchers do in a qualitative inquiry is to learn personally about the social world that they are studying through personal participation and observation of the actors in the social set up.

The researcher and the research subjects interact with one another in the process of the researcher seeking to understand the issues under consideration. During this interaction, the researcher and the research subjects communicate about the issues that are of interest to the researcher and possibly also of interest to the research subjects.

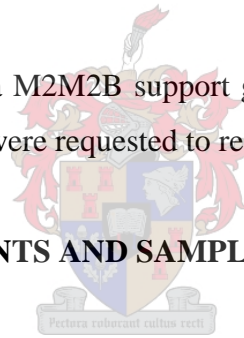
Van Maanen (1990) states that the raw materials of qualitative research are generated in vivo. This means that data is collected, as the phenomenon of interest is in process or as soon as possible after it has happened. The implication of this is that in qualitative research, the researcher identifies a phenomenon, which is of interest to him or her or to a third party.

After identifying this phenomenon and studying it as it occurs, the researcher analyses the social phenomenon and then gives an interpretation of the occurrence. Hence in qualitative research, description is more important in contrast to quantitative research in which calculation is more important.

When one refers to description in qualitative research, one is not referring to a superficial treatment of data but a more thorough understanding of the action, its context or motivation, its process, its results and subsequent evolution (Denzin, 1978a). Context is important in description because it is connected to the creation of meaning since action makes sense if one understands its location and context. Hence one finds that qualitative research is always characterised by the description of the situation in which an action occurs. In this study of HIV positive women participating in support groups, we are interested in what the women in the support groups say and do.

This particular study occurs in a M2M2B support group environment. Women who were trained about the PMTCT were requested to respond to a questionnaire.

2.3 RESEARCH PARTICIPANTS AND SAMPLING



2.3.1 Sampling

The target group that was sampled for this study consisted of fifteen HIV positive women who had given birth between April 2004 and April 2005. The minimum age of the respondents is twenty years and the maximum is thirty-four years. The mean is twenty-seven years.

The following table gives the distribution of the ages of the respondents:

Table 1: **Distribution of the ages of the respondents**

Age Intervals (Years)	20 - 24	25 - 29	30 - 34
Number of women	3	8	4
Percentages (Approx.)	20%	53%	27%

Nine of these respondents or sixty percent have one child each, five or thirty percent have two children each and one has four children. The following distribution table represents this data. Four of these respondents were born and bred in the Western Cape and eleven arrived in the Western Cape between 1992 and 2005. Fourteen of the respondents are Xhosa first language speakers whilst one of them is an Afrikaans first language speaker who has a basic understanding of Xhosa and a good command of English. These respondents have participated in the support group of the M2M2B program and have been trained about the PMTCT program. One of the respondents indicated that she has attended eight sessions so far because she works at night and the rest indicated that they have attended over thirty sessions and more. Some put it thus: “It is countless”(sic). The issues covered in the M2M2B support group are specified in annexure A. Seven or forty percent of the women are married.

A purpose sampling strategy was used. The researcher selected the group of women described above. According to De Vos, Strydom, Fouch’e and Delport (2002), purposive sampling is based entirely on the judgement of the researcher. Patton (1990) states that a purposive sample is composed of elements that contain most characteristics or attributes of the population researched. In this case the sample comes from the population of women who are HIV positive and have given birth already.

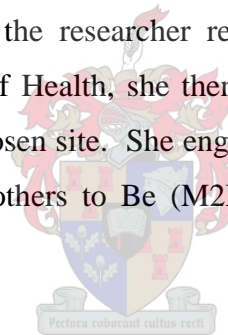
All the babies of the sampled women have been tested at fourteen weeks. These women are also characterized by having participated in the Mothers to Mothers To Be (M2B2B) support group and hence have been trained about the PMTCT program.

2.4 DATA COLLECTION

2.4.1 Negotiating Access

The process of data gathering was preceded by a long process of negotiation of access to the clinic where the data was going to be collected

The researcher wrote a letter to the Department of Health requesting permission to conduct the research at the chosen site (Annexure A). The departmental official sought ethical approval from my university (Annexure B). This process took over six weeks to be finalized. When the researcher received permission to conduct the research from the Department of Health, she then negotiated entry to the Maternity Obstetric Unit (MOU) of the chosen site. She engaged with the unit head and the coordinator of the Mothers to Mothers to Be (M2M2B) program who organised the participants.



2.4.2 The Research Instrument

The research instrument that was used in this study is a structured questionnaire (Annexure C). A questionnaire is a method of obtaining information about a particular issue or issues through the use of a written list of questions that respondents are requested to answer (Mbekwa, 2003).

The advantage of a structured questionnaire is that the respondent does not respond to open-ended questions but is directed to the kind of responses that the researcher desires, which would be relevant to the research questions that he/she is interested in. Only two out of twenty-eight questions, in the questionnaire used for this study, can be regarded as open-ended questions.

The questionnaire consists of three sections, namely:

- A. Background and Biographical Information:
- B. HIV/AIDS and PMTCT knowledge
- C. Evaluation of the M2M2B support group programme.

The background and biographical section deals with information relating to the respondents' personal background like their origins, language, age, and number of children and personal information on voluntary testing and counselling. This section has blank spaces that respondents had to fill in, in response to direct questions like: "How many children do you have?."

The second section has questions that deal with the respondents' basic knowledge of HIV and PMTCT. Some of the questions in this section are Likert scale type questions wherein the respondents had to choose from three possible answers: "(i) Agree (ii) Not sure (iii) Disagree" and the rest are questions which required the women to respond directly to the questions like in the first section. The last section relates to the respondents' views on the M2M2B support group. This in effect is an evaluation section of the M2M2B support group programme. This section required women to indicate their feelings about the support group and whether they viewed the support group as effective in providing them with the necessary information, support and empowerment in dealing with their HIV positive status.

2.4.3 Administering the Questionnaire

The researcher administered the research questionnaire over two days. On the first day, the researcher was introduced to seven women by their mentor and they all agreed to participate in the research. They were interviewed individually in private and the researcher wrote their responses in the questionnaire herself. On the second day a different procedure was followed to save time. On this day the researcher found twelve women in the support group and only eight of the women agreed to participate in the research. The researcher introduced herself to the women and explained the research and its purpose to them. This was granted in writing, in Xhosa, by seven of the eight women and in English by the Afrikaans speaking woman.

