MATERNAL KNOWLEDGE AND ATTITUDE TO EARLY INFANT HIV DIAGNOSIS

by

Vincent Oladele Adeniyi

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Supervisor: Prof. Elza Thomson

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DECLARATION

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

The global targets of zero deaths from AIDS-related illness by the year 2015 can only be met if all HIV infected infants can be diagnosed and initiated on anti-retroviral therapy as early as four to six weeks. WHO/UNICEF reported in 2010 that only 8% of eligible infants were tested worldwide. There seems to be more attention directed towards service delivery and less attention on empowering mothers to make voluntary decision to access the services. The influence of maternal knowledge of infant HIV infection and the impact on the attitude towards knowing the status of their children so early in life remains uncertain. The aim of this study was to explore the knowledge and attitude of the HIV positive mothers to early infant diagnosis in order to make strategic recommendations to the health authorities on how to scale up the services in the various health facilities. A qualitative study was conducted in two health centres in King Sabata Dalindyebo Municipality of Eastern Cape Province, South Africa. This qualitative study drew in-depth interview with twenty-four HIV positive mothers/ exposed infants' pair attending the immunization clinics. The results obtained were presented to two focus groups for discussion and validation of findings. Thematic analysis explored the emerging themes relevant to the objective of the study and health authorities. The study found that there is a high level of awareness about infant HIV infection. Majority of the participants were aware of MTCT of HIV and the timing of transmission (pregnancy, delivery and breastfeeding). Majority of the participants were aware about the protection offered by maternal exposure to ARVs however, only few participants knew about the risk of transmission despite ARV use. Majority of the participants did not know the right time to bring their infant for HIV test. Majority of the participants never thought about HIV test for their infant as early as six weeks. Majority of the mothers have fears about bringing their infants for HIV test so early. They have concerns about recommending early infant diagnosis to other children in their community due to the perceived disclosure of their own status. The study found that despite good knowledge of mothers about infant HIV infection and prevention methods, the knowledge about early infant diagnosis is lacking. The attitude of the mothers to knowing the status of their infant so early in life is challenging for them. The health authorities have more work to do to

empower these mothers with knowledge about early infant diagnosis and early ART initiation to increase the chances of survival of HIV infected infants.

OPSOMMING

Die internasionale mikpunt van geen sterftes weens vigsverwante siektes teen die jaar 2015 kan slegs bereik word as alle MIV-besmette babas reeds op vier tot ses weke gediagnoseer word en antiretrovirale terapie (ART) ontvang. Die WGO/UNICEF het in 2010 berig dat slegs 8% van babas wat getoets moet word, in werklikheid wêreldwyd getoets is. Dit blyk dat meer aandag aan dienslewering en minder aan die bemagtiging van moeders om die vrywillige besluit om van die dienste gebruik te maak, geskenk word. Die invloed van moeders se kennis op MIV-besmetting van babas en die impak op die houding teenoor kennis van die status van hul kinders op so ’n vroeë ouderdom is steeds onbekend. Die doel van hierdie studie was om die kennis en houding van MIV-positiewe moeders rakende vroeë diagnose van babas te ondersoek ten einde strategiese aanbevelings aan die gesondheidsowerhede te maak oor verbetering van die dienste in die onderskeie gesondheidsfasiliteite. ’n Kwalitatiewe studie is in twee gesondheidsentrums in King Sabata Dalindyebo-munisipaliteit in die provinsie Oos-Kaap, Suid-Afrika, onderneem. Dit het diepte-onderhoude met 24 MIV-positiewe moeders/blootgestelde babas wat die immuniseringsklinieke besoek het, behels. Die resultate is aan twee fokusgroepe vir bespreking en bekragtiging van die bevindings voorgelê. Tydens ’n tematiese ontleding is die temas wat aan die lig gekom het wat betrekking het op die doelstellings van die studie en gesondheidsowerhede ondersoek. Daar is gevind dat daar ’n hoë vlak bewustheid van MIV-besmetting van babas is. Die meerderheid van die deelnemers was bewus van moeder-na-kind-oordrag van MIV en die tydsberekening van oordrag (swangerskap, geboorte en borsvoeding). Die meerderheid van die deelnemers was ook bewus van die beskerming wat gebied word deur die moeder se blootstelling aan ART, maar net ’n paar deelnemers het egter geweet van die risiko van oordrag ongeag die gebruik van ART. Die meerderheid van die deelnemers het nie geweet wat die korrekte tyd is om hul baba vir ’n MIV-toets te bring nie. Die meerderheid het nog nooit ’n MIV-toets vir hul baba voor die ouderdom van ses weke oorweeg nie. Die meerderheid van die moeders was bang om hul babas so vroeg reeds vir MIV te laat toets. Hulle is begaan oor die aanbeveling van vroeë diagnose vir ander mense in hul gemeenskap weens die waargenome bekendmaking van hul eie status. Die studie het bevind dat ongeag moeders se grondige kennis van

