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Pule, Matseliso

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Exploring Perceptions and Attitudes of Users and Providers on Interventions towards Prevention of Mother to Child Transmission of HIV in Soweto, South Africa

(Focus: Knowledge and Experience)

By

Matseliso Pule

A research report submitted to the School of Public Health, University of the Witwatersrand (Johannesburg, South Africa) in partial fulfilment of the requirements for the degree of Master of Public Health for the year 2014

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

Supervisor: Prof. Glenda Gray

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Declaration

I, Matseliso Pule, hereby declare that this research report is my own original work. It is being submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg. It is submitted in partial fulfilment of the requirement for the degree of Master of Public Health. I declare that to the best of my knowledge it has not been submitted before in part or in full for any degree or examination at this or any other university.

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Matseliso Pule

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Abstract

Introduction: After 12 years of implementing the national Prevention of Mother-to-Child Transmission of HIV (PMTCT) programme in South Africa, interventions to prevent MTCT of HIV are now offered in more than 95% of public antenatal and maternity facilities country-wide free of charge (MRC, 2010), even though HIV/AIDS-related diseases are said to be a major cause of death in young children (UNICEF, 2011). The context within which women make decisions about PMTCT participation depends on, amongst other things, the level of their knowledge about HIV/AIDS (Leonard et al, 2001; Sematimba et al, 2004). The concept of behavior-based programming is central to a behavior change approach to reducing Mother-to-Child Transmission of HIV. This places behaviours at the centre of the program design process (Moore, 2003). Understanding the providers and users of the PMTCT interventions' knowledge and experience on HIV and PMTCT is therefore important to ensure appropriate interventions to address beliefs, attitudes, myths and misunderstandings.

Methodology: Semi-structured interviews were conducted with users of the PMTCT programme, while structured survey questionnaires were collected with the providers of the PMTCT programme in early 2012. Users of the PMTCT programme were asked questions regarding HIV knowledge, experience of HIV testing in pregnancy, PMTCT knowledge and experience of the PMTCT programme. We also asked questions on infant feeding choices and practices. Forty six interviews were carried out with participants at three ANC Clinics with PMTCT services in Soweto - Gauteng. Thirty were users of PMTCT programme and sixteen were providers of PMTCT service.

Results: All participants understood that HIV was a virus that affected the immune system. Results show that there is generally a good understanding of HIV and how it is transmitted. In addition there was a good understanding on methods to prevent acquiring HIV. There was a general feeling that a lot of people were afraid of being tested. Interestingly, most participants believed that people who were pregnant or sick had no choice but to get tested. Most of the participants believed that education should be a tool used to motivate more people to get tested for HIV. Most users in this study disclosed their HIV status and PMTCT programme use. Overwhelmingly the decision to participate was based on the desire not to infect their infants. Women had been informed that mixed feeding increased the risk of transmission by breast feeding. There were a few participants who believed that HIV infected women should not breastfed. It was found that almost two-thirds of the women in this study were formula feeding their infants. Reason cited for formula feeding was that they did not want to infect their infants.

As far as PMTCT knowledge was concerned, it was found that almost all health care providers knew that the most common route of HIV acquisition was through heterosexual sexual practices. All the HCWs knew that prolonged breastfeeding increased the risk of transmission. Reassuringly all HCWs knew not to use invasive delivery procedures and that risk of transmission was decreased with low maternal viral load. Only 50% of the HCWs indicated that the first choice of WHO- recommended mother-to-child regimen for antiretroviral prophylaxis in PMTCT was Zidovudine (ZDV) and Nevirapine (NVP) (WHO, 2012). The HCWs understood that infant formula did not provide superior nutritional support or antibody protection. They also knew that formula feeding carried increased risk of diahorrea or bacterial infections. There was confusion

regarding the duration of exclusive breast feeding. Only half of the HCWs stated that post-natal infant-feeding counselling and follow-up are required whenever a mother decides to change her feeding practice. HCW participants felt that most patients fail to adhere to their medication requirements. This was cited to be mainly due to the fact that patients may not have disclosed their HIV status to the household members. Baby feeding choices are cited as the strongest barriers to the success of the PMTCT programmes. Mothers who have not disclosed their HIV status to their household members find it difficult to comply with the chosen feeding choices especially bottle feeding; they therefore opt for exclusive breastfeeding –which family members attempt to interrupt with mixed feeding practices for a number of reasons.

Conclusion: Contrary to studies cited in the literature review, health systems failure was not a major problem in Soweto and therefore was not a factor that could impact on either the knowledge or the experience of users and providers. Even though disclosure rates were high amongst the users interviewed in this study, participants believed that the biggest barrier to people participating in the PMTCT programme was because of stigma, ignorance, and fear that they may be recognised while accessing services by people they may know. Although women had been provided with information on exclusively breastfeed, most users of the PMTCT programme interviewed were bottle-feeding – not due to stigma, but due to fear of transmission. In terms of barriers – adherence was noted as a major problem by providers. This linked to issues of feeding practices - if mothers bottle-feed they are stigmatised and opt for exclusive feeding, but are then forced by family to supplement with the bottle for various reasons. Mothers do not reveal their status, which jeopardises their success on the programme.

Key Words

Acquired immunodeficiency syndrome (AIDS); Human Immunodeficiency Virus (HIV); Transmission; PMTCT; South Africa, Soweto

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CHAPTER 1: INTRODUCTION

1.1. Background and Statement of the Problem

In just three decades, the HIV/AIDS epidemic has become massive public health concern, undermining not just the health prospects of entire nations but also their ability to reduce poverty, and promote and continue to develop. The HIV/AIDS epidemic continues to infect people on a daily basis around the world, with 7 400 new infections, and nearly 5 500 people dying from AIDS related illnesses each day (UNAIDS, 2012). Although the global incidence rate of HIV has decreased by 20% between 2001 and 2011, there are regional variations that still exist. The sharpest declines in the numbers of people acquiring HIV infection since 2001 have occurred in the Caribbean (42%) and sub-Saharan Africa (25%). However, it is still women who bear the burden of the HIV epidemic, particularly in sub-Saharan Africa, which continues to have the highest HIV/AIDS burden in the world (UNAIDS, 2012). Although HIV prevalence has levelled-out, the absolute number of people living with HIV (PLHIV) is said to be increasing – there are approximately 100,000 additional PLHIV each year. The estimated number of PLHIV in 2009 was 5.6 million (ASSA, 2011).

Mother-to-child transmission (MTCT) of HIV persists as a key public health problem worldwide. In sub-Saharan Africa, AIDS has a “woman’s face” - of the 22.9 million people living with HIV, an estimated 59% are women. Furthermore, AIDS is the number one cause of death globally for women of childbearing age. In 2010, 71% of people living with HIV aged 15-24 were women and more than a quarter of all new HIV infections globally are in young women aged 15–24. In sub-Saharan Africa, an estimated 1,360,000 pregnant women were living with HIV in 2010 and only 42% of

these women had received HIV counselling and testing (The Stephen Lewis Foundation, 2012). In 2011 around 330 000 children acquired HIV infection a 24% drop since 2009 (UNAIDS, 2012). Astonishingly, more than 90% of the children who acquired HIV infection in 2011 lived in sub-Saharan Africa (UNAIDS, 2012). HIV/AIDS remains a challenge with women at particular risk and children born to such women vulnerable to infection.

In South Africa, the HIV prevalence amongst antenatal clients aged 15-49 was 29.5 in 2012, 30.2% in 2010, an increase from 29.3% in early 2008 29.4% in 2009. The HIV prevalence among women aged 30-34 years was the highest (42.6% in 2010), and increased by 3.3 % since 2007 (Department of Health, 2011). Among the most tragic aspects of the HIV and AIDS pandemic is the number of infants who become HIV positive through maternal transmission of the HI virus that can occur during pregnancy, birth and during breastfeeding (Moore 2003).

Children born from HIV-infected mothers are at great risk of becoming infected with HIV at various stages of the child birth process, as well as during the post-natal breastfeeding period. The HI virus may be transmitted during pregnancy (mainly late in the pregnancy), delivery, or breastfeeding (De Cock et al, 2000, Nunez et al, 2001, WHO, 2007). In the absence of prevention measures, the risk of a baby acquiring the virus from an infected mother ranges from 15% to 25% in developed countries, and 25% to 35% in developing countries (UNAIDS, 1999). The difference is due largely to feeding practices: breast feeding is more common and usually practised for a longer period in developing countries than in developed countries (UNAIDS, 1999, De Cock et al, 2000, Nunez et al, 2001, WHO, 2007). Transmission occurring during pregnancy

accounts for about 15-20% of infections to babies, 10-20% during labour or delivery, and 33% during breastfeeding (UNICEF, 2002; De Cock et al, 2000, Nunez et al, 2001, WHO, 2007, UNAIDS, 1999)). These figures apply if no steps are taken to prevent the transmission of the virus from the mother to the child.

There are a number of reasons associated with the increased risk of MTCT during labour and delivery. Many infants who acquire HIV during labour and delivery do so by sucking, imbibing, or aspirating maternal blood or cervical secretions that contain HIV (Onyango, 2006). Others can acquire HIV through the mixing of foetal and maternal blood as the placenta separates. The duration of membrane rupture (often performed deliberately to augment or induce labour); acute chorioamnionitis (resulting from untreated sexually transmitted diseases or other infections); and invasive delivery techniques that increase the baby's contact with the mother's blood (Anderson, 1997; WHO, 1999).

A number of studies have shown that the protective benefit of drugs is diminished when babies continue to be exposed to HIV through breastfeeding (UNAIDS, 1999, De Cock et al, 2000, Nunez et al, 2001, WHO, 2007). HIV is present in breast milk, although the viral concentrations in it are significantly lower than those found in blood (UNAIDS, 1999, De Cock et al, 2000, Nunez et al, 2001, WHO, 2007) . Between 10 and 20 percent of infants born to HIV-infected mothers become infected through sustained breastfeeding (18 months or longer) (UNAIDS, 1999, De Cock et al, 2000, Nunez et al, 2001, WHO, 2007). However, several recent studies suggest that the risk of HIV transmission during breastfeeding depends on several factors, including the infant's age, as well as the pattern and duration of breastfeeding, breast health, maternal viral

load and maternal immune status, infant oral lesions and whether the mother became HIV-infected during the breast-feeding phase (McIntyre, 2008; NIH, 2005).