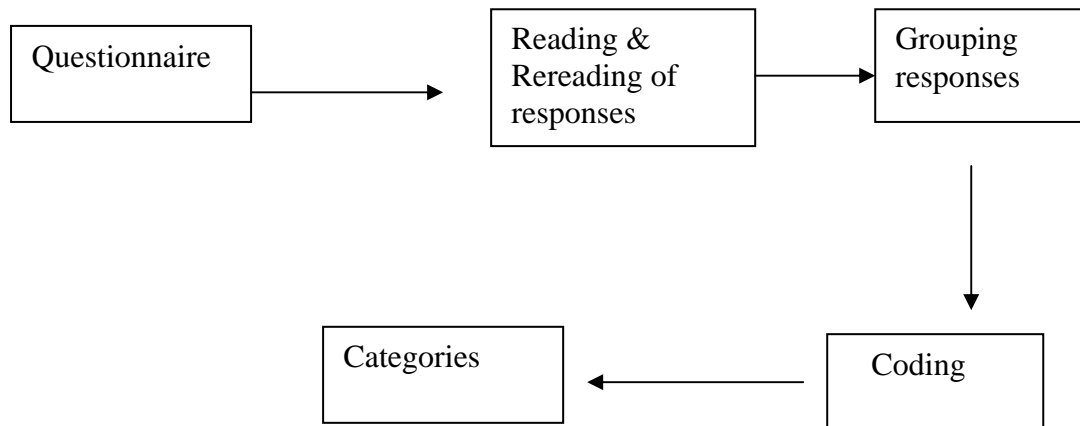
The eight women were encouraged to sit far away from one another and respond to the questionnaire individually.

The researcher took the role of an open observer, which involves the monitoring of people who know that they are being watched (McDaniel & Gates, 2004). The researcher was also assisting those women who needed clarification and assistance with some of the questions. The women responded to the questionnaire and after they had finished, they thanked the researcher for the opportunity she had given them to show their knowledge. They also asked for answers to the questions they thought they were unable to answer correctly. The researcher gave them the answers after she had collected the completed questionnaires. Those who had obtained correct answers were quite excited at finding out that they had given correct answers. Those who had given incorrect answers were unhappy at their lack of knowledge because knowledge of the PMTCT protocol is crucial in prolonging their lives and those of their babies. The researcher promised to come back and give assistance to those who need it, to understand the PMTCT protocol better.

2.5 DATA ANALYSIS

The researcher received the completed questionnaires from the respondents and then transcribed all their responses according to each question in the questionnaire. The responses were read and reread with the number of correct and incorrect responses per question being noted, counted and converted into percentages. Each question was coded. After the coding all the codes were aggregated into categories. The following is a diagrammatical representation of the data analysis, coding and the categorisation process:

Figure 1. Representation of data analysis, coding and categorisation.



Three categories of questions in section B were identified. The three categories that were identified are: (i) Physiological knowledge (ii) Viral Transmission knowledge (iii) Treatment knowledge

2.6 LIMITATIONS OF THE STUDY

There are various limitations to this study. The first limitation that can be mentioned is the fact that the study cannot be generalised to the whole population because the sample of fifteen women chosen is fairly small. The study gives a glimpse of what happens in a small group of HIV positive women.

Another limitation of the study is that no pilot study was made and hence the researcher could not gauge what could possibly go wrong with the administration of the questionnaire.

2.7 CONCLUSION

This chapter explained the research approach and sample used. It also discussed how data was gathered, analysed and discusses briefly the limitations of the study.

CHAPTER 3

PRESENTATION OF FINDINGS

3.1 INTRODUCTION

The previous chapter on data analysis mentioned that the categories of questions in the questionnaire were of three types, namely (i) Physiological Knowledge (ii) Viral Transmission Knowledge and (iii) Treatment Knowledge. This chapter presents the findings of the study in terms of the above-mentioned categories.

It is necessary to define firstly what this study understands about these categories.

3.2 CATEGORIES OF KNOWLEDGE

3.2.1 Physiological Knowledge

By physiological knowledge in this study is meant the knowledge that each respondent has of the behaviour of the virus and its effect on her physiological make up. This would refer for instance the mutability of the virus and how it affects the human immune system. Indicators of such a change, for instance, would be the reduction of the CD4 count.

3.2.2 Viral Transmission Knowledge

Viral Transmission knowledge in this study refers to the way that the transmission of the virus occurs from an outside source to the mother and from the mother to the baby.

This would refer to transmission of the virus during sexual activity, blood transfusion or during pregnancy, during labour and during breastfeeding. This kind of knowledge also includes all intervention programmes that seek to counter and manage HIV infection.

3.2.3 Treatment Knowledge

Treatment knowledge in this study refers to the manner in which a person understands the treatment for the control or management of HIV in the immune system of the infected person. The treatment also prevents the infection of the foetus during pregnancy, during labour and after the baby is born. It also refers to the kind of tests used to check the virus and the levels of immune system.

Questions relating to these categories are listed in the following table:

Table 2. Categories of questions

Physiological Knowledge	Viral Transmission Knowledge	Treatment Knowledge
<p>1. A woman with HIV antibodies in her blood stream is HIV positive.</p> <p>4. A CD4 count is a measure of how strong the immune system is</p>	<p>3. A woman is given the choice to join the PMTCT programme if infected with HIV.</p> <p>9. What do we give babies after birth to prevent transmission of HIV?</p> <p>14. A baby born from a HIV positive woman should be fed exclusively, either formula or breast milk for up to 4 to 6 months.</p> <p>15. Breast milk from an HIV positive mother does have HIV?</p> <p>16. Why must babies not be fed from cracked nipples?</p> <p>17. What happens to an HIV negative baby who was tested at 14 months but breastfeeding continued.</p> <p>18. Do we test the baby again</p>	<p>2. An HIV positive woman has a 30% chance of having an HIV negative baby without NVP and AZT.</p> <p>5. What is HAART?</p> <p>6. When do HIV positive women receive ARVs?</p> <p>7. Must a woman receive tablets during labour?</p> <p>8. What kind of tablets do they receive?</p> <p>10. How long should the baby receive the syrup preventing the transmission of HIV at home?</p> <p>11. What is the name of the syrup?</p> <p>12. When must the baby receive bactrim?</p> <p>13. How many times must the baby receive the bactrim?</p> <p>20. When is the baby tested for HIV?</p>

	and why? 19. What do you use to sterilise a baby's bottle 22. What happens to an HIV positive woman when she does not practise safer sex?	20. What test is usedf to test the baby?
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3.3 FINDINGS

3.3.1 Physiological Knowledge

The findings of this study with respect to the above category of questions reveals that on average the women have a 97% understanding of physiological knowledge of the HIV virus through 93% of them answering the first question correctly and all of them answered the second question correctly. These questions were Likert scale type questions. Taking the mean of these percentages yields 97%.