MIV-besmetting van babas en voorsorgmaatreëls, daar ’n gebrek aan kennis oor vroeë diagnose van babas is. Die houding van die moeders teenoor kennis van die status van hul baba op so ’n vroeë ouderdom hou vir hulle ’n uitdaging in. Die gesondheidsowerhede moet hulle daarop toespits om hierdie moeders sonder kennis oor vroeë diagnose van babas en vroeë nakoming van ART te bemagtig ten einde MIV-besmette babas se kanse op oorlewing te verhoog.

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I also dedicate this to my patients - people living with HIV/AIDS; working with you really inspired me to acquire more qualifications to improve the quality of service offered to you.

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARVs	Anti-Retroviral drugs
AZT	Zidovudine or Azidothymidine
CHER Study	Children with HIV Early Anti-retroviral Therapy
EID	Early Infant Diagnosis
DNA-PCR	Deoxyribonucleic Acid - Polymerase Chain Reaction
FPD	Foundation for Professional Development
HAART	Highly Active Anti-retroviral Therapy
HIV	Human Immunodeficiency Virus
MTCT	Mother-To-Child Transmission
NDoH	National Department of Health (South Africa)
NVP	Nevirapine
PMTCT	Prevention of Mother-To-Child Transmission
PLWHA	People Living With HIV/AIDS
UNAIDS	United Nations Programme on AIDS
UNICEF	United Nations Children Funds
WHO	World Health Organisation
WITS	Women and Infants Study

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CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

HIV/AIDS is one of the world's most serious health challenges in the last three decades. Globally, 34.0 million people were living with HIV by the end of 2011. Sub-Saharan Africa is the region most affected with the epidemic of HIV (nearly 1 in every 20 adults are living with HIV). This region accounts for 69% of the world burden of HIV/AIDS (UNAIDS Report 2012). South Africa has about 5 million currently living with HIV. The new infection worldwide in 2011 was estimated to be 2.5 million (about 20% less than in 2001) while majority occurred in Sub-Saharan Africa (about 1.8 million). This figure showed a 25% decline in HIV incidence in 2011 compared with 2001.

The prevalence of HIV among women in their reproductive age group (15 - 49 years) in South Africa is 29% (Nicholay, 2009) when compared with a occurrence of 0.8% among similar age group worldwide, there is growing concern for childbirth (UNAIDS Report, 2012). Worldwide, there are about 2 million children currently living with HIV and 90% are from Sub-Sahara Africa (Hassan et al. 2012). UNAIDS Report on the Global AIDS Epidemic 2010 showed there were 130,000 (90000 - 160000) new HIV infections in children in South Africa. AIDS-related death among children less than five years was 90000 (61000 - 110000) (UNAIDS, 2010). Many HIV-infected infants and children die from HIV-related illnesses without the diagnosis of HIV being made or without access to comprehensive care for HIV (Hassan et al. 2012).

The provision of dual therapy and highly active anti-retroviral therapy (HAART) to HIV positive pregnant women has reduced the risk of mother-to-child transmission to less than 5% (Goga et al. 2011). Kuhn, Sinkala, Thea, Kankasa and Aldrovandi (2009) wrote in his reviewed article HIV prevention is not enough; child survival in the context of MTCT prevention is very essential. These infants have good chance of normal growth and development if they can be diagnosed and commenced on HAART as early as four to six weeks prior to onset of HIV-related illnesses.

1.2 BACKGROUND OF THE PROBLEM AND MOTIVATION FOR THE STUDY

It was noticed with concern that despite various strategies to expand access to early infant diagnosis of HIV; a number of children still present to health facilities in critical conditions and die from HIV-related diseases. Meyers et al. (2007) noted hospitals are still witnessing large numbers of admissions of HIV-infected children. So far only 8% of eligible infants have been screened worldwide (WHO/UNICEF, 2010). Though, the figures vary from country to country and regions to regions. There is also concern that few infants who get tested are lost to follow up. Too few infants and children are entering care through early diagnosis (Meyers et al. 2007).