In 2006, the South African government committed itself to scaling-up HIV prevention and treatment responses to ensure universal access by 2010. Between 2006 and 2011, treatment access expanded rapidly, however the number of new infections did not decrease (estimated at 4.3 million in 2006) – with many people unable to access prevention programmes to prevent HIV infection. It was also generally agreed that the country has not been successful in strengthening HIV prevention programmes that ensure that those most vulnerable to HIV infection and those living with HIV are meaningfully involved in the response (UNIADS, 2007). More recent developments are promising and are generally hailed as significant steps in the right direction. For instance, during 2010/2011, the government of South Africa achieved a significant reduction in the price of antiretroviral medicines. The Department of Health awarded a tender for the supply of antiretroviral medicines to the value of R4.2 billion over two years which resulted in savings of R4.4 billion (53%) – when compared with previous tender prices. (UNAIDS, 2012) The lower prices enabled the health sector to re-allocate more resources towards enrolling people on antiretroviral treatment (ART) with its existing budget. Access to ART was expanded to an additional 650 000 people in 2011, which culminated in 1.6 million people living with HIV receiving treatment by the end of that financial year (UNAIDS, 2012).

Moving forward, the National Strategic Plan (NSP) 2012–2016 is driven by a long-term vision for the country with respect to the HIV and TB epidemics. It has adopted, as a 20-year vision, the Three Zeros advocated by UNAIDS. The vision for South Africa is

based on total eradication of new HIV and TB infections; new infections due to vertical transmission, preventable deaths associated with HIV and TB and discrimination associated with HIV and TB. In an effort to achieve the above 20-year vision, South Africa through the NSP 2012-2016 has committed to reduction of all the above by 50% and also to initiate at least 80% of eligible patients on antiretroviral treatment (ART).

The PMTCT package consists of a series of interventions namely ARV prophylaxis, HCT, infant feeding counseling, and postnatal follow-up care. Each aspect of the programme is important and a deficiency in any of the programme aspects will impact negatively on overall effectiveness thereby comprising the ultimate goal of PMTCT, which is infant HIV-free survival (Nkonki et al, 2007).

The HIV prevalence in women aged 15-49 attending government antenatal clinics in South Africa in 2012 was 29.5% as shown, with as many as 40% of pregnant women in some clinics being HIV positive (Department of Health, 2009). In Soweto prevalence is 26% of the sexually active population (Department of Health, 2008) One study done by the HSRC (Kartik et al, 2011) indicated that HIV testing in Soweto was reported to be less than the recent national South African survey data in which only about half of the participants reported past testing. This was not different than what is reported in studies conducted in Botswana and Zimbabwe reflecting about 50% testing uptake (Weiser et al, 2006, Sherr, 2007). In Sub-Saharan Africa it is estimated that nearly 80% of HIV-infected adults are unaware of their status (Bunnell et al, 2008).

According to PlusNews (2012) South Africa has recorded a significant decline in mother-to-child HIV transmission for the second consecutive year, with new data showing that just 2.7 percent of babies born to HIV-positive mums contracted the virus

by six weeks of age, compared to 8 percent in 2008. To further reduce the mother-to-child transmission risk, the country started promoting exclusive breast feeding in April 2012. In welcoming the results and embracing the Tshwane Declaration on exclusive breast feeding by HIV infected mothers, the minister of Health declared that "As we implement our exclusive breastfeeding policy, I would like us to ensure that all eligible HIV-positive mothers are on antiretroviral therapy for the duration of breastfeeding, so that there is no HIV transmission after six weeks of age," said Motsoaledi". However, critics argue that the decision is short-sighted as it is going one step forward and two steps backwards in that this decision does not take into serious consideration the many existing barriers to exclusive breast-feeding (Saloojee et al, 2012). Annually, more than half a million infants globally acquire HIV through breastfeeding, highlighting the failure of previous strategies, including those promoting exclusive breastfeeding. There are currently only two recognised postnatal preventive strategies – antiretroviral prophylaxis provided to mother or infant, and avoiding HIV exposure through replacement feeding. To deliberately discard one of these two strategies is a luxury that the country can ill-afford and requires substantial evidence that the strategy is either ineffective or results in major harm. Evidence to support either of these contentions in the South African setting is lacking according to critics.

To maximally reduce risk of MTCT and to ensure women who could benefit from HAART receive it, specific categories of women can be defined, as shown below. The use of ARVs in infants is also detailed.

Table1: South African PMTCT Regimen Protocol

2010 South African National Protocol for PMTCT Regimen		
Mother	Start all HIV-positive pregnant women on AZT at 14 weeks	
Pregnancy	CD4 cell count≤350 or WHO clinical stage 3 or 4: HAART	CD4 cell count>350 and WHO stage 1 or 2
	Start AZT. Same day referral to ARV clinic	Start AZT. Same day referral to ARV clinic
Labour and delivery	Continue HAART as usual during labour	Single dose nevirapine (200mg) at onset of labour + AZT 300mg 12 hourly until the neonate is delivered
Postnatal	Continue HAART as usual	TDF + FTC (Truvada) single dose (stat) after delivery
HIV-EXPOSED INFANTS		
Mother breastfeeds (and not on HAART)	Mother meets specified criteria and does not Breastfeed	
Daily infant nevirapine throughout the	Daily infant nevirapine for 6 weeks only	

breastfeeding period until 1 week after breastfeeding stops	

Source: WHO, 2012

1.2. Study Objectives

1.2.1. Overall Objective

The overall objective of the study is to explore knowledge and experience of users and providers who participated in interventions towards Prevention of Mother to Child transmission of HIV/AIDS programmes in Soweto.

1.2.2. Specific Objectives

- To explore knowledge and experience of users and providers that impact on the success of PMTCT programmes;
- To determine the knowledge and experience of HIV counselling and testing during pregnancy amongst women who are HIV infected;
- To determine the knowledge and experience of treatment provided in PMTCT Programmes,
- To assess the level of understanding of both users and providers of feeding methods/choices in PMTCT programmes.

1.3. Justification for the Study

The current low levels of success of PMTCT programmes in reaching pregnant women and their newborns with ART and other programme components demonstrates the need for rapid action to refine and strengthen PMTCT behaviour change strategies (Moore, 2003). The South African Department of Health's Antenatal Survey (2010) found that HIV prevalence in pregnant women aged 15 to 49 using public antenatal facilities was 30.2%. This was a slight increase from the 2007 survey, which showed a prevalence of 29.4%. This occurrence underscores the importance of strengthening both prevention and PMTCT interventions.

The context within which women make decisions about PMTCT participation depends on, amongst other things, the level of their knowledge about HIV/AIDS (Leonard et al, 2001; Temmerman et al, 1995; Sematimba et al, 2004). The concept of behaviour-based programming is central to a behaviour change approach for reducing Mother-to-Child Transmission of HIV. This places behaviour at the center of the programme design process (Moore, 2003). Understanding the providers and users of the PMTCT interventions' knowledge and experience is therefore important to ensure appropriate interventions to address beliefs, attitudes, myths and misunderstandings that users and providers may have. However, there is limited information about this in the developing countries, including in South Africa Therefore, it is important to evaluate whether the knowledge and experience of users and providers impacts on successful PMTCT implementation in South Africa.

A comprehensive approach to behaviour change to prevent mother-to-child HIV transmission recognises that behaviour change does not result from increasing

knowledge alone. But many contextual factors, including the behaviors of a wide family and community network, influence individual behavior change. Creating an “enabling environment” - addressing barriers, resistances and motivators – is essential. These interventions can help to create supportive, “enabling” environment at household, community, health facility and policy levels, within which the recommended behavior change can best occur (Moore, 2003).

This study will be used to provide guidance to the strategies and initiatives targeting scale-up of comprehensive PMTCT, taking into consideration the knowledge and experience of the users and providers in the Soweto area of Gauteng.

CHAPTER 2: LITERATURE REVIEW

2.1 Key Components in PMTCT Programmes

2.1.1. ART Approach

According to WHO (2012), the following details the recommended ART approach *(beginning of direct quote)*: "recent developments suggest that substantial clinical and programmatic advantages can come from adopting a single, universal regimen both to treat HIV-infected pregnant women and to prevent mother-to-child transmission of HIV. This streamlining should maximise PMTCT programme performance through better alignment and linkages with antiretroviral therapy (ART) programmes at every level of service delivery. One of WHOs two currently recommended PMTCT antiretroviral (ARV) programme options, Option B, takes this unified approach.

A new, third option (Option B+) proposes further evolution—not only providing the same triple ARV drugs to all HIV-infected pregnant women beginning in the antenatal clinic setting but also continuing this therapy for all of these women for life. Important advantages of Option B+ include: further simplification of regimen and service delivery and harmonization with ART programmes, protection against mother-to-child transmission in future pregnancies, a continuing prevention benefit against sexual transmission to sero-discordant partners, and avoiding stopping and starting of ARV drugs. While these benefits need to be evaluated in programme settings, and systems and support requirements need careful consideration, this is an appropriate time for countries to start assessing their situation and experience to make optimal programmatic choices.

This programmatic update is meant to provide a current perspective for countries on the important changes and new considerations arising since publication of WHOs PMTCT ARV guidelines (2010 version), especially as a number of countries are now preparing to adopt Option B+. WHO has begun a comprehensive revision of all ARV guidelines, including guidance on ARVs for pregnant women, planned for release in early 2013" (WHO, 2012) *(end of direct quote*). Operational studies, however, have found that less than half of mothers testing HIV positive routinely receive medication in developing countries (Nkonki et al,9 2007). This poor performance raises questions on success of PMTCT services in Africa.

2.1.2. HIV Counselling and Testing (HCT)

HCT is a process where an individual voluntarily chooses to find out their status though testing for antibodies to the HI virus. Because of the implication of the results it is important that individuals are counseled before and after undergoing the test (Botma et al, 2007). Counselling was designed to help individuals interpret the meaning of negative or positive antibody results, to initiate and sustain behavioural changes that reduce the risk of becoming infected and to assist HIV positive individuals in avoiding infecting others (WHO, 2012; CDC, 1994). The mothers who are HIV positive are counselled on choices of infant feeding. The mother's choice of feeding is also dependent on counseling that is why it is important for health care workers especially counselors to have an extensive knowledge of PMTCT intervention programs including breastfeeding (Makokela-Nene, 2002). HCT is the most vital step towards preventive strategies to reduce transmission of HIV and AIDS from mother to child; mothers need

to know their HIV status before they can engage in the prevention of HIV for mother to child (CDC, 1994).