3.3.2 Viral Transmission Knowledge

There are eleven questions classified under this category. Correct answers ranged from 33% to 87%. The following bar diagram shows how these correct answers range:

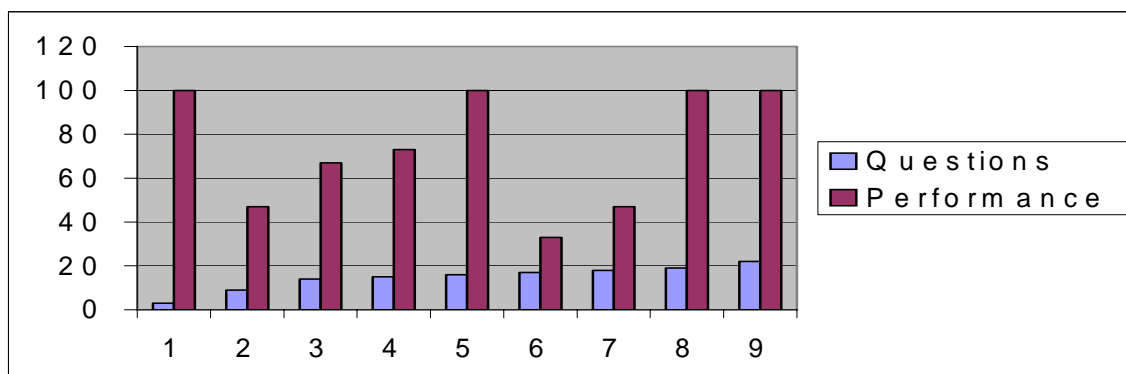


Figure 2. Viral Transmission Knowledge.

The mean of all these correct answers is 74%, which can be interpreted to mean that on average the women have knowledge of 74% of viral transmission.

3.3.3 Treatment Knowledge

As can be seen in table 2, there are also eleven questions in this category. Correct answers that were obtained by the women ranged from 33% to 100%. The average percentage of correct answers from these scores is 73%, which is almost the same score as obtained under viral transmission knowledge. The graph below shows the distribution of scores under this category.

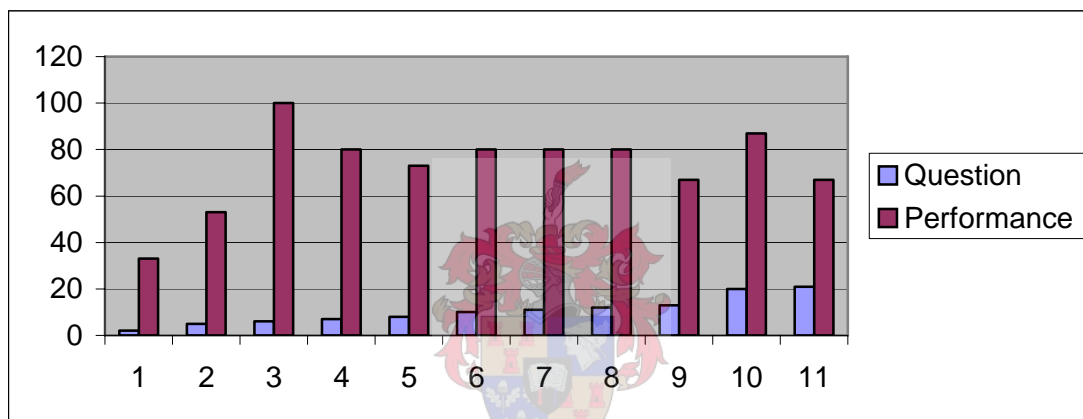


Figure 3: Treatment Knowledge

In summary, we can comparatively put the knowledge that women have in terms of the categories of physiological knowledge as 97%, viral transmission knowledge as 74% and treatment knowledge as 73%. These percentages of knowledge can be represented by the following 3-D exploded pie chart.

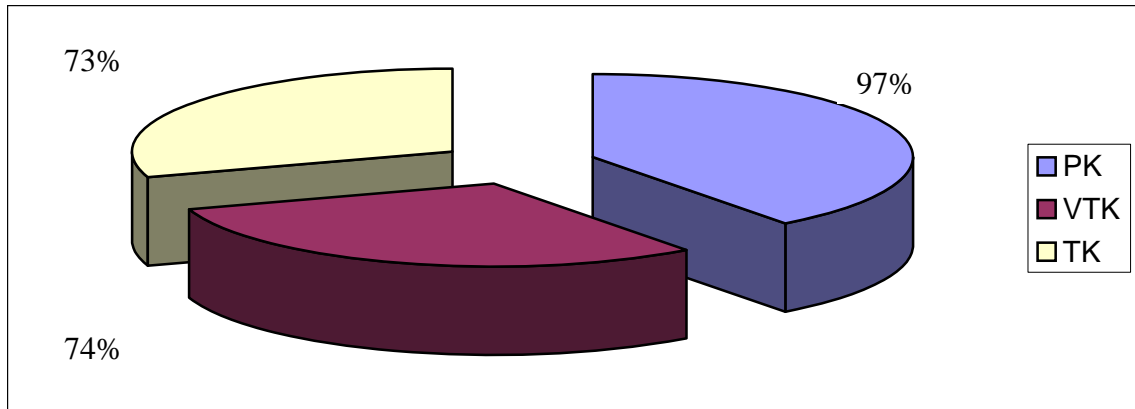
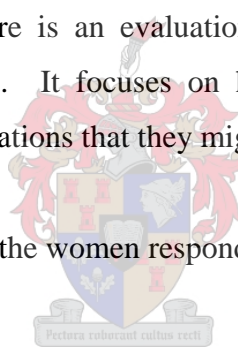


Figure 4: Knowledge that women have of HIV. Legend: PK: Physiological Knowledge; VTK: Viral Transmission Knowledge; TK: Treatment Knowledge

3.4 SECTION C: Evaluation of the M2M2B support group program

This section of the questionnaire is an evaluation of the M2M2B programme as experienced by the respondents. It focuses on how the women experienced the programme, and any recommendations that they might have.