The low utilization of health services for early infant HIV diagnosis is worrisome and constitutes a barrier to mitigating the infant morbidity and mortality. Without care and treatment, about one-third of HIV infected infants will die before their first year and about 50% will die by the second year on their birthday (UNICEF, 2009). It is essential that efforts are put in place to identify and commence HIV-infected infants on anti-retroviral medications as early as possible. Several studies conducted in resource rich countries as well as resource poor countries have proven beyond doubt the survival benefits of early initiation of ART.

Chiappini et al. (2006) in their multi-centre nationwide case control study comparing ART initiation in infants less than six months against infants with delayed ART initiation (more than six months) and 4.1 year follow up period. The result showed virologic, immunologic and clinical benefits of early initiation versus delayed initiation. These findings were supported by Violari et al. (2008) in the CHER study. The study demonstrated that early diagnosis and initiation of HAART will reduce all-cause mortality and morbidity from HIV/AIDS by 76% and 75% respectively. This is further supported by the US Prospective Perinatal AIDS Collaborative Transmission Study and The French Perinatal Cohort which confirmed that HIV infected infant has significant reduction in the rate of progression to AIDS and death when ART is initiated early (Wool and Giaquito, 2008). The European Collaborative study conducted by Goetgbebue et al. (2009) confirmed that HIV infected infants have significant reduction in the rate of progression to AIDS and death when ART is initiated before three months.

Early initiation of ART is associated with better treatment outcomes and increased survival in HIV-infected infants (Hassan et al. 2012). This was the basis for the National Paediatric HIV Management Policy (NDoH, 2010) which emphasized early infant diagnosis and early initiation of ART. The goal of early infant diagnosis is to identify HIV-infected children, commence ART and follow-up care prior to onset of HIV-related illnesses. HIV-exposed infants with negative result of DNA-Polymerase Chain Reaction (PCR) have the opportunity of appropriate feeding options without fear and anxiety of infections. More worrisome is the rate of drop-out from HIV care services when infants are diagnosed; Hassan et a., (2010) reported three quarter of mothers drop out of care of HIV before six months of age and 85% by the twelfth month of follow up. This was supported by earlier studies in South Africa by Sherman et al. (2004) and Patton et al. (2007).

Worldwide, there are several strategies put in place to scale up the uptake of early infant diagnosis of HIV while less focus is paid to the knowledge and attitude of the mothers who make decisions on behalf of the HIV-infected infants. The accessibility of the HIV exposed infant to the DNA-PCR test is at the prerogative of the mother or the caregiver whose knowledge of the rationale and benefits of early HIV diagnosis is the determining factor. The attitude of the mothers or caregivers towards knowing the HIV status of the child and the readiness to accept the result must be evaluated in a research study. Otherwise, the efforts and resources committed to prevention may not achieve the target of zero infant HIV infection by 2015. The mother makes health care decisions for the infant whether such actions are in the best interest of the child can be debated. She gives consent for HIV test to be carried out as well as determines whether the infants will get treatment (HAART) or not.

The efforts of Government through the provision of test kits, medications (HAART), training of health personnel and awareness campaigns mean nothing if the end-users (mother-infant pair) do not access the facility and the treatment offered to them.. Therefore, the target of reduction of all-cause mortality and morbidity from HIV/AIDS in children will not be met. Infant HIV/AIDS-related mortality, which is one of the key determinants of health programme evaluation tool, will continue to go up despite increase in budgetary allocations to mitigate the impact of HIV/AIDS epidemic in the country.

The researcher observed that mothers with HIV-exposed infants do not come forward to demand for HIV screening in their babies. The question that needs to be answered therefore is how much do these mothers know about early infant diagnosis and its benefits or do they have negative attitudes towards the test? If it were possible, the attitude of HIV-infected mothers should be they should be demanding HIV test in the health facilities as early as possible when the child is healthy; this will lead to 100% coverage of the early infant diagnosis worldwide. This research will focus on exploring the knowledge of the mothers about infant HIV infection, effects of HIV on the development of the child (from pregnancy through infancy to childhood), prevention strategies, benefits of ARVs in prevention of mother to child transmission and treatment of infant HIV infection. The attitude of the mothers to the diagnosis of HIV infection as early as six weeks and the impact of the test on their hopes and fears while waiting for the result for two weeks will be explored in greater details.