HCT is the backbone of PMTCT, the quality of counseling and the time taken in a counseling session. This determines the acceptability of the programme to pregnant women. Provider-initiated routine HIV testing with the right of refusal is now offered to all new ANC clients in a bid to improve uptake of HCT.

2.1.3. Feeding Choices

The appropriate feeding regime for infants born to HIV-positive mothers is critical in enhancing a reduction in the spread of post-natal mother to child transmission of HIV and child mortality. Until the end of 2011 the South African government's policy favoured bottle feeding by offering mothers with HIV commercial infant formula milk through public health services. It was found that most mothers opting for the formula were unemployed and that at least a quarter of them admitted to selling it as they were desperate for income, so there was little benefit to their babies. HIV positive mothers who opted for the free formula usually ended up practicing mixed feeding increasing the chances of HIV transmission. In light of this, in April 2012, South Africa adopted the 2010 WHO guidelines on HIV and infant feeding and recommended that all HIV infected mothers should breastfeed their infants and receive anti-retroviral drugs to prevent HIV transmission. As a result free formula supply at the health care facilities was stopped.

However, a study that was done by the Medical Research Council (MRC) across Botswana, Malawi, Kenya and Uganda found that most health care workers (70%) were unable to correctly estimate the transmission risks of breastfeeding irrespective of

exposure to MTCT training. Only 6% of counsellors/health workers discussed feeding issues in any depth during the counselling sessions; of these fifty four (54%) were rated as very poor. The same study also revealed that there was a universal belief that an HIV-infected mother who breastfeeds will always infect the child. It is also believed that intentional avoidance of breastfeeding by the mother indicates that she is HIV positive (Chopra et al, 2007). These encompass both knowledge and experience factors.

Another study in KwaZulu-Natal (South Africa) assessed breastfeeding knowledge amongst health workers in an area of high HIV prevalence. According to the findings, over fifty percent (50%) of the participants had given advice about breast feeding to clients over the previous month. However, there were discrepancies in the levels of breastfeeding knowledge. Thirty seven percent of community health care workers knew that breastfeeding should be initiated within thirty (30) minutes of delivery, 68% thought breastfeeding should be on schedule and not on demand, and the majority would recommend supplements to infants under six (6) months of age. The most commonly given responses to problems of babies who were perceived to be thirsty or crying after feeds was to supplement with other fluids or feeds (Doherty et al, 2005). This is problematic because mixed feeding makes the baby susceptible to contracting HIV.

It is generally agreed that the health care workers were not giving the advice or were not encouraging the mothers to breastfeed. In fact the healthcare workers were encouraging mixed feeding if they were giving advice to supplement fluids or feeds to the babies that were thirsty or crying after feeding. In this context the health care workers were not giving consideration to the mothers who have social factors that force them to breastfeed such as cultural norms, family obligations and partner

expectations(Doherty et al, 2005). The study was done in KwaZulu-Natal, which means some of the women might have been staying in rural areas where infrastructure and other socio-economic limitations do not allow them to bottle feed.

One of the recommendations of the above study is a need for systematic and ongoing training in breastfeeding and infant feeding counseling in the context of HIV, so that breastfeeding is not undermined by the current HIV pandemic, and exclusive breastfeeding continues to be promoted for all HIV uninfected women, women of unknown status, and HIV infected women who choose to breastfeed (Doherty et al, 2005).

2.2 The Role of Social Factors on PMTCT Adherence

Stigma, involuntary disclosure and lack of family support are some of the social factors that influence women's attitudes towards accessing PMTCT programmes. According to a study that was done in Nigeria of attitudes of antenatal clients towards HIV and PMTCT the main reasons for declined use of the PMTCT intervention were fear of stigmatization, isolation and effect on marriage security (Oganji et al, 2008). Another study that was done in Zimbabwe reported that a decrease in use of antenatal care (ANC) services with an increase in home deliveries is affecting the coverage of PMTCT interventions in a context of accelerated economic crisis (Perez et al, 2008).

Another study that was done in Malawi on pregnant women reported that, "it is important to remember that being tested may bring conflict to women whose partners have not consented to it" (Kasenga et al, 2009). The study revealed that even when ARVs are available, women who live in close-knit families and communities might

choose not to protect themselves or their unborn children rather than risk rejection by their families and community if they are known or perceived to have HIV or AIDS. This fear of rejection is largely due to the stigma that is associated with the disease. A young pregnant woman in Botswana reported that “when you get AIDS you are ridiculed by society… You are ill- treated… People think you have been careless, promiscuous” (Kasenga et al, 2009).

Another study that was done in Nigeria on attitudes and beliefs of pregnant women towards VCT asserts that women who refused VCT attribute their refusal to the social and cultural stigmatisation associated with HIV (Okonkwo, 2007). Many women, and couples, were prepared to try out formula milk after receiving counseling about to the possibility of breast milk infecting the infant after birth and information on formula feeds. But the problem begins when the woman go back home with the extended family who are not aware of the HIV status of the mother or the couple (Suniti, 2008).

According to Esplen (2007) “women living with HIV and AIDS may also be deterred from returning to health clinics by the judgmental attitudes of health workers, who sometimes deny women the opportunity to give informed consent to HIV testing and treatment, violate their confidentiality, treat them with disrespect, deny them with services, or push them to access services without providing comprehensive information about alternatives. Esplen points out that health care workers sometimes bluntly refuse to care for HIV patients - refusing to let them access clean water, stretchers, waiting rooms, seats, food and even toilets. Furthermore, women who are able to access health clinics, fear of disclosing a positive diagnosis can interfere with their ability to maintain adherence to antiretroviral therapy, and may prohibit them from adhering to prevention

of mother to child transmission programmes for fear that using alternative feeding options (rather than breastfeeding) will reveal their positive status" (Esplen, 2007).

HIV and AIDS stigma and discrimination is thus widespread amongst health workers as well. Some stigma among providers is undeniably related to assumptions about the educational, social, and economic and class status of HIV positive clients (Moore, 2003). Stigma around health workers can delay or prevent patients from receiving necessary care. "The cultural necessity of breastfeeding and fear of disclosure of HIV status through unexplained deviation from accepted breastfeeding practice can be strong barriers to replacement feeding. For example, in a study that was done in South Africa, HIV positive women who were given infant formula on discharge from the hospital frequently left the formula at the hospital gate" (Moore, 2003).

Research has also revealed that unfortunately, for some HIV positive women, the choice of whether or not to disclose may be out of their control, either because their actions may signal their status by, for example, using HIV related services, or visibly suffering the side effects of ART-or as a result of breaches of confidentiality by indiscreet family members or health workers. For example, in India, it was reported that health care workers often disclosed a woman's HIV positive diagnosis to her husband in the belief that the women herself would not understand the information given to her and its implications (Center for Reproductive Rights, 2006). The possibility that their status will be made public without their consent strongly discourages women from obtaining an HIV test, seeking necessary treatment, or being open about their HIV status (Merkel, 2006). The above examples, drawn from different parts of Africa, point to social factors that pose barriers to accessing and complying with PMTCT programmes.

From this point of view then, challenges for women living with HIV range from systems failure, gender inequality, health care workers knowledge and attitudes as well as general access issues such as lack of mobility and transport to health care facilities. These continue to be important talking points in the South African HIV prevention policy arena. Whether this would result in tangible changes remains to be seen and is subject for another research project.

Disclosure may reduce transmission of HIV by raising awareness and decreasing risky sexual behaviors. In a study that was done in South Africa, after disclosure the majority (82%) of participants asked their partners to get tested. Participants reported receiving support after disclosing. The findings of the study suggest that disclosing to others may not only lead to safer outcomes after HIV testing but also safer health behaviors after disclosure. The majority of HIV positive individuals reported receiving more social support after disclosure, which is important, given the reported negative stigma surrounding the disease (Wong et al, 2009).

Finally, scientists agree that the low up-take of treatment by HIV positive women is also a result of the gendered barriers that positive women face in accessing care, treatment and support services. Entrenched economic and social inequality within their relationships with men can constrain women's ability to access services or abide by the advice given to them by health workers. The costs of transport to the clinics, coupled with the time lost from work or caring responsibilities, as well as the costs associated with childcare, present severe obstacles to women's ability to access treatment. These barriers are more severe for women than men because women are often financially dependent on men. Women's lack of decision-making power and the constraints on

their mobility mean that they may have to obtain permission in order to seek health care or account for their time to their husbands or other family members. In Asia, discrimination against sex workers is so strong that many HIV positive women will not go to the reproductive health clinic for fear of being labeled as a sex worker (UNAIDS, 2004).

This chapter discussed the factors that influence HIV-positive women's knowledge and experience of PMTCT programmes. It was argued that a number of social factors including woman's gendered position and negative attitudes of health care workers towards women living with HIV/AIDS. These factors influence women's participation in PMTCT programmes and ultimately their success.

2.3 Health System's Failures in Implementing the PMTCT Programme

A study that was done by the Medical Research Council (MRC) in 2007 reported that PMTCT in South Africa has reached its national coverage as seventy percent (70%) of women who attend ante-natal clinic do present themselves for HIV testing. However, data from a 2003 programmatic evaluation showed that whereas there is HIV testing uptake at ante-natal clinics (ANC), fifty percent (50%) of women who are recruited into the PMTCT programme do not actually receive Nevirapine according to the national protocol (Nkonki et al, 2007).

A study that was done in three sites in South Africa in 2007 revealed that 15 out of 58 women missed their Nevirapine, not because of stigma and ignorance (as it sometimes postulated to be the case) but because of health system failures. This means the 15

women who were recruited for PMTCT programme did not get treatment to save their children from being infected with HIV. The reasons stipulated were that 6 women were not tested, 2 women tested but did not receive results, 7 women tested and received results but did not receive Nevirapine at a correct time because the health care workers did not look at the patient file before delivery and ask the patient if they have taken the medication (Nkonki et al, 2007).

Yet another study that was done at Tintswalo Hospital in the Limpopo Province reported that rural facilities experience staff shortage, the nurses/clinic staff were unsatisfied with management of lay counselors, a lack of proper supply and distribution of consumables, such as NVP, test kits and formula milk (Ridgard, 2004). HIV counseling and testing as part of the antenatal care was routinely available in only (30%) of facilities. Thus counseling and testing of HIV, a critical element of PMTCT services was the least available among ANC services included in the study (Moore, 2003).