The following are questions that the women responded to in this section and how they responded to them.



Question 1 – Did you experience any problems during the support group?

Eighty percent of the respondents indicated that they did not receive or experience problems in the support group, but received a lot of support. They also gained strength and courage to disclose their HIV positive status to their husbands and families because of the support they had obtained from the M2M2B programme.

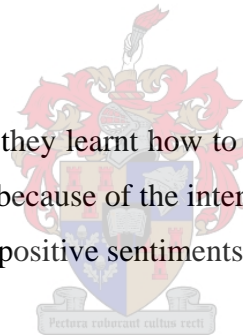
One of the respondents stated that, amongst problems that they had encountered at the beginning of their education sessions on HIV and AIDS, is that many of the women in the support group did not understand the difference between HIV and AIDS. Nevertheless this distinction became clearer as their education progressed. One respondent said she was already experiencing side the side effects of antiretrovirals when she joined the support group and was consequently extremely depressed. Joining the group helped her to understand that she was not the only person suffering

from the side effects and thus her pain lessened by the knowledge that she was not alone. Another respondent said her pain was to see women who are infected but were experiencing stigmatisation and discrimination from their families and their communities instead of understanding, empathy and support from their loved ones. The respondent said that she had also been scared of death. The M2M2B programme made her realise that HIV did not mean early death but that one could live long with good management of the infection.

Question 2 – Do you think information gained was helpful?

All of the respondents indicated that the M2M2B support group was helpful and it is where they learnt how to live positively with HIV. They also said that now they understand what is happening in their bodies. One of the respondents indicated that the support group helped her to stop thinking about death and instead plan for her future and accept that HIV is one of the challenges that life has to offer to human beings.

The respondents also stated that they learnt how to care for their unborn children and to look after the baby after birth because of the intervention of the support group. All the respondents shared the same positive sentiments about the support group.



Question 3 – Was it easy to understand the group facilitator?

Eighty seven percent of the respondents indicated that it was easy to understand the facilitator because she was talking to them in their own language, which is Xhosa.

However, some respondents said it was difficult at times to understand because they were dealing with the spectre of being HIV positive and would continually be asking themselves how does the facilitator know how they feel because they thought she was not HIV positive and hence could not understand their innermost feelings.

The respondents said that it is only when the facilitator disclosed her status that she was also HIV positive that they began to trust her and to trust the programme. The respondent said that they developed trust and interest in her and they also started to share openly and unreservedly their situations with her. One of the respondents put it thus:

that it is very easy to understand her facilitator because she is very knowledgeable because has exposure and networking experience from organisations like the Treatment Action Campaign (TAC). She then comes back and shares information and developments on HIV/AIDS information with us. We understand her because she is very patient with us and she loves her work. [Respondent, 2005]

Question 4 – Were there any barriers that could make it difficult to learn?

Forty seven percent of the respondents indicated that there were no barriers in the support group because they were treated equally. Some of the respondents stated that there were no barriers because they were eager to learn more about living with HIV.

Seven respondents indicated that there were barriers to learning because during the support group their babies would be crying and that would make it difficult for them to focus in the group. One respondent said she missed some of the discussions whilst caring for the baby. Another respondent said she was too depressed about her HIV positive status and had not disclosed to her husband and the fear was making her to feel very exhausted and she would also lose concentration in the group.

The respondents indicated that language was not an issue because when they were addressed in English it would be interpreted in Xhosa.

Question 5 – What is it that can be done to improve the M2M2B support group?

Fifty three percent of the respondents indicated that they had no suggestions. Other respondents said they would be happy if the support group and training was done in Xhosa only. They also want the training on HIV/AIDS to be continuous and women must be exposed to video cassettes that educate them about infant feeding and different kinds of infections that attack the breasts of those women who decide to breastfeed. One of the respondent indicated that they need their own “container” so that they can be able to cook for themselves. She put it this way: “ An HIV positive person cannot be eating a healthy meal if they eat bread everyday”. This respondent expressed the need to move away from the hospital environment. The women stop attending the support group after giving birth because they get bored. They also

proposed life skills programmes, which train women to do beading and sewing to generate funds for self-sustainability.

Question 6 – Do you have any other comments regarding the M2M2B support group program?

Sixty seven percent of the respondents indicated that the program is very good and it should be replicated in many other provinces and other countries. The program should be advertised in the various media in South Africa like the radio, television and local newspapers. One of the respondents put it statistically when she said “ The program must be expanded world wide to reach 98% of HIV positive pregnant women.”

The respondents expressed the wish to see people living with HIV being treated well and with dignity by everybody. The respondents also want women to come and join the group immediately they know their status. This should happen so that they can know that there are other women living with the virus and they will get help in the M2M2B support group program.



3.5 CONCLUSION

This chapter outlined data analysis and research findings. The following chapter provides an interpretation of these findings and concludes the study.

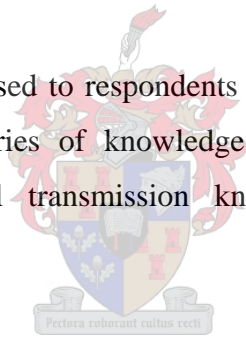
CHAPTER 4

INTERPRETATION OF FINDINGS, SUMMARY AND REFLECTION

4.1 INTRODUCTION

The main aim of this study was to investigate the knowledge women have about the Prevention of Mother To Child Transmission (PMTCT) whilst participating in the Mother To Mothers To Be (M2M2B) support group program. The study sought to find out what knowledge HIV positive women have of the HI virus and its transmission. Secondly it sought to find out the knowledge that HIV positive women have of the PMTCT programme and lastly the study sought to find out the knowledge that these women have about adherence to ARV therapy. This chapter gives an interpretation of the findings in relation to these questions.

In categorising the questions posed to respondents and their responses, the previous chapter discussed three categories of knowledge that the women have, namely physiological knowledge, viral transmission knowledge and thirdly treatment knowledge.