Despite knowledge of mother-to-child transmission, early diagnosis of infant HIV infection remains low: is the maternal knowledge and attitude towards testing for HIV in their infants so early the main problem? Research output on this topic in South Africa and in Eastern Cape Province is limited. In order to strategize on the upscaling of the early infant diagnosis of HIV in Eastern Cape Province and National Department of Health of South Africa, this research will be conducted to provide answers for the knowledge gap identified.

1.3 RESEARCH QUESTION

The study has generated the following question that will serve as roadmap for the direction to be taken: What is the knowledge and attitude of HIV positive mothers to early infant HIV diagnosis (EID)?

1.4 AIM OF THE STUDY

The aim of the research is to establish the knowledge and attitude of the HIV positive mothers to early infant diagnosis in order to make strategic recommendations to the health authorities on how to scale up the services in the various health facilities.

1.5 OBJECTIVES

The formulated objectives are:

- To assess the level of knowledge of HIV positive mothers on early infant HIV diagnosis.
- To evaluate the attitude of HIV positive mothers to early infant HIV diagnosis.
- To make recommendations based on the findings to the department of health on strategies to address the expansion of early infant diagnosis services.

1.6 SIGNIFICANCE OF THE STUDY

The research will be used to gain a good understanding of how much mothers know about infant HIV infection, the effect on the development of the child, benefits of early diagnosis and initiation of ARVs. The study will explore the attitude of the mothers to the knowledge that a six week old infant can be infected with HIV and their preparedness to care for an HIV-infected child who would have to live with HIV throughout his life. The study will provide insight to the hopes and fears of mothers of HIV-exposed infants who have to wait for two weeks to know the result which will change their lives. Whether the knowledge of infant HIV infection will influence their attitude towards the utilization of infant diagnosis services will be provided by this study.

The study will add to existing body of knowledge on infant HIV prevention. The research will generate discussions on what mothers want to know about the impact of HIV on their children's growth and development. The study will help health departmental authorities to strategize on ways to upscale early infant diagnosis services. This study therefore, will be very useful for the Paediatric HIV care in South Africa and Sub-Saharan Africa. The HIV trainers and lay counsellors will find the study useful in order to re-focus their counselling to empower mothers to make voluntary decision on early infant diagnosis and change health seeking attitudes.

1.7 OVERVIEW OF THE STUDY

The work is organized into five chapters. Chapter one covers the introduction, background of the problem, research question, aims, objectives of the study and significance of the study. The second chapter covers an extensive review of the existing

literature on the problem and set the context for the present research. The third chapter provides the motivation for the research methodology, process of the field work and the ethical considerations. The research findings and analysis is captured in chapter four. The fifth and final chapter discusses the result in perspective of previous studies; provides conclusion and recommendations of the entire assignment.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter appraised and critiqued existing literature on the research topic. An estimated 33.3 million people were living with HIV worldwide in 2008; out of which 2 million were children (WHO/UNAIDS, 2010). There were 2.7million new infections and 2 million deaths in the year 2008. 430,000 children became infected in 2008. It was estimated that about 14 million children lost one or both parents in 2008. 70% of the world HIV burden occurs in Sub-Saharan Africa. According to the summary of the provincial HIV and AIDS Statistics for South Africa; this country has the highest prevalence of HIV in the world, an estimated 5.6 million people are living with HIV which represents 17% of the world HIV burden, a country with only 1% of the world population (Nicholay, 2008).

The prevalence of HIV in South Africa is 12% nationwide; however, the prevalence is 20% in the category of 20 – 64 years, while the prevalence among child bearing age group is 29% (Nicholay, 2008). There are variations in the level of epidemics in different provinces of South Africa; Kwazulu-Natal has the highest burden of HIV with about 1.5 million people living with HIV (28% prevalence), followed by Gauteng (1.4 million) and lastly, Western Cape (298,000 PLWH) with 9% prevalence. The burden of HIV in pregnant women ranges from prevalence of 40% in KwaZulu-Natal Province, 36% in Gauteng Province to 16% in Western Cape Province. This has direct correlation to the new infections among the children.