The findings from all these research projects suggest that the reason some women missed opportunities of participating in a PMTCT programme is because of health systems failure. The programme leakages ranged from non- availability of counselors, supplies such as HIV test kits, consent forms, health staff giving the women incorrect instructions about when to take the tablet and health staff not supplying the women with the tablet to take. These factors undermine the well-set-out, well-defined ART approach of preventing mother-to-child-prevention.

CHAPTER 3: METHODOLOGY

3.1. Study Design and Target Population

This is a quasi-quantitative study. The study examines the knowledge and experience of participants, using semi-structured and structured questionnaires. Semi-structured interviews were conducted with users of the PMTCT programme, while structured survey questionnaires were collected with the providers of the PMTCT programme. Users of the PMTCT programme were asked questions regarding HIV knowledge, experience of HIV testing in pregnancy, PMTCT knowledge and experience of the PMTCT programme. We also asked questions on infant feeding choices and practices.

The study aimed at carrying out 46 interviews at three antenatal Clinics (ANC) in Soweto - thirty (30) users of the PMTCT programmes and fifteen (16) service providers took part in this study. Eleven front line service providers (health care workers directly involved in the provision of PMTCT services) and five clinic managers, who had participated in the implementation of the PMTCT programme in the last 12 months, were selected from the three ANC clinics in Soweto. The front line service providers were randomly selected through convenient sampling, while clinic managers were selected using simple random sampling.

Furthermore, the 30 clients (HIV infected mothers) who used the PMTCT services were purposively selected. The service providers assisted in letting the researcher know the pattern of service utilisation to allow for optimal sampling. This means that the research was conducted during the days that the clinics offer ANC services. The women who

were selected were HIV infected women who had participated in the PMTCT programme in the privious 6 to 12 months.

The exact breakdown of service providers and users interviewed at each clinic is show in table 2 below.

Table 2: Summary of the Study Population by Clinic (n=46)

Lilian Ngoyi Clinic	
Service Providers	
Front line service providers	4
Local managers	1
Service Users	10
Chiawelo Clinic	
Service Providers	
Front line service providers	3
Local managers	2
Service Users	10
Mofolo Clinic	
Service Providers	
Front line service providers	4
Local managers	2
Service Users	10

Data collection took place between January and April 2012 at Lilian Ngoyi, Chiawelo and Mofolo clinics in Soweto. These clinics are public health care facilities that offer

preventive medicine, hence their involvement in PMTCT. These clinics are also accredited as per the DoH guidelines to offer PMTCT programmes.

3.2. Data Collection

Questions for the questionnaire guide were compiled taking into account what has been found in the literature to affect the knowledge and experience of clients using the PMTCT programme in other countries and areas in South Africa. To pilot the tools, the provider and user questionnaires were administered to five participants within the target population. However, individual written informed consent was first obtained. The main aim of the piloting exercise was to help adjust any final confusion or problem areas and also to adjust language so that it was better suited to the audience. Questionnaires were administered in South Sotho and IsiZulu for ease of comprehension - no changes were made to the questionnaires - all tools were administered as approved by the Ethics Committee .

In order to facilitate the understanding of the breadth, depth and complexity of the research and to formulate appropriate strategies, the following data collection technique was employed:

- A self-administered questionnaire to the PMTCT providers
- Face to face interviews with the PMTCT users. Interviews were held privately in the rooms allocated to the researcher by the clinic managers. After the usual clinic routine, prospective participants were informed that a study was being

conducted on HIV and that those willing to spare an hour to participate in the interviews were welcome to do so.

3.3. Ethical Consideration

The researcher obtained permission from the health centre to invite people to take part in the study. Research ethics guidelines regarding confidentiality were adhered to.

Ethical considerations were based on the University of the Witwatersrand Human Research Ethics Committee (HREC) guidelines on research on human subjects, and approval was obtained by them. Permission to conduct the study at the various public health facilities was also granted by the Department Health.

Written Informed Consent was obtained from all participants prior to the interviews. The consent form detailed the aims and objectives of the study, participant involvement including how possible harms would be safeguarded against, use of study findings and data storage.

3.4. Analysis

The data from the semi-structured questionnaires (for the users of the PMTCT programme) and the survey questionnaire (for the providers) were analysed using univariate and descriptive statistics – namely percentages, together with their n-values. The semi-structured questionnaire was designed to elicit more descriptive responses,

but it was found that the users of the PMTCT programme often answered similarly to each other. Therefore, data from the semi-structured interviews were aggregated for the analysis. Short verbatim quotes were used in the analysis of the information collected from users of the PMTCT programme - where these were found to be applicable, relevant and value-additive to the quantitative results.

All the quantitative data was captured and analysed using Excel, and the verbatim quotes were picked manually from the transcripts of the interviews.

CHAPTER 4: RESULTS

4.1. Findings from PMTCT Users

All women involved in this study lived in Soweto and were between 18 to 40 years. The majority of these women were single (n=28; 96%) and unemployed (n=20; 75%). Almost all mothers had more than one child (n=25; 83%). Only two women were pregnant and still active in the PMTCT programme while 28 had already had their babies and were now in the post PMTCT programme.

More than half of the women interviewed (n= 17; 58%) had learnt about their HIV status during the current pregnancy. The others (n= 13; 48%) knew about their status before becoming pregnant. Reassuringly almost all the participants (n=28; 96%) got their HIV test results on the same day of testing and only two (n=2; 4%) had to wait for 2 days or longer. It appeared that the time taken to receive results after testing was short and the process appeared efficient.

4.1.1. Knowledge and Experience with HIV and HCT

Where participants first heard about HIV: 29% (n=9) of the participants heard about HIV through media like television, radio, community newspapers, billboards and pamphlets. Some participants (n=8; 27%) heard about HIV in their communities from people talking about it or through the death of an HIV-infected resident. Just under a quarter (n=7; 22%) reported that they heard about HIV while they were still at school, whereas only two participants (n= 2; 6%) said they had first heard about HIV at the local clinic. This shows that there are many HIV/AIDS information dissemination outlets in Soweto.

Knowledge on general HIV information: In trying to assess the understanding of HIV, we discovered that all participants understood that HIV was a virus that affected the immune system. We found that there were local words attributed to HIV, namely "*Z4*", "*Tsumami*", "*Z3*", "*amagama amathathu*" as words locally used to refer to HIV. Z4 and Z3 are BMW models. These cars are sports cars, they are fast and small. Like the virus they are small and get from point A to Point B very fast. The term Tsunami speaks for its self: reflecting devastation, destruction and chaos. "*Amagama amathathu*" means three words in IsiZulu depicting the three words "Human Immunodeficiency Virus". The incorporation of these terms in daily language indicates how common and stigmatised HIV is in the community. This selection of word also indicates the fear factor of HIV.

Results show that there is generally a good understanding of HIV and how it is transmitted. Everyone knew that HIV is transmitted after exposure to HIV through unprotected sex. There was also a general understanding that multiple sexual partners increased the risk of HIV acquisition as one participant noted in IsiZulu "*o lala la… o lala la*" (meaning sleeping here, there and everywhere). Most respondents also understood that transmission could occur from exposure to contaminated blood, and that a mother can transmit HIV to her baby during pregnancy, birth and through breastfeeding. Participants also understood that HIV was a manageable disease with no cure.

In addition there was a good understanding on methods to prevent acquiring HIV. Participants (n=24; 80%) understood that one could prevent HIV infection by using condoms. Others (n=6; 20%) cited other prevention methods such as abstinence and staying faithful with one partner. In South Africa most Community Health Care Workers (CHWs) talk about the concept of re-infection meaning that participants can be re-

infected by different strains of HIV. It is thought that re-infection can affect disease progression.

Knowledge and Experience of HIV Counselling and Testing: Most participants (n= 28; 92%) knew that a person must have a HIV blood test to know their status. However, a minority (n=2; 8%) believed that having symptoms like swollen glands and illness like tonsillitis was an indication of being HIV positive. There was a general feeling that a lot of people were afraid of being tested. Interestingly, most participants believed that people who were pregnant or sick had no choice but to get tested.

When we asked about participants' experience of HIV testing we found the anticipated spectrum of feelings. The majority of the participants (n=26; 86%) indicated feelings of sadness, devastation and disappointment. One of the participants (26 year old with one child) declared that she was afraid and thought she was going to die immediately "*ke ne ke tsohile ke nahana ke tlo shoa hang hang!!".* Another participant (22 year old with two children) felt guilty and surprised because she had only one partner over a period of six years. Her partner had fathered her two children.

Six participants were in relationships classified as discordant couples, claiming that their partners had tested several times after they had tested positive and their partners had remained HIV negative. We found that women did not understand the concept of discordancy in relationships and were baffled about their situation. We also found that partners reacted negatively to being in a discordant relationship:" *I told my partner who also went for an HIV test results came back negative was very cross with me did not talk to me for 2 weeks, he went for another test again after 3 months and that one was also negative*".

Participant recommendations to increase number of people who test: Most of the participants (n=24; 80%) believed that education should be a tool used to motivate more people to get tested for HIV. Participants argued that celebrities and people in high positions in society who are HIV positive must be used to educate people in local communities about HIV and AIDS. Communities would therefore see that HIV is not a virus for poor people and it can be managed like other chronic illnesses. Participants also mentioned that people can be encouraged to test through incentives such as branded t-shirts, caps etc. However, about 20% of the participants said people must not be forced to test if they do not want to test because testing for HIV could lead to negative consequences by others, whether they tested positive or negative.

Disclosure: Most women disclosed their HIV status. Only one woman had not disclosed at all. Over half (n=17; 58%) of the participants had disclosed only to their family members. More than one third of women (n=11; 38%) had disclosed to both partners and family members. The reasons cited for not disclosing to partners included fear of rejection, fear of loss of income, and fear that they may be subjected to intimate partner violence.

4.1.2. Experience in the PMTCT programme

Knowledge on timing of transmission, as well as methods to prevent HIV transmission from mother to child, was assessed. Furthermore, mothers experience around stigma and discrimination was also investigated. Most importantly, mothers were asked why they had decided to participate in the PMTCT programme.

Participation in the PMTCT Programme: The most common reason cited for participating in PMTCT programme was the avoidance of transmitting HIV to their infants. Almost all the participants (n=29; 98%) decided to participate in the PMTCT programme because they did not want their babies to be infected with HIV. Only one did not give a reason for her participation.