4.1.1 Physiological knowledge

The findings show that on the whole 97% of the women have physiological knowledge about HIV/AIDS. As indicated in the previous chapter, physiological knowledge refers to the knowledge that women have of the virus and its behaviour. This can clearly be linked to the first research question. However the respondents indicated that the support group has been joined by women who have recently been diagnosed as HIV positive. They still need ongoing training and education so as to be on the same level as other women. The 3% lack of knowledge discrepancy might be because of these new women. In general one can be pleased with the nearly 100% knowledge performance, which implies that the M2M2B support group is indeed delivering on its mandate.

4.1.2 Viral Transmission Knowledge

Seventy four percent of women have knowledge about the PMTCT program. However the findings show that it was difficult for other respondents to answer the question, on “What happens to a negative baby who was tested at 14 weeks but the woman continued with breastfeeding”. The researcher can assume that the respondents do not know how to answer the question because there is a gap in their knowledge of breastfeeding. Some of the respondents did not know when the baby will be retested if the mother continued with exclusive breastfeeding. The period of waiting after weaning the baby was not clear in their responses. Some of the respondents still understand the old PMTCT protocol, which was testing the baby at nine months and at eighteen months. Of course this protocol is outdated and does not conform to the new PMTCT protocol. It is important therefore that the new protocol be emphasized in PMTCT training.

One of the respondents openly stated that they were not encouraged to breastfeed their babies and hence it is difficult for her to answer the questions about breastfeeding and testing. If this is true then it needs to be emphasized to mentors to adhere to the new protocol, because correct and up to date information is critical to for the longevity of HIV positive people and their management of HIV to protect their babies from HIV infection. The respondents showed great concern about themselves and the new members of the support group who were not receiving correct information. They resolved to raise this with the co-ordinators of the M2M2B support group.

Only one of the respondents was able to give a full correct explanation in response to the question on the testing of the baby. She gave the answer: “ The baby is tested at 14 weeks but if the mother continues to breastfeed she should wean and keep the baby off breast milk for four weeks and come to the clinic for another test, which is not the Polymerase Chain Reaction (PCR) this time but the RAPID test. The breastfeeding mother must never exceed six months”. The incorrect responses of the women to the above question raises concern because, if these women were not following the correct protocol as articulated by the respondent above, they are in danger of exposing their babies to the virus. One of the questions in this category related to the sterilisation of the baby’s bottle.

It is gratifying to realise that almost all the women know how to sterilise and hence understand the importance of hygiene to ensure a healthy baby. This would free the baby from stomach complications that can increase the rate of HIV infection.

4.1.3 Treatment Knowledge

This finding, linked to the third research question, relates to the respondents' knowledge of antiretroviral therapy. The finding indicates that seventy three percent of the respondents have knowledge about treatment of HIV/AIDS. Only 33% of the respondents gave a correct answer to this question. This is perhaps due to the way that the question was phrased. The question reads thus: "An HIV positive woman has 30% chance of having an HIV negative baby without NVP and AZT?" Perhaps if the same question was worded differently it would have elicited a different response.

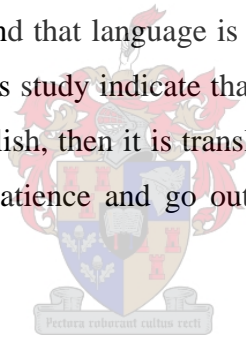
Forty seven percent of respondents also showed a lack of knowledge to a question that asked them about the meaning of HAART, which stands for Highly Active Antiretroviral Therapy. HAART stands for a combination of three drugs given to a pregnant HIV positive woman who has a CD4 count below 200. It is very crucial that the respondents understand and give a correct response to this question because during labour, a pregnant HIV positive woman is not given antiretroviral treatment in the same way as one who has been receiving dual therapy [AZT and Nevirapine]. The fact that nearly 50% of the women do not know anything about HAART is worrying because it is at the core of the PMTCT protocol.

Thirty three percent of the respondents again showed lack of knowledge to the question about how many times should the baby receive bactrim? Most of the respondents were confused and gave completely wrong answers. One of the respondents said the baby should be given the bactrim twice a day in the morning and at night and another said baby should receive the bactrim five days three times a day. The correct answer is that the baby must receive the bactrim three times a week Monday, Wednesday and Friday - once on each day. The concern is that babies who are given the bactrim incorrectly are in danger of developing side effects and resistance to the medication. The mothers would tend to blame the PMTCT program

and the M2M2B support group and stop attending the program if the baby develops these side effects.

The respondents are supposed to understand the test used to test the baby. If they do not understand, they will be reluctant to take the baby back to the well baby clinic for the test due to fear of the unknown. All the women were supposed to give the correct answer in this question because it is the area that motivates women to come back to the well baby clinic because they need to know that their status did not infect their babies. The respondents were supposed to know the names of two baby tests, the PCR which is used to test the baby at 14 weeks and the Rapid test, which is used when the baby is tested for the second time four weeks after the baby has been weaned from breast milk.

In general, the study finds that the respondents have knowledge of the PMTCT programme. This study has found that language is not a barrier to learning for these respondents. The findings of this study indicate that women are trained in Xhosa or if the training material is in English, then it is translated into Xhosa. The facilitators of the support group exercise patience and go out of their way to ensure that the women understand the PMTCT.



Seth & Kalichman (2003) state that if a woman fails to practise consistent correct use of condoms with her partner, the HI virus can be passed on to the foetus through the placenta. The findings indicate that the women understand the dangers of unprotected sex. These findings indicate that both programs, that is, the PMTCT and M2M2B support group are making a positive impact in changing the mind set of women in ensuring that their babies are protected from HIV infection. One of the respondents hailed the work of the support groups by stating: “ Yes. I’m not thinking of death, instead I’m thinking about the future. I’m planning a lot of things because life has a lot of challenges.” This statement shows a change in attitude from one of the women, who is now having a positive outlook on life because of the intervention of the intervention of the M2M2B support group.

They are also learning to take full responsibility of their lives and assist others in the same predicament. One of the women put it thus: “They gave us a change to help

others as they did help us. That means we are sharing experience and we are earning something. They bring back our dignity.”

The findings of this study corroborate the findings of a study by the Voices and Choices (2002), which stated that support groups are effective in providing emotional support. The findings in this study show the same that the respondents felt supported in the group. For instance the respondent cited above feels emotionally strong that she is no longer thinking about death. The respondents have begun to see or feel worthy in life and look at their HIV situation in a positive way. They look forward into the future, feelings of guilt and fear of death have faded as they interact with other women in the support group.