The Eastern Cape Province is home to approximately 11% of South African population and has the third largest HIV burden in the country. The HIV prevalence is 20% (among 20 – 64years) and 29% among pregnant women. An estimated 81,000 new infections occur in Eastern Cape and 44,000 HIV/AIDS related deaths occur annually. Only 44% of people in need of ART are currently accessing it in the country. The AIDS-related death is estimated to be 120 per day while new infection rate is 223 per day (Nicholay, 2008).

2.2 INFANT HIV INFECTION

Approximately 300,000 babies are exposed to HIV annually through mother-to-child transmission (MTCT). Without treatment; 90,000 of these children (one-third) will be infected with HIV. HIV/AIDS account for 40% of deaths in children before age five (NDOH, 2009). HIV infections now account for more than 50% of paediatric admissions in most hospitals in South Africa (FDP, 2010). Studies of the natural progression of the disease in children showed regional variation; in Europe and America, only about 10 – 20% of infants will progress rapidly to AIDS within the first year and about 50% can reach their ten years without anti-retroviral drugs. However, in resource poor countries of the world, up to 80% of the infected infants will progressed to death within twenty-four months of life. Evidences from researches confirmed that about 40% of HIV-infected infants die before their first birthday and commonly the deaths do occur before six months (Violari et al. 2008).

2.3 INFANT HIV TRANSMISSION

This area remains a well investigate aspect of HIV infection and the understanding of infant infection emanated from well conducted researches in the early 90's. Yousef et al. 1995 reported 15 - 25% of infants born to HIV-1 seropositive mothers will acquire HIV infection. About 95% of infant HIV infection occurs through mother to child transmission (MTCT): transplacental/in-utero transmission account for about 10%; peri-partum (during delivery) account for about 60%; and breast feeding account for about 30%. Less common mode of transmission among the paediatric age group include: sexual abuse/rape; blood product transfusion (very rare but not impossible in third world countries); unexplained means like surrogate breast-feeding, nosocomial infection (within the hospital through the use of contaminated instruments or unlabelled breast milk) (FDP, 2010).

Earlier studies on mother to child transmission of HIV showed maternal viral load and the degree of immune deficiency are the significant risk factors (Pitt et al. 1992). The level of p24 antigenaemia, high CD8 lymphocyte counts and the presence of placental inflammation correlated with the highest MTCT rates (St. Louis et al. 1993). The presence

of other sexually transmitted diseases (Nair et al. 1993) and high maternal IgA levels have been implicated in MTCT (Hutto et al. 1989). The presence of active genital herpes infection during labour increases the risk of HIV transmission to the infant.

The role of viral load and its replication was further supported by the Thai study which showed both had a capacity significantly higher in transmitters versus non-transmitters. This study further explained maternal (humoral) immune response is not important in MTCT. It is relevant that HIV-1 isolates involved in MTCT use CCR-5 co-receptor for transmission (Kittinunvorakoon et al. 2009). The presence of chorioamnionitis and elevated cell-associated or plasma viral load is associated with increased risk of HIV-1 MTCT (Lynne et al. 1999).

Chorioamnionitis causes placental inflammation, immune-cell activation and breaches in placental barrier which allow passage of HIV or infected lymphocytes from the mother to the fetus. Prolonged rupture of membranes is a risk factor for chorioamnionitis. Risk of transmission increases linearly with duration of rupture of membrane, however, the effect of rupture of membranes with low viral loads is not known. Invasive procedures performed at any time during pregnancy or delivery could increase the risk of transmission; amniocentesis, scalp electrode monitoring, episiotomy, forcep delivery and artificial rupture of membranes. The mode of delivery could influence transmission; scheduled Caesarian section in women with viral load above 1000copies/ml decreases the rate of perinatal transmission (Burr, 2011)

There is about 5-20% risk of transmission of HIV from breast feeding (Dunn et al. 1992). This risk can increase in the presence of cracked nipples or other breast conditions. Post-natally acquired HIV infection in mothers may increase the risk of breast feeding transmission to 29% (Dunn et al. 1992). Infant factors include prematurity, low birth weight, skin and mucous membrane lesions (thrush) and invasive fetal monitoring (Burr, 2011). The survival of the infant depends on the care offered by the mother in relation to access to antiretroviral therapy, good nutrition including vitamin A and other micronutrient supplementation (FDP, 2010). Other maternal factors that influence transmission of HIV-1 include illicit drugs, cigarette smoking, and unprotected sexual intercourse with multiple partners (Burr, 2011).