Again high rates of women disclosing their participation in the PMTCT programme to their family members was found. Most (n= 23; 76%) of the participants did tell their relatives about their participation in the programme. Those that did not tell of their participation (24%) were concerned about the stigma associated with the programme. Participants believed that most of the people do not want to participate in the PMTCT programme because of stigma, ignorance, lack of knowledge, afraid of being judged, criticised, and lack of belief in western medication, unaware of benefits of the programme, afraid that they may be recognised by someone they knew. We see discrepancy between disclosure of HIV status and participation in PMTCT programme in our study.

PMTCT information provided at the clinics: It appears that the clinics provide adequate information to participants in the antenatal setting. Most of the participants (n=20; 68%) believe that the information sessions given at the clinics were enough to disseminate valuable and important information. Participants said they had 8 sessions, each focusing on a different topic, in which they were taught by different people and they believe when one health worker forgets particular information the other health worker was able to cover that. On the contrary, very few (n=10; 32%) participants believed that the information was not enough. One client said "*the PMTCT health care*

workers could not even help me to tell my partner who is HIV negative that I am HIV positive". Instead, she was helped by one sister at antenatal clinic after the baby was born. The other participant said the health care workers did not tell her she has to take medication before the baby was born as a result she took medication after the birth of the baby. These challenges resonate with some of the challenges raised by the literature review.

4.1.3. Knowledge about PMTCT

Infection of babies with HIV: Most of the mothers (n= 29; 91%) knew the importance of participating in a PMTCT programme. Overwhelmingly the decision to participate was based on the desire not to infect their infants. Women had been informed and knew that mixed feeding increased the risk of transmission by breast feeding. However, there was confusion around the role of unprotected sex in HIV infected pregnant women and HIV transmission from mother to child. During information sessions at the clinic women were taught that women who were not infected by HIV should be counselled to use condoms to prevent sero-conversion, with concomitant transmission to the infant. This has been interpreted by HIV infected women as an additional risk of mother infant transmission. It was clear that all HIV infected women knew that they could transmit HIV during pregnancy, delivery and via breast-feeding.

There were a few participants (n=3; 9%) who believed that HIV infected women should not breastfeed. It was found that almost two-thirds of the women in this study were formula feeding (n= 19; 63%) their infants. Reasons cited for not breast feeding were fear of transmitting HIV by this mode. At that stage, formula was also provided free of charge by the clinics, making this an easy choice.

Prevention of HIV transmission to infants: Most of the participants (n= 28; 91%) believed that as long as one followed the Health Care Workers “rules”, one could prevent transmission to their infant. These rules included: taking ARV or AZT while pregnant; choosing the right feeding option; using condoms during pregnancy and when breast feeding; using single dose Nevirapine during labour; and “rushing” to the clinic before the baby was born so that both the baby and the mother could receive appropriate prevention care.

Most participants also believed that in order to prevent one’s child from being infected by HIV, mothers should refrain from breastfeeding. Only one participant said that she did not know how babies could be prevented from getting HIV. In addition mothers made the point of looking after their babies adequately so that they did not play with blood or needles.

When participants heard about the PMTCT programme: In trying to assess how women heard about PMTCT programme, two-thirds of the participants (n=20; 68%) heard about the PMTCT programme during their pregnancies. Some participants (n=7; 32%) said they knew about the programme before falling pregnant through reading pamphlets and on the radio.

Treatment by HCW: Almost all participants (n=29; 95%) indicated that Health Care Workers treated them well. They gave them enough information and were comfortable to ask questions and felt they were able to put them in their own shoes. One participant mentioned that she was comfortable around Health Care Workers because they do not disclose her confidential information to the other pregnant mothers. However, one participant felt discriminated by the use of green stickers that identify HIV-positive

mothers. Only one participant felt that she was not treated well by Health Care Workers. Participants showed a general feeling of satisfaction with the treatment they were provided with. One participant indicated that she was happy with the treatment because she had nothing else to compare with. She further highlighted that she could not go to the other clinics to seek services as it took her courage to present to the clinic she was at. "*It is very embarrassing to show up with this disease*" she whispered". Generally the users reflected positive perception regarding the programme by feeling comfortable, satisfied and well treated by the health care workers.

Benefits from the PMTCT programme: Most of the participants (n=29; 96%) believed that they had benefited from the PMTCT programme because now they had more information about HIV and AIDS, their babies had been helped to stay HIV negative, and they could now speak freely about HIV and AIDS. Only one participant felt that she was not sure whether she benefited from the programme because her baby was not yet tested for HIV.

With regards to support, sixty percent of the participants mentioned that the only support they were getting from the clinic was the free milk formula. About 20% of the participants said they were not getting any support from the clinic. Another 20% said they were not sure whether they were getting any support from the clinics. The participants reflected a positive attitude to the programme.

4.1.4. Should HIV positive mothers have children?

Most of the participants (n=28; 91%) believed that HIV infected women should have babies if they so desired, and if they did not have children already. There were

comments on the "*rights to reproduction*" but always with caveat around being healthy, able to care adequately for the baby and getting advice. They used statements like "*ARV are available which gives you freedom to have children*". Women cautioned that having children was okay as long as you followed the PMTCT programme. Some made comments like as long as an HIV pregnant woman follows Health care worker "*rules*" it was okay. Interestingly, one woman indicated that pregnancy should only occur if CD4 counts were high. Reasons why it was felt that HIV infected women could have babies were related to the increased availability of treatment and PMTCT programmes. One of the participants pointed out that "*some of the people who are HIV positive do not have children so it was very interesting to know that one can have an HIV negative child whereas before one thought one could not have a child because one is HIV positive and one's child might be infected with the virus"*. They argued that they want to have children like any other women. One woman stated that HIV infected women were also human and had rights "*whether you are poor or a prisoner, unless you have another problems that will cause a child to have other abnormalities"*

Only a minority (n=2; 4%) of HIV infected women stated that HIV infected women should not have children. One woman remarked that the chances of a child being alive and healthy were slim and did not feel right generally about having a baby. She further pointed out that having children put mothers' lives at risk. One woman only said "*no*" and was unwilling to give reasons. One woman was unsure of whether or not women who were HIV infected should have babies. She recognised that they might want children like any other mother; she also stated that "*having a child when HIV-positive was quite exciting especially when you thought before that you could not have any"*.

She also added that "being pregnant while HIV positive is really not a right thing because one always got worried about whether the child will be positive or not."

Other women who were unsure gave various reasons for their doubts. They stated that "*when one has a baby one can lose a lot of blood and that could put a strain one one's CD4 count and health; one can never know the HIV outcome of her child; one can die during child birth; one cannot know how long she will live for the child*"

4.1.5. Baby feeding choices

There has been a lot controversy around infant feeding choices around HIV infected women. We were interested in finding out what mothers thought and felt about breast feeding and formula feeding. Almost all participants about (n=29; 96%) felt that they learned about baby feeding choices from the clinics. They said the health care workers educated them about baby feeding options at the clinics and they encouraged them to breastfeed their babies because breast milk is healthy for the babies. The participants stated that the information that they got from the health care workers on feeding options was enough. Only one participant was unsure where she learnt about feeding options.

In the sample of women interviewed we saw a lot of women choosing to formula feed (65%). It is important to note that this study took place before the PMTCT guideline changed. Reason cited for formula feeding was that they did not want to infect their infants. Some women (n=5; 15%) did report that they were mixed feeding (breast milk and formula) of their babies. One participant said she was giving the baby formula from the clinic but due to stock-outs she decided to breast feed her baby. Amongst mothers who were still pregnant (n=2; 7%) there were some uncertainty regarding mode of

feeding. For women who had already delivered their children only one was breast feeding. The reason for her decision was attributed to health care workers' instructions. She quoted one health care worker to have said "*Breast milk is good for the baby even when the baby is sick breast milk can help to speed up the healing process*." In contrast to health care worker advice to breast feed, most of the women who participated in this study were not following the advice. This is one of the pitfalls of education that is general and does not specifically speak to the needs and concerns of the target population.

We were interested to know how families felt about infant feeding choices. Less than half (n=12; 41%) of the participants said their families were very supportive of their choice of feeding option. This was attributed to family members knowing their HIV status. One participant quoted "*at first it was difficult, the child didn't want the bottle*". The family wanted her to breast feed but she told them about her status. One woman reported that her family was supportive and even bought her formula milk before she arrived home from the clinic. Another woman cited her reason for formula feeding as the fact that she did not have enough breast milk. One woman said that she had TB that is why she bottle-fed her baby. Others said that they were working and therefore could not breast feed and the other said that because she had twins she could not breast feed. Others n= 41% said they did not have any idea on how their family members would respond because they are no longer part of their lives as they are not living with them. Some of the participants (11%) said they were staying alone so they do not know how their family members would have responded had they stayed with them. Very few (n= 7%) participants indicated that their family members initially had a problem but supported them later.

In assessing whether mothers were comfortable with their feeding options, mothers were asked how comfortable they were with their choices of feeding. Two-thirds of the participants (n= 19; 64%) assured us that they felt comfortable with their feeding option because they know that their babies will not be infected through their feeding choice. About (n=8; 25%) a quarter of the participants indicated a feeling of uncertainty in their feeding choice. They mentioned that they did not know but they just did what they were told is best for the baby, and would be waiting for their children's HIV results. A minority of the participants (n=3; 11%) alleged that they were not comfortable about their feeding options and did not give reasons.

Because not breast feeding is highly stigmatised in the community and automatically associated with being HIV-infected we inquired about feelings of stigma and shame. Sixty percent of the participants declared that they were not treated differently by the people they were living with because of the way they fed their babies. The two who had not yet delivered were unsure what the response from their family and community would be. We did find that some women were treated differently but would not give a reason why they said they were treated differently by the people living with them.

4.2. Findings from PMTCT Providers

All providers had received PMTCT training in the past. This study was interested in ascertaining knowledge and understanding of basic PMTCT concepts and practices by providers who offer PMTCT at public health facilities in Soweto (see appendix 2). On

average the health care workers saw fifteen clients per day. In the study sample the managers indicated they were involved in patient care.

4.2.1. PMTCT knowledge amongst providers

As far as PMTCT knowledge was concerned, it was found that almost all health care providers (n=13; 80%) knew that the most common route of HIV acquisition was through heterosexual sexual practices. Those that did not answer that heterosexual transmission was the most common route, reported that mother to child transmission was the most common way of transmission. Only one thought that intravenous drug use was the most common route of HIV transmission. When the interviewer enquired about the adult WHO staging system of HIV infection; only two HCWs could not answer this correctly. According to WHO the staging system of HIV infection, a clinical symptom of stage II HIV is recurrent upper respiratory tract infections. The HCWs who could not answer this question correctly belonged to the counsellors' category. Of the nurses and managers answering this question all got this right indicating very good clinical acumen.