Haley & Stern (2003) argue that the members of the support group give a sense of identity and a collective strength. Women in this study attest to this because they said that their fears of death and denial faded away when they joined the support group. The fact that some of the mentors are also HIV positive gives a sense of fellowship, support and confidence to the support group members. For instance, one of the respondents said: “Immediately the facilitator disclosed that she was also HIV positive, I could immediately identify with her and knew that she speaks from broader understanding about HIV/AIDS issues and began to listen to the facilitator.”

The support group has been successful in help the women to cope with discrimination and stigma. One of the woman said that the group helped her to easily disclose her status at home and within the group. She said it was very difficult for her before she joined the M2M2B to even talk about her status. Fear of rejection was no longer an issue for her because she knew that she would receive support in the support group. She also understood her rights as an HIV positive person. The findings reveal that the women learnt well on how to live positively with the virus. They said they learnt that being HIV positive is not the end of life rather the beginning of challenges.

One said she is an example of being supported well by the programs. She said: “ Here I am. I beat the side effects of ARV’s and I am so well now.”

4.2 REFLECTION

In reflecting on the findings of the study, one can state that generally, intervention programmes like the PMCTC and the support groups of the M2M2B have been successful in providing the necessary information and support to HIV positive women.

The study also shows that whilst the knowledge that HIV positive women have of their status and its management is commendable, there is still room for improvement especially in the provision of up to date information about new PMTCT protocols. The psychological boost they obtain from belonging to a collective of people who are homogeneous with respect to their HIV status is also one of the more commendable aspects of these HIV intervention initiatives. Whilst there are good outcomes of these intervention programmes, there are similarly gaps that need to be plugged if the HIV positive women are to reap maximum benefits from these programmes. One, of course, is aware that the findings of this study cannot be generalised to the whole population.



4.3 RECOMMENDATIONS

- On going training on breastfeeding must be encouraged. The findings reveal that women do not understand much about breastfeeding especially regarding the period in which the baby can be breastfed.
- Women need ongoing training in area of weaning the baby from breast milk and when the baby should be brought back for the second test after the woman continued with breastfeeding after 14 weeks.
- The women did not give convincing answers about the acronym HAART. More focus should be put on this central aspect of PMTCT.

- Another recommendation came from the women themselves when they expressed the wish that the M2M2B support group program to be piloted to other countries so as to benefit HIV positive women internationally.
- A program that focuses on life skills and income generation to increase the level of independence of the women should be looked into.
- Such a program can emulate the models of other successful programs, such as IYABONGA, a program that empowers HIV positive women to cope and live positively with HIV/AIDS and take good care of their babies. The program also has an income-generating component. It helps women to generate income for their families. This is what the women want for M2M2B program.
- Lastly, because of the small scale nature of this study, a nationwide study on the effectiveness of intervention programmes like the PMTCT and M2M2B programmes in educating and supporting HIV positive women is recommended.

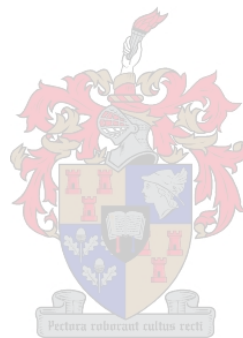


4.4 CONCLUSION

In conclusion, it should be re-emphasised that humankind is presently confronted by the most sophisticated pandemic in history. It is a disease that has confounded humankind by the sheer magnitude of distribution and virulence. The HIV/AIDS pandemic needs all the collective wisdom and experience of humans to confront it, to wage a war such as never been waged before in the history of modern humanity. One of the key weapons in confronting and eradicating disease is knowledge. With knowledge one is halfway towards defeating the disease. It has been the experience of humans that ignorance is the cause of many people succumbing to the enemy made up of unseen armies of deadly bacteria and viruses.

It is in the context of finding out whether the time-tested strategy of providing knowledge to afflicted persons is working that this study was undertaken.

It has been found in this study that HIV positive women do indeed, to a large extent, have knowledge of the disease that afflicts them and know how to manage the disease by taking the necessary medication to control it. Nevertheless, the study has also found that, unfortunately, there are gaps that exist in this knowledge because of outdated information and maybe because of omission on the part of those who are given the responsibility to provide this knowledge. This omission leaves a gap that allows the virus to thrive and defeats the whole purpose of providing knowledge to HIV positive women. It is crucial therefore to ensure that the correct information is given to these women. In this, the providers dare not fail.



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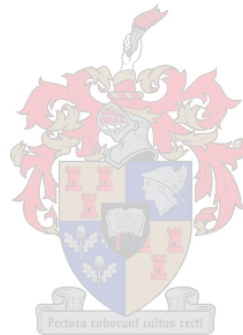
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ANNEXURE A

Sipress Mews 30B
Unit 1 Sipress Avenue
Thornton
7460
30 Aug. 05

The Acting Director : Ms Brenda Smuts
Directorate: HIV/AIDS and TB
Department of Health
1st Floor Southern Life Building
Riebeeck Street
CAPE TOWN

Dear Ms Smuts



APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I hereby request permission to conduct research at Michael Mapongwana Day Hospital during September 2005, with a group of HIV positive pregnant mothers who have been participating in the Mothers 2 Mothers 2 Be support group program (M2M2B).

I am an M. Phil student at the University of Stellenbosch, studying HIV/AIDS Management in the World of Work in South Africa. As part of my studies, I am conducting research to find out what knowledge HIV positive pregnant women have gained about PMTCT during their participation in the Mothers To Mothers To Be (M2M2B) support group programme for HIV positive pregnant women

On the 12 June 2004, I met Dr Mitch Besser and discussed my interest in doing this research.

During the discussion, it became evident that it would assist both programmes to assess and evaluate the knowledge that women gain about the Prevention of Mother To Child Transmission (PMTCT), during their participation in the Mothers 2 Mothers 2 Be program (M2M2B) support group at Khayelitsha sites. One of the objectives in this programme is to educate HIV positive pregnant women about the Prevention of Mother To Child Transmission of HIV and offer them emotional support.

The research will explore the HIV positive women's knowledge of with regard to the PMTCT protocol so the M2M2B training can be improved after gaps have been identified of the PMTCT.