2.4 EFFECT OF HIV ON THE PREGNANCY

HIV in pregnant woman poses a risk to the outcome of the pregnancy; not only through the infection of the unborn baby but the growth and development of the fetus are affected. Leroy et al. (1998) described the pregnancy outcomes of HIV infected women; they confirmed that maternal HIV infection is associated with adverse outcomes both for the mothers as well as the babies. More cases of stillbirth were recorded; more low birth weight babies were born by HIV positive women when compared with similar characteristics in their HIV negative counterpart; risk increase of 58%. More death occurred during the delivery in HIV positive group compared with HIV negative women. Maternal HIV infection increases the risk of prematurity by 62%. All these effects are associated with increase in perinatal and neonatal mortality and morbidity; 0.5 neonatal deaths per 1000 in the HIV-positive group.

The effect of maternal HIV infection on intra-uterine growth restrictions is inconclusive; Leroy et al. (1998) reported a two fold increase in Kigali. Stephen Arpadi quoted prospective studies performed in Haiti and Africa indicated that pregnancy outcomes of HIV infected women were adversely affected. They found more maternal deaths post-delivery in the HIV positive group compared with HIV negative group. Maternal HIV infection is associated with lower placental weight and substantially increases the risk of post-partum haemorrhage. The estimation of the consequences of maternal HIV infection on neonatal and obstetric outcome is important strategic information for health planning of a country like South Africa with high prevalence of HIV. Furthermore, the consequent infection of the infants of these mothers with HIV is a valuable public health issue because of the projection into the infant mortality that could result from it. Such projections would help in proposals on interventional strategies aimed to reduce these adverse outcomes.

2.5 EFFECT ON THE GROWTH AND DEVELOPMENT OF A CHILD

HIV infection has negative impact on the growth and development of the infant. This occurs through direct effect of the virus on the child or through recurrent opportunistic infections (Lowenthal and Millon, 2006). The growth and development of the child are

good indicators of the health of the child. Also, maternal HIV infection leading to recurrent illnesses and death impacts negatively on the growth and development of the child through poor nutrition. According to Arpadi (2005) abnormalities in growth and metabolism are common in children infected with HIV. The poor growth seen in HIV infected children have a significant impact on short-term survival. The alterations in the body fat distribution and lipid, glucose and bone metabolism put HIV infected children at increased risk for future morbidities (Arpadi, 2005).

2.6 EFFECT OF HIV ON BIRTH WEIGHT

Lowenthal and Millon (2006) indicated the European Collaborative Study and a study in Durban, South Africa, newborn height and weight of infected and uninfected children born to HIV-positive mothers are not significantly different. However, the Kigali study showed there is a 58% risk of low birth weight HIV exposed infants. Similar result was replicated in US-based study that children born to HIV-infected mothers are at increased risk of low birth weight as well as prematurity. The treatment of maternal HIV infection with HAART seems not to affect the prematurity of the infants; this was shown in a multi-centre study in the US, as quoted by Lowenthal and Millon, 2006. After adjustment for other confounders, the incidence for prematurity was 17% in the HAART-treated group and 16% among those not receiving HAART. Despite the multiple aetiologies for failure to thrive, HIV still rank highly as one of the causes. The European Collaborative Study, after 10 year follow-up period, HIV infected children were 7kg lighter and 7.5cm shorter than HIV uninfected children. HIV infected children grow slowly than HIV uninfected children. Poor growth is a sensitive indicator of disease progression and an independent risk factor for death in HIV infected infant (Arpadi, 2005).

It is important that HIV infected mothers should be fully aware of the effect of HIV on the growth and development of their children if infected with HIV. This could provide the necessary motivation for the mothers to come forward for screening of HIV in their children before the babies start to have regression in their growth and development. Also, HIV counsellors should be aware of the consequences of HIV infection in the growth and development of the children; this will provide a more direct and focused counselling that

will motivate the change in attitude towards early diagnosis of HIV infection in the exposed infants.