All the HCWs knew that prolonged breastfeeding increased the risk of transmission. Reassuringly all HCWs knew not to use invasive delivery procedures and that risk of transmission was decreased with low maternal viral load. In addition, HCWs knew the importance of treating sexually transmitted infections early and was an important strategy to minimise the risk of mother child transmission.

Most (n=12; 75%) HCWs knew that primary prevention of HIV infection included correct and consistent use of condom, delaying the age of first sexual intercourse and being

faithful to one uninfected partner who is faithful as well. All agreed that excluding male partners from HIV education programmes was not helpful.

Regarding tuberculosis (TB) Screening and treatment all agreed that these services should be available to women who are HIV-infected and not receiving antiretroviral therapy; to women presenting for ANC services with a cough of more than 2 weeks; and for those women who were HIV-infected with recent exposure to tuberculosis.

Knowledge around the antiretroviral regimens for PMTCT was not as good as expected. Only 50% (n=8) of the HCWs indicated that the first choice of WHO- recommended mother-to-child regimen for antiretroviral prophylaxis in PMTCT was Zidovudine (ZDV) and Nevirapine (NVP). The HCWs that correctly named the antiretroviral were the managers (5) and nurses (3). Of those reporting that single dose Nevirapine was the PMTCT regimen were 3 nurses and all counsellors.

All participants knew that the one advantage of using commercial infant formula was that other family members can feed the baby as well. The HCWs understood that infant formula did not provide superior nutritional support or antibody protection. They also knew that formula feeding carried increased risk of diahorrea or bacterial infections.

There was confusion regarding the duration of exclusive breast feeding. Only 40% (n=6) of HCWs knew that exclusive breastfeeding could cease when local circumstances were safe. Of those that answered correctly were 4 managers and 3 nurses. The rest (4 nurses, 4 counsellors, and 1 manager) did not know how long one should exclusively breastfed for.

Only half (n=8, 50%) of the HCWs (3 nurses, 3 managers and 2 counsellors) stated that post-natal infant-feeding counselling and follow-up are required whenever a mother decides to change her feeding practice .This is a difficult question as post natal infant counselling is not consistently practised. It is our opinion that all the options given on this WHO questionnaire could be correct.

It was good to see that the question regarding the rights of persons living with HIV was answered correctly. All HCWs agreed that access to antiretroviral treatment and to be free from HIV/AIDS related discrimination was an international human right declaration for PLWHA. No one answered that HIV infected people should be isolated from their communities or have their diagnosis disclosed to employers.

All HCWs agreed that pre-test information included confidentiality, benefits of partner testing and safer sex practices. In addition all HCWs knew that HIV rapid tests measure HIV sero-status by detecting the presence of the HIV antibody. They understood that rapid testing did not include measuring the presence of antigen or viral DNA. They also knew that the rapid test did not measure the presence of viral load. They accurately ascertained that HIV could be diagnosed early in infants using HIV-DNA PCR.

Only one HCW (counsellor) did not know that Prophylaxis for Pneumocystis Carinii Pneumonia (PCP) with cotrimoxazole is recommended for all HIV-exposed infants until HIV infection is ruled out. HCWs understood the increase risk of TB co-infection.

With regards to the implementation of universal precautions, most HCW (N= 17; 95%) knew that the first step in making contaminated instruments and equipment safe was to decontaminate using a bleach solution. The only one (counsellor) who did not get this

correct stated that watching instruments by just water and soap would be enough to make contaminated instruments safe.

Knowledge on the management of occupational exposure to HIV was poor. Only two HCWs (n= 3; 20%) knew that antiretroviral prophylaxis should be administered to the worker within 2 hours post exposure. Most HCWs thought that antiretroviral prophylaxis should be administered as soon as the rapid testing confirms HIV diagnosis of the source, or once clearance is obtained from the medical supervisor irrespective of the waiting time frame (n=13; 80%). This indicates the need for urgent training in this regard.

Most HCWs (n=13; 80%) knew that monitoring describes the routine assessment of on-going activities through record keeping and regular reporting. Those (n=3; 20%) who answered incorrectly indicated that evaluation process involves on-going tracking of activities.

Surprisingly only a quarter (n=4; 25%) of the participants knew that the percentage of women receiving pre-test information in ANC clinic who are tested for HIV represents a health facility indicator that can be monitored to determine programme activity. Those were only managers. In contrast, all participants knew that collection of usable data in programme management requires understanding the data to be collected; standardising collection tools and terms used; and recording the data each time in the same way.

4.2.2. Handling HIV infected pregnant women

All PMTCT providers declared that they are comfortable handling HIV-infected pregnant women because of availability of information regarding transmission routes of HIV. They

disclosed that they knew that they cannot get infected. All they care about is the welfare of the unborn or new child. "*I know I'm doing a lot of difference in the mothers' lives, I feel very happy and blessed when they come back to thank me*" cited one of the service providers.

4.2.3. Should HIV-infected mother have babies?

All service providers felt that HIV infected mothers can have babies because it is their right. However, some (56%) felt that mothers must know their HIV status before falling pregnant. Knowing one's HIV status was therefore seen as a pre-condition for considering falling pregnant. Others (38%) felt that these days there are PMTCT programmes that protect mothers and their babies.

4.2.4. Enhancing the PMTCT programme

All service providers felt that a lot has been done to enhance the current PMTCT programme. The general feeling was that mothers need to comply with the system to make it a success. Providers appreciate the effort that government has made to this end regarding the programme. However, one on the providers stated "*I wish more resources can be channelled towards follow-up of mother who is no longer coming for the postnatal clinic to get their babies tested until the age of two years. This will give us a clear picture of our work, thus babies born to HIV-positive mother who tested positive at 6 weeks will still be negative at two years*."

Some (70%) of service providers felt that they have been provided with enough information to run the PMTCT programme. Others (30%) felt that they have not been

provided with enough information. They would like to be provided with more training as especially on the new development around HIV/AIDS and PMTCT.

4.2.5. Barriers towards the success of PMTCT

The following data were collected through open ended questions. This is contrary to the above data that were collected through a structured multiple choice questionnaire.

Drug administration: Concerning drug administration as a barrier towards the success of PMTCT programme most (n=13; 80%) participants felt that most patients fail to adhere to their medication requirements. This was cited to be mainly due to the fact that patients may not have disclosed their HIV status to the household members; it therefore made it difficult for them to take medication in their family members' presence. The HCWs confirmed that drugs were always available at the clinics.

HIV Counselling and Testing: Regarding HIV-Counselling and Testing; the general feeling by all participants was that clients were afraid to test regularly, they therefore tested for the first time or after a long time when they were pregnant. Limited space was also cited as a hindering factor to the success of HCT within the clinics by a few (n=30%) participants. According to this view, clients are crammed in small spaces which make them uncomfortable. Shortage of staff is also cited as another barrier to optimal uptake of HCT. Counsellors end up seeing too many clients - more than 20 per day. This leads to staff fatigue and may compromise the quality of the service rendered. Stigmatization of HIV positive people was also cited as one of the factors preventing people from coming to test.

Baby feeding choices: Baby feeding choices are cited (95% of participants) as the strongest barrier to the success of the PMTCT programme. Mothers who have not disclosed their HIV status to their household members find it difficult to comply with the chosen feeding choices especially bottle feeding; they therefore opt for exclusive breastfeeding. Breast-feeding comes with major complications “If a baby cries too much mothers are forced by family members to give theirs babies’ commercial formula to supplement breast-milk because they believe baby is still not fulfilled.” said one participant. “if only people can be transparent about their positive HIV status then this programme can be successful. You tell them this today, and then tomorrow they tell you that they have forgotten, but it will only learn later that it was because they could not do something in the presence of other household members.” said the other.

It was also reported that mothers who opt for bottle feeding are discriminated against by people around them. Bottle feeding is seen as a sign that one is HIV-positive. However, some (35) service providers felt that bottle feeding seemed easier for the mothers as they are provided with formula.

Compliance of mothers in the programme: According to all PMTCT service providers mothers play a vital role in the success of the PMTCT programme; thus by simply complying with the programme requirements. Service providers viewed noncompliance to the programme requirement as due to disclosure of one’s HIV status (45%), fear of rejection by family members including partners (30) and the rest thought that it may be due to the fact that once the babies are declared HIV-negative, then mothers feel that there is no point continuing with the programme. One participant indicated “*After the first test, some mothers just default from the program because they think their babies are*

fine with a negative HIV-test and need no follow-up; some even think that they no longer have the virus". In other cases "*some mothers do not take medication as prescribed leading to complications during pregnancy, and some do not come for the pre-natal visits as recommended.*"

CHAPTER 5: DISCUSSION AND CONCLUSION

After 12 years of implementing the national Prevention of Mother-to-Child Transmission of HIV (PMTCT) programme in South Africa, interventions for PMTCT of HIV are now offered in more than 95% of public antenatal and maternity facilities country-wide free of charge (MRC, 2010). HIV/AIDS-related diseases are said to be a major cause of death in young children followed by pneumonia and acute diarrhoea (UNICEF, 2011). In South Africa, indications continue to be that the fight against HIV-related infant mortality is continuing. In light of the above, it is important to understand the knowledge and experience of users and providers towards the current PMTCT programme.

A positive general finding is that contrary to studies cited in the literature review, most of which were conducted in poorer regions of the continent and of South Africa, health systems failure was not a major problem in Soweto and therefore was not a factor that could impact on either the knowledge or the experience of users and providers. This has the potential to further entrench PMTCT in the community as success stories spread by word-of-mouth and other means. This also has the potential to impact on stigma in a high prevalence area, such as Soweto.

5.1. Knowledge and Experience of PMTCT Users

Three decades into the HIV/AIDS epidemic and in view of the resources expended to educate and promote awareness, it was not surprising to find that generally participants understood *what HIV is, and the different modes of HIV transmission*. This is now contrary to the findings that South Africans in the townships have limited knowledge

regarding modes of transmission of HIV (Esplen, 2007). The same article on HIV/AIDS in the township alludes to the fact that there is a belief that testing often prevents HIV/AIDS infection. This is contrary to the findings of this study – participants had heard of PMTCT and had a sound knowledge regarding HIV and how it is transmitted; including through sexual intercourse, multiple partners and MTCT. They were also knowledgeable on how the virus was transmitted. However, this could be due to the fact that they were on the PMTCT programme, and had therefore been counselled a number of times.