The interviews will be conducted at the Michael Mapongwana Day hospital in September 2005. Dr Besser is very knowledgeable about my intention to conduct this research and has advised me to get permission from the Department of Health authorities. Enclosed find my research proposal. A qualitative structured questionnaire, which has been translated into Xhosa from English will be given to the participants.

The identity of the participants will be kept confidential during the research process in conformity with research ethics. The researcher will share the research findings with the Department of Health and the M2M2B program and give recommendations.

I trust that this request will receive your favourable consideration

Yours Truly

Ms Ivy Hude

HIV and AIDS Manager

Directorate: Policy and Program Design

Department of Social Services and Poverty Alleviation

Tel: 021 483 3956 Cell: 082 974 2125 Home: 021 534 4758

E-mail nhude@pgwc.gov.za

ANNEXURE B



Verwysing
Reference
Isalathiso

Navrae
Enquiries
Imibuzo

Dr Fareed Abdullah

Telefoon
Telephone
Ifowuni

021 – 483 3567

Departement van Gesondheid
Department of Health
iSebe lezeMnino

Ms Ivy Hude
Sipress Mews 30B
Unit 1 Sipress Avenue
THORNTON
7460

Dear Ms Hude

Permission to conduct research on the knowledge that women have of the PMTCT

Thank you for submitting documentation regarding ethical approval for your research entitled "An investigation into the knowledge that women have of the PMTCT" for our consideration.

Permission is therefore granted to undertake research at Michael Maphongwana CHC as per your approved proposal. We would appreciate it if you could provide us the expected date for the final report.

We wish you the best and look forward to receiving your final report.

Yours sincerely

Dr Fareed Abdullah
DDG: District Health Services & Health Programmes

Date:

24/10/2005

CC: Dr L. Bitalo
Director: Metro District Health Services

Dorpstraat 4
Posbus 2060
KAAPSTAD
8000

4 Dorp Street
PO Box 2060
CAPE TOWN
8000

ANNEXURE C

Uxwebhu Lwemfuna Lwazi

Knowledge Questionnaire

Umhla wokuzalwa-----

Date of Birth_____

Olu xwebhu luzama ukufumana ubungakanani bolwazi oomama abanalo malunga nokuKhusela ukuSuleleka kwabaNtwana yintsholongwane kaGawulayo ngooMama (PMTCT). Ukuzalisa oluxwebhu akusosinyanzelo. Iimpiculo ozinikayo ziya kugcinwa ngokukhuselekileyo. Olu xwebhu lugocagoca imeko yakho yolwazi ngokweNtsholongwane yeHIV, indlela yokuziphatha ngokwesondo nokuzikhusela ekusululekeni. Nceda uphendule yonke imibuzo. Uya kuthabatha imizuzu engama shumi amabini ukuphendula yonke imibuzo. Sinovuyo ngenkxaso yakho ukuphendula olu xwebhu.

This questionnaire aims at gauging the knowledge women have about the Prevention of Mother To Child Transmission (PMTCT). Completion of this questionnaire is voluntary and your answer to these questions will remain completely confidential. The questionnaire considers your current HIV knowledge, sexual behaviour, and prevention of (MTCT). Please answer all the questions. It should take you 20 minutes to complete the questionnaire. Your co-operation in completing this questionnaire is greatly appreciated.

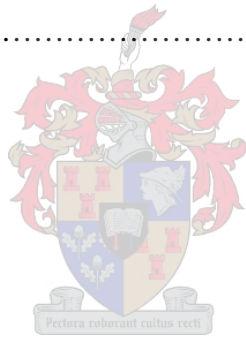
SECTION A

BACKGROUND BIOGRAPHICAL INFORMATION

Personal information/ Iinkcukacha ngawe

1. How old are you? / Mingaphi iminyaka yakho yokuzalwa?
.....
2. How many children do you have?/Bangaphi abantwana bakho?
.....
3. When did you arrive in Cape Town?/Ufike nini apha eKapa?.....
4. What language do you speak?/Loluphi ulwimi lwakho lwenkobe?
.....
5. Did you attend Voluntary Counselling and Testing?/ Ukhe wathabatha inxaxheba kuvavanyo lobume malunga nokuba unayo okanye akunayo na intsholongwane kaGawulayo?
.....
6. Did you get involved in PMTCT?/ Ukhe wathabatha inxaxheba kwiphulo lokunqanda ukusuleleka kosana yintsholongwane esuka kunina (PMTCT)?
.....
7. Did you get involved in the support group?/Ukhe wathabatha inxaxheba kwiqela lokuxhasana koomama abasulelekileyo yintsholongwane kaGawulayo?
.....
8. Who was coordinating the group?/ Ngubani obe ngumququzeleli weqela elo?
.....
9. How many sessions did you attend?/ Zingaphi iintlanganiso othe wazi zimasa?
.....
10. What was covered in the sessions?/ Ziintoni ekwakuxoxwa ngazo kwezo ntlanganiso?
.....

11. What language was used?/Loluphi ulwimi obe lusetyenziswa?
.....
12. What have you learnt?/Ufunde ntoni?
.....
13. Did you have knowledge of PMTCT before joining?/ Ube unalo ulwazi ngePMTCT phambi kokuba ube lilungu?
.....
14. Where did you get the knowledge?/ Ulufumene phi ulwazi?
.....
15. What was the experience for you?/Ulifumene linjani iqela?
.....
16. Are you married?/Utshatile?
.....
17. What is your religion?/ Uhamba eyiphi inkonzo?
.....



SECTION B

KNOWLEDGE ABOUT HIV/AIDS/ IMFUNA LWAZI NGE HIV/AIDS

Nceda uphendule yonke imibuzo ngokubhala ungxabalaza (X) phantsi kwempendulo eyiyo. Eminye imibuzo ifuna impendulo epheleleyo ngokuthi ubhale okanye unike incazo.

Please answer all questions by marking with **an (X)** below the correct answer. You must mark only **ONE** answer. Some answers will need to be responded to by giving full sentences.

1. Umama onamajoni eHIV egazini lakhe wosulelekile yintsholongwane yeHIV.
1. A woman with HIV antibodies in her bloodstream is HIV positive.

Ndiyavuma/Agree	Andiqinisekanga/Not sure	Andivumi/Do not agree

2. Umama onentsholongwane yeHIV, kumathuba angamashumi amathathu ekhulwini unokuba nosana olungasulelekanga ukuba akatyi amachiza iNevirapine neAZT.