2.7 HEAD CIRCUMFERENCE AND HIV

The head circumference measured is a good indicator of brain volume. The brain cells especially the microglial cells are infected by HIV and form the primary target for HIV. This leads to reduced brain volume and poor growth of this part of the HIV infected infant. Small brain volume tend to have developmental delays experienced by the HIV infected infants and consequently poor academic performance. As quoted by Lowenthal and Millon (2006) the Women and Infants Study (WITS) showed a trend toward smaller birth head circumference in HIV infected infants. This trend continues during childhood as they continue with poor brain growth. WITS also showed a strong association between early HIV-positive culture and higher risk of neurologic outcome. The head circumference can be used to predict the infants who are at risk of developmental delays and poor academic performance. Also, it can be used as early predictor of HIV-associated progressive encephalopathy in infants. This measurement would be most useful in the first two years when the brain volume is growing rapidly.

The outcomes of infant infected with HIV have been used in the classification of clinical progression of infant HIV infection; rapid progressors die or experience AIDS defining illnesses within the first year of life while intermediate progressors experience AIDS-defining illnesses or death within one to five years of life. The slow progressors do not develop symptoms and survive beyond five years. Children who experienced growth failure tend to have accelerated progression from asymptomatic HIV infection to AIDS within one year of life (Lowenthal and Millon, 2006). As quoted by Lowenthal and Millon; studies in Thailand, Rwanda and the US showed that babies that failed to gain 2kg by four months of age, as well as those with low CD4 counts at time of birth and high viral loads at two months were most likely to have rapid disease progression. The monitoring of the parameters above is the recommended investigations for assessing the risk of disease progression especially in poor resource settings. Cognitive and motor developmental deficits have been reported in HIV infected children, beginning from infancy. As quoted by Lowenthal and Millon (2006) from the US study; children with the

lowest rates of neuropsychological functioning are at the highest risk of rapid HIV disease progression.

2.8 BONE GROWTH AND HIV

HIV infected infant tend to accumulate bone density at a slower rate than uninfected children. Children with poor rate of bone formation are at risk of early osteoporosis. HIV affects bone development directly and indirectly. HIV has been implicated in the stimulation of osteoclastic activity leading to increased breakdown of bone substance. HIV is associated with vitamin D deficiency which consequently affects bone metabolism in HIV infected individual. There is a strong possibility of high risk for fractures later in life in HIV infected individual because of early development of osteopaenia and osteoporosis.

HIV infection is associated with increased risk of osteonecrosis of the hip. Children with growth failure (weight for age < 60%) meet the criteria for WHO III (severe) disease. Abnormal growth is included in the criteria for diagnosis of AIDS waisting (CDC category C). AIDS waisting is defined as weight loss of 10% or more of body weight or deceleration in weight gain resulting in downward crossing of 2 or more of the percentile lines for age (95^{th}, 75^{th}, 50^{th}, 25^{th}, 5^{th}) in a child older than 1 year or in the 25^{th} percentile of weight for height on consecutive measurements separated by more than 30days in addition to the presence of chronic diarrhoea or chronic fever (Arpadi, 2005). Benjamin et al. (2004) showed height velocity was more strongly associated with disease progression than was weight velocity.

2.9 EFFECT OF HAART ON GROWTH AND DEVELOPMENT

The Netherland study showed children who responded to HAART had positive effect on the height and weight over the 96 weeks study period. Virologic responders demonstrated a significant increase in the height and weight compared to non-responders. Body mass index did not show any appreciable difference between the two groups. But differences were noted for the clinical stage of the disease. The increase in weight occurred first (48 weeks) and height later (96 weeks) (quoted by Lowenthal and Dillon, 2006). Few case studies showed improvement in neurocognitive functioning with initiation of HAARTS especially those with better CNS penetration. Mothers of HIV exposed infants should

know some of these effects which are preventable by ARVs if HIV is diagnosed and intervention with ARVs early enough.

2.10 EFFECT OF HIV ON THE PSYCHOLOGICAL DEVELOPMENT OF A CHILD

It is a valid concern for mothers to be worried about the effect of HIV infection on the adaptive behaviour, emotional well-being and ability to participate in the school and home activities. The study conducted among haemophiliacs by Nichols et al. (2000) showed that the burdens and social stigma associated with HIV add to the stress of the haemophiliacs and their families. The HIV negative participants in the study showed better adaptive functioning in all domains than those with HIV positive. HIV positive with low CD4 counts did poorly