Although most participants knew they should be tested, they had only done so when they became pregnant or had gotten ill. Many reported feeling sad, devastated and guilty when receiving their positive result. Participants felt that people had to be further educated, perhaps with input from celebrities living with the disease to normalise getting tested and increasing the idea that HIV is a “chronic” disease when well managed. This, according to the participants, could increase the number of people who test for HIV.

Despite the disappointments experienced by participants when discovering their positive HIV status, at the time of this study, participants seem to have accepted their positive HIV status. They attributed this to the counselling they received. It is evident that information received from the counsellors is very important to the mothers as beneficiaries of the programme. Some mothers mentioned HIV status discordancy between themselves and their partners but did not understand what that was all about. It may be possible that there are more of such cases and other unique cases or that communication about one’s HIV status between couples is still far from optimal. It is vital

that health care workers including counsellors be provided with on-going training to ensure quality services.

In this study, there was a general understanding of HCT by the mothers and that blood testing is the only way to verify one's HIV status. However, some thought that some conditions like swollen glands or tonsils are an indication of HIV-infection. There was also general reassurance that there was a lot of HIV information available in to the participants. In light of the above, it was unsatisfactory that the majority of participants tested because they were pregnant and were offered testing by the facility. One study (HSRC, 2008) indicated that HIV testing in Soweto was reported to be less than the recent national South African survey data in which only about half of the participants reported past testing. This was not different than what is reported in studies conducted in Botswana and Zimbabwe reflecting about 50% testing uptake (Weiser et al, 2006; Sherr, 2007). In Sub-Saharan Africa it is estimated that nearly 80% of HIV-infected adults are unaware of their status (Bunnell et al, 2008).

Unlike what has been found in other studies, and what was reported by the HCWs, disclosure of their HIV positive status was not a problem amongst users of the PMTCT programme interviewed in this study. While disclosure was not a problem, it is worth noting that it was not a problem disclosing to direct family members and seemed to be a problem disclosing to partners. Furthermore, disclosure of being on the PMTCT problem was not a problem either – most had disclosed their status as well as being on the PMTCT programme to their family and kin, and knew the importance of participating in the programme in order to avoid transmission to their children.

Even though disclosure rates were high amongst the users interviewed in this study, participants believed that the biggest barrier to people participating in the PMTCT programme was because of stigma, ignorance, and fear that they may be recognised while accessing services by people they may know.

Although women had been provided with information on exclusive breastfeeding, most users of the PMTCT programme interviewed were bottle-feeding – not due to stigma, but due to fear of transmission. Some of the participants believed that HIV positive women should not breastfeed at all. Strangely, however, participants also believed that the chances of transmitting to the child would be decreased if they followed the HCWs "rules" – which include exclusive breastfeeding.

The majority of participants decided to participate in the PMTCT programme because they did not want their babies to be infected with HIV. Nevertheless disclosure was still uneven prompting health care workers to reach the conclusion that lack of disclosure remains one of the most fundamental barriers to compliance with PMTCT programme requirements. Participants in this study believed that PMTCT programmes are highly stigmatized therefore some mothers do not want to be associated with PMTCT programmes. Other mothers chose not disclose their positive HIV status to their partners due to fear of rejection.

According to a study published by Kalichman et al (2004), South Africans who attributed HIV/AIDS to spirits and the supernatural were more likely to claim that people with HIV/AIDS were "dirty," "repulsive," "cursed," and "foolish" and should "have restrictions on their freedom," "be isolated," and "feel guilty and ashamed. These sentiments may discourage participation in PMTCT programmes. However, barriers to PMTCT uptake

include that non-adherence and dysfunctional health systems demonstrate PMTCT to be ineffective in reducing infant HIV infections (Magwa, 2012). Sprague et al (2011) further found that stigma, along with other dysfunctional aspects evident in within health care systems posed as challenges against mothers adhering to PMTCT. It is therefore highly crucial to consider models that minimise stigmatisation of PMTCT programmes like the model proposed by Prudden et al (2012). The proposed model projects that the reduction of stigma to minimal levels can reduce HIV infections by about 44%. The model projects low rate of HIV infection at low levels of stigma setting, and high levels of infection at the setting where levels of stigma are high.

Stigma also plays a big role in mothers feeding choices for their babies. Data collected from this study show that mothers feeding choices tells their HIV status amongst their communities and families. Koricho et al (2012) reveal that mothers feel the need to protect their children against HIV infections but often their choices are questioned by others. It is very important for a mother to make informed choices when it comes to feeding options that would be best for her and her baby. However, due to HIV stigma and lack of information, these choices are often influenced by fear and guilt. Some mothers cited by health care workers to have fallen to mixed feeding to avoid stigmatisation. A study conducted in Zimbabwe revealed that there are indeed stigmatisation beliefs against non-breast feeding mothers (Israel-Ballard et al., 2006).

5.2. Knowledge and Experience of PMTCT Providers

HCWs had a good knowledge regarding HIV transmission, WHO staging system of HIV (except counsellors), and that prolonged breastfeeding and invasive delivery procedures increased the risk of MTCT. However, the knowledge of ARV regimen for PMTCT was weak, and there was confusion regarding the duration that breastfeeding should be promoted. From the results of this study, PMTCT knowledge amongst HCWs for the critical aspects of PMTCT was worrisome. HCWs were not familiar with the correct PMTCT regimen for HIV infected mothers. The AZT based regimen was piloted in South Africa in 1998, and yet in 2012, the HCWs still did not know the correct ARV regimen. Not surprisingly, knowledge around infant feeding was incorrect. There was poor knowledge around post-exposure prophylaxis protocols indicating the need for training on implementation of occupational health. Furthermore, post-natal infant feeding counselling was only stated by half of the providers in the event that mothers want to change their feeding practices.

In terms of barriers – adherence was noted as a major problem. This is mainly due to people not wanting to disclose their status. This links to issues of feeding practices - if mothers bottle-feed they are stigmatised and opt for exclusive feeding, but are then forced by family to supplement with the bottle for various reasons. Mothers do not reveal their status, which jeopardises their success on the programme.

While strides are made to get every sexually active South African citizen to verify their HIV status as evidenced by the on-going deputy president's campaign, uptake is still far from ideal. It is worrying that participants mentioned that more education is required to get more people tested at the same time they mentioned that there is a lot of HIV

information. It therefore means that the messages available are not effectively increasing the testing rates.

CHAPTER 6: RECOMMENDATIONS

This section outlines the recommendations that are derived from the study, that are required to aid the knowledge and experience of both users and providers in the PMTCT programme.

6.1. Recommendations

6.1.1 Knowledge and experience of PMTCT users

- Mothers need to be provided with extensive education to enable them to make informed decisions around falling pregnant and the importance of knowing their HIV status for the success of the national PMTCT programme.
- Partners' involvement will be crucial for the success of the PMTCT programme. Therefore the communication interventions need to focus on providing accurate facts about HIV/AIDS, MTCT and PMTCT, while also emphasizing the importance of male support and engagement.
- Testing outside the PMTCT programmes must be more popularised to attract more people to HTC. Provider initiated testing must also be promoted.
- Initiatives for HCT need to be implemented that move beyond the health facilities. Participants only got tested when they became pregnant or fell ill. Therefore initiatives need to normalise testing, knowing one's status, and going onto an ARV regimen, as well as disclosing one's status.
- People are aware of the HIV and how it is transmitted, but are not knowledgeable about the signs of HIV and couple discordancy and should therefore be

strengthened in HIV messaging. This is especially so since many participants had heard of PMTCT and HIV from pamphlets, billboards, radio, TV, and other commonly used social mediums.

6.1.2 Knowledge and experience of PMTCT providers

- There is need for ongoing education of counselors to ensure that correct information to pass on to participants. Counseling strategies should also be enhanced. Information around HIV discordant couples should be openly shared with the mothers by PMTCT providers
- Provider education should be on-going to ensure relevance to the updates and compliance.
- Counsellor training on PMTCT, HIV and how the disease is transmitted and treated needs to be strengthened.
- Means to increase adherence, disclosure and home-based care programmes, need to be included in the PMTCT programme.

6.2. Limitations of the Study

The self-administered questionnaire provided to the providers of the PMTCT services yielded limited information, and was therefore not able to yield detailed results. However, it does provide a starting point in which further studies can request more in-depth responses.

The limited sample size (30 users and 16 providers), and the fact that the study was conducted in three clinics in Soweto, means that the results of this study are not generalisable to South Africa, Johannesburg, or even greater Soweto. However, the study does provide valid and useful results in understanding the knowledge and experience of users and providers in the PMTCT programme. These results can be used to inform further and larger studies in the same area of interest.

It is acknowledged that a lot has changed in the health care system therefore Health System's Failures in Implementing the PMTCT Programme chapter may not be a current reflection of the system.

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Appendices

Appendix 1: Questionnaire for PMTCT Users

PMTCT Users --- Mothers who participated in the PMTCT Programme.

Interview No.

Age:

Marital Status:

Employment Status:

Number of own biological Children:

1. General HIV Knowledge

a) What is HIV?

b) How can one get HIV?

c) How can one prevent HIV?

2. Mother to Child Transmission of HIV Knowledge

a) How can small babies be infected with HIV?

b) How can small babies be prevented from getting HIV?

c) When did you know about PMTCT? During your last pregnancy? Or before being pregnant?

3. Voluntary Counselling and testing

a) How can people know whether they HIV infected?

b) When did you learn about your HIV status?

c) How long did you wait for your results?

d) How did you feel after getting your results

e) Whom did you tell?

f) Why did you decide to participate in the PMTCT programme?

g) Whom did you tell about your participation?

h) Why do some people refuse to participate in the PMTCT programme?
i) What do you think should be done to get more people tested?

4. Baby feeding Choices

a) How did you learn about Feeding choices to prevent transmission of HIV to the baby?
b) How are you feeding your baby? Why?
c) Why are other women not complying with the safe feeding options?
d) How did your family members respond when you told them about you feeding option?

Appendix 2: Questionnaire for PMTCT providers

Study Questionnaire

PMTCT Providers --- (PMTCT Programme Health Care Workers)

Exploring Perceptions and Attitudes of Users and Providers on Interventions towards Prevention of Mother to Child Transmission in Soweto

Interview No.