2. A woman who is HIV positive has 30% chance of having an HIV negative baby without the Nevirapine and AZT.

Ndiyavuma/Agree	Andiqinisekanga/Noit sure	Andivumi/Disagree

3. Umama unikwa ithuba lokuba angenele ubulungu be PMTCT ukuba wosulelekile yintsholongwane yeHIV.

3. A woman is given the choice to join the PMTCT program if she is HIV positive

Ndiyavuma	Andiqinisekanga	Andivumi
Agree	Not sure	Disagree

4. Inani le CD4 liqondo lokhuseleko lomzimba kwizifo

4. A CD4 count is a measure of how strong the immune system is.

Ndiyavuma	Andiqinisekanga	Andivumi
Agree	Not sure	Disagree

5. Usana oluzelwe mgumama osulelekileyo yiHIV kufuneka lutyiswe ubisi lwetoti okanye luncance ibele ukusuka kwiinyanga ezi-4 ukuya kwezi-6. Ubisi lwetoti nebele azidityaniswa.

5. A baby born from an HIV positive woman should be fed EXCLUSIVELY on either formula or breast for up to 4-6months.

Ndiyangqina	Andiqinisekanga	Andivumi
Agree	Not sure	Disagree

6. Ubisi lwebele lomama onentsholongwane yeHIV lunayo intsholongwane yeHIV.

6. Breast milk does have HIV.

Ndiyangqina	Andiqinisekanga	Andivumi
Agree	Not sure	Disagree

7. Yintoni I HAART?

.....
.....

7. What is HAART?

.....
.....

8. Awafumana nini amachiza (ARV's) amakhosikazi akhulelweyo osulelekileyo yintsholongwane ka gawulayo?

.....

8. When do HIV positive pregnant woman receive ARV's?

.....

9. Ingaba kubalulekile ukuba inkosikazi ifumane ipilisi ngeli xa ilunywayo?

.....

9. Must a woman receive tablets during labour?

.....

10. Yintoni igama lezipilisi azifumanayo?

.....

10. What kind of tablets?

.....

11. Yintoni ekufuneka inikwe usana xa lusandula ukuzalwa ukulukhusela ekosulelekeni yintsholongwane kagawulayo?

.....

.....

11. What do we give babies after birth to prevent transmission of HIV?

.....

.....

12. Usana luyifumana itsuku ezingaphi isirapu ekhusela usuleleko kwintsholongwane?

.....

.....

12. How long should the baby receive the syrup preventing transmission of HIV at home?

.....

.....

13. Yintoni igama lale sirapu?

.....

.....

13. What is the name of the syrup?

.....

.....

14. Usana luyifumana nini i bactrim?

.....

.....

14. When must the baby receive bactrim?

.....
.....

15. Usana kufuneka luyinikwe kangaphi i bactrim?

.....
.....

15. How many times must the bactrim be given to the baby?

.....
.....

16. Kutheni usana kufuneka lunga ncanciswa kumabele aqhekekileyo?

.....
.....

16. Why must babies not be breastfed on cracked nipples?

.....
.....

17. Kwenzeka ntoni kusana olufumaneke lungosulelekanga yintsholongwane kagawulayo (at 14 weeks) kodwa umama aqhubekeke eluncancisa?

.....
.....

17. What happens to a negative baby who was tested at 14 weeks and breastfeeding continued?

.....
.....

18. Ingaba luphinda luvavanywe na usana? (**Xhasa impendulo yakho**)

.....
.....

Do we test the baby again ? Explain.

.....
.....

19. Usebenzisa ntoni ukuzigcina zicocekile ibotile zosana lakho?

.....
.....

19. What do you use to sterilize babies' bottles?

.....
.....

20. Lwenziwa nini uvavanyo lwentsholongwane esaneni?

.....
.....

20. When is the baby tested for HIV?

.....
.....

21. Yintoni igama lovavanyo olusetyenziswayo?

.....
.....

21. What do they use to test the baby?

.....
.....



22. Kwenzeka ntoni kumama osulelekiyo yintsholongwane ekhulelwe xa engasebenzisi i condom xa esabelana isondo neqabane lakhe?

.....
.....

22. What happens to an HIV positive woman when she does not practice safer sex?

.....
.....

THANK YOU FOR YOUR CO-OPERATION/ ENKOSI NGENTSEBENZISWANO

SECTION C

M2M2B PROGRAM EVALUATION

1) Did you experience any problems during the support group

Please motivate

.....
.....

1) Zikhona ingxaki okhe wanazo ngokwasemphefumleni ngexesha obusiya kwi support group ngalo?

Nceda cacisa

.....
.....

2) Do you think that the information gained was helpful?

Please motivate

.....
.....

2) Ingaba imfundiso ozifumene kwi support group beziluncedo kuwe?

Nceda ucacise

.....
.....

3) Was it easy to understand the trainer or group facilitator?

Please motivate your answer

.....
.....

3) Ingaba bekulula ukumva okanye uyilandela into anifundisa yona u trainer okanye u group facilitator?

Nceda ucacise impendulo yakho

.....
.....

4) Were there any barriers that could made it difficult to learn?

Please motivate your answer

.....
.....

4)Ingaba bezikhona na izinto ebezinokubangela kubenzima ukufunda

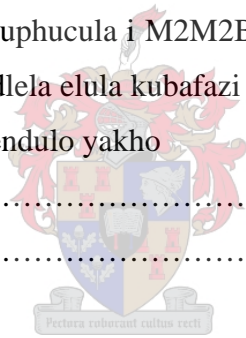
Nceda ucacise impendulo yakho

.....
.....

5) What is it that can be done to improve the M2M2B support group so that knowledge about HIV and AIDS can be enhanced for the HIV positive pregnant women? Please motivate your answer

.....
.....

5) Yeyiphi into enokwenziwa ukuphucula i M2M2B support group ukuze ulwazi nge HIV and AIDS lufundiswe ngendlela elula kubafazi abaphila nentsholongwane kwaye bekhulelwe. Nceda ucacise impendulo yakho



.....
.....

6) Do you have any other comments regarding the M2M2B support group program
Please motivate your answer

.....
.....

6) Ingaba ikhona enye into ofuna ukuyongezelela nge M2M2B support group
Nceda ucacise impendulo yakho

.....
.....

THANK YOU FOR YOUR COOPERATION/ ENKOSI NGENXAXHEBA YAKHO