Position:

Duration of service:

Duration of Involvement in PMTCT:

Received PMTCT Training:

Number of people you see daily:

PMTCT Knowledge Assessment

***Directions**: Please read each question carefully and circle the letter of the **most accurate** response to the question.*

1.	What is the most common route of HIV transmission worldwide? a) Blood transfusions b) Heterosexual contact c) Intravenous drug use d) Mother-to-child transmission
2.	According to the adult WHO Staging System of HIV infection, a clinical symptom of Stage II is a) Chronic diarrhoea lasting more than one month b) Normal activity level without symptoms c) Recurrent upper respiratory tract infections d) Kaposi's sarcoma
3.	The risk of mother-to-child transmission of HIV infection increases when a) Breastfeeding is continued over time b) Non-invasive delivery procedures are used c) Maternal viral load is low d) Sexually transmitted infections are treated early
4.	Primary prevention of HIV infection includes all of these, ***except*** a) Correct and consistent use of condoms b) Excluding male partners from HIV education programs c) Delaying the age of first sexual intercourse d) Being faithful to one uninfected partner who is faithful as well
5.	Screening and treatment for tuberculosis (TB) should be available to a) Women who are HIV-infected who are not receiving antiretroviral treatment b) All women presenting for ANC services with a cough of more than 2 weeks c) Women who are HIV-infected with recent exposure to tuberculosis d) All the above
6.	The ***first choice*** WHO-recommended mother-infant regimen for antiretroviral prophylaxis in PMTCT is a) Single dose nevirapine b) Zidovudine (ZDV) and nevirapine (NVP) c) Zidovudine (ZDV) and lamivudine (3TC) d) Zidovudine (ZDV), lamivudine (3TC) and saquinavir/ritonavir (SQV/r)
7.	What is one advantage of using commercial infant-feeding formula? a) It provides all the nutrients and antibodies a baby may need b) It is always available

	c) Other family members can help feed the baby d) It carries very little risk of causing diarrhoea or bacterial infections
8.	When exclusive breastfeeding with early cessation is the chosen infant-feeding option, at what age should cessation take place? a) Eight months b) Within four months c) As soon as safely possible given local circumstances d) Twelve months
9.	Postnatal infant-feeding counselling and follow-up are required a) Mainly during the first few months of breastfeeding b) When replacement feeding is the chosen option c) Whenever a mother decides to change her feeding practice d) At selected intervals based on clinic protocols
10.	International human rights declarations include the rights of persons living with HIV/AIDS (PLWHA) to a) Reduce the number of working hours b) Socially isolate themselves within their communities c) Access antiretroviral treatment and be free from HIV/AIDS related discrimination d) Disclose their diagnosis within a specified period of time to employers
11.	Before HIV testing, pre-test information may include the following a) Confidentiality b) Benefits of partner testing c) Safer sex practices d) All of the above
12.	How do the HIV rapid tests measure HIV serostatus? a) Detecting the presence of HIV antigen b) Detecting the presence of HIV antibody c) Determining the quantity of HIV d) Detecting the presence of viral DNA
13.	Standard diagnosis of HIV infection in infants according to WHO guidelines occurs a) Between 4 and 6 weeks of birth using HIV-DNA PCR testing b) At 12 months using the Western Blot c) At 18 months using antibody testing d) At 12 months using the ELISA
14.	Prophylaxis for *Pneumocystis Carinii* Pneumonia (PCP) with cotrimoxazole is recommended for a) Persons with symptomatic HIV b) Adults/adolescents with CD4 cell counts less than 500/mm^3 c) All HIV-exposed infants until HIV infection is ruled out d) All of the above

15.	PLWHA have a 40% lifetime risk of becoming co-infected with a) Malaria b) Helminth infection c) Tuberculosis d) Cytomegalovirus
16.	The first step in making contaminated instruments and equipment safe to handle is a) Cleaning with soap and hot running water b) Sterilisation using heat or steam c) Boiling for 20 minutes d) Decontamination by soaking in a bleach solution for 10 minutes
17.	Protocols for managing occupational exposure to HIV infection include antiretroviral prophylaxis administered to the worker a) As soon as rapid testing confirms HIV diagnosis of the source b) Within 2 hours after the exposure c) Once clearance from the medical supervisor is obtained d) Within 24 hours after the exposure
18.	Which of the following describes the routine assessment of ongoing activities through record keeping and regular reporting? a) Situation assessment b) Implementation c) Monitoring d) Evaluation
19.	Which of the following represents a health facility indicator that can be monitored to determine programme activity? a) Percentage of orphans linked to mothers who are HIV-infected in Asia b) Nationwide statistics on HIV prevalence in pregnant women between 15 and 25 years or age c) Percentage of women receiving pre-test information in ANC clinic who are tested for HIV d) Number of PLWHA who are co-infected with tuberculosis worldwide
20.	Collection of usable data in programme management requires a) Understanding the data to be collected b) Standardising collection tools and terms used c) Recording the data each time in the same way d) All of the above

Correct answers: 1(b), 2 (c), 3(a), 4(b), 5(d), 6(b), 7(c), 8(c), 9(c), 10(c), 11(d), 12(b), 13(a), 14(c), 15(c), 16(d), 17(b), 18(c), 19(c), 20(d)

Source: WHO/HHS-CDC, PMYCT Generic Training Package,2009.

According to you what are the Barriers towards the success of PMTCT programmes in terms of

1. *Drug Administration*

2. *Voluntary Counselling and Testing*

3. *Breastfeeding Choices*

4. *HIV-infected mothers compliance in the program*

5. *According to you, is there anything that can be done to the programmes? If yes what?*

6. *Are you comfortable handling HIV infected pregnant women ? Why?*

7. *Do you think HIV infected women should have babies?*

8. *Do you feel you have enough information on PMTCT?*

9. *Do you feel you have enough resources to handle PMTCT cases*

Thank you for your time

Appendix 3: Information Sheet and Informed Consent for Users

Exploring Perceptions and Attitudes of Users and Providers on Interventions towards Prevention of Mother to Child Transmission in Soweto

Good day, my name is Matseliso Pule. I am a student at the University of the Witwatersrand, school of Public Health. I would like to ***invite*** you to consider participating in a research study, entitled Exploring Perceptions of the providers and users on interventions towards PMTCT.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, and your right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. You need to understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me.

You should not agree to take part unless you are satisfied about all the procedures involved.

If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study.

Purpose of the Study

You are being invited to take part in this research because we feel that your experience in PMTCT interventions can contribute much to our understanding and knowledge of local health practices.

Mother-to-child transmission (MTCT) is when an HIV-infected woman passes the virus to her baby. This can occur during pregnancy, labour and delivery, or breastfeeding.

In 2008, around 430,000 children under 15 became infected with HIV, mainly through mother-to-child transmission. About 90% of these MTCT infections occurred in Africa. Despite the Government's commitment to implementing strategies to PMTCT, South Africa is still seeing new HIV infections through Mother to Child Transmission (MTCT).

The study is therefore trying to check what people know and think about the PMTCT system. The study will also help to improve the system based on what we will learn from study participants.

Procedures

If you accept, you will be asked to participate in an interview with myself. You may answer the questionnaire yourself, or it can be read to you and you can say out loud the answer you want me to write down. If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question.
The interview will take about an hour to complete

Confidentiality

All information obtained during the course of this study will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

Voluntary Participation

Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Your withdrawal will not affect your access to other medical care.

The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

Ethical Approval

This clinical study protocol has been submitted to the University of the Witwatersrand, **Human Research Ethics Committee (HREC)** and written approval has been granted by that committee.

INFORMED CONSENT:

I hereby confirm that I have been informed by the researcher Matseliso Pule about the study procedures, benefits of the study

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare

myself prepared to participate in the study.

PARTICIPANT:

Printed Name Signature / Mark or Thumbprint Date and Time

I, Matseliso Pule herewith confirm that the above participant has been fully informed about the nature, conduct of the above study.

Researcher

Printed Name Signature Date and Time

Appendix 4: Information Sheet and Informed Consent for Providers

Exploring Perceptions and Attitudes of Users and Providers on Interventions towards Prevention of Mother to Child Transmission in Soweto

Good day, my name is Matseliso Pule. I am a student at the University of the Witwatersrand, school of Public Health. I would like to ***invite*** you to consider participating in a research study, entitled Exploring Perceptions of the providers and users on interventions towards PMTCT.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, and your right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. You need to understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me.

You should not agree to take part unless you are satisfied about all the procedures involved.

If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study.

Purpose of the Study

You are being invited to take part in this research because we feel that your experience in PMTCT interventions can contribute much to our understanding and knowledge of local health practices.

Mother-to-child transmission (MTCT) is when an HIV-infected woman passes the virus to her baby. This can occur during pregnancy, labour and delivery, or breastfeeding.

In 2008, around 430,000 children under 15 became infected with HIV, mainly through mother-to-child transmission. About 90% of these MTCT infections occurred in Africa.

Despite the Government's commitment to implementing strategies to PMTCT, South Africa is still seeing new HIV infections through Mother to Child Transmission (MTCT).

The study is therefore trying to check what people know and think about the PMTCT system. The study will also help to improve the system based on what we will learn from study participants.

Procedures

If you accept, you will be asked to participate in an interview with myself. You may answer the questionnaire yourself, or it can be read to you and you can say out loud the answer you want me to write down. If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question.

You will also be asked some questions testing your knowledge around prevention of mother to child transmission of HIV.

The interview will take about an hour to complete

Confidentiality

All information obtained during the course of this study will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

Please note that confidentiality in this study will include non-disclosure to health authorities.

Voluntary Participation

Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Your withdrawal will not affect your access to other medical care.

The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

Ethical Approval

This clinical study protocol has been submitted to the University of the Witwatersrand, **Human Research Ethics Committee (HREC)** and written approval has been granted by that committee.

INFORMED CONSENT:

I hereby confirm that I have been informed by the researcher Matseliso Pule about the study procedures, benefits of the study

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare

myself prepared to participate in the study.

PARTICIPANT:

Printed Name Signature / Mark or Thumbprint Date and Time

I, Matseliso Pule herewith confirm that the above participant has been fully informed about the nature, conduct of the above study.

Researcher

Printed Name Signature Date and Time

Appendix 5: Ethics Approval

M110333

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Matseliso Pule

CLEARANCE CERTIFICATE	**M110333**
PROJECT	Exploring Perceptions and Attitudes of Users and Providers on Interventions Towards Prevention of
Mother	to Child Transmission in Soweto
INVESTIGATORS	Mrs Matseliso Pule.
DEPARTMENT	School of Public Health
DATE CONSIDERED	25/03/2011
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 03/06/2011 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Professor Glenda Gray

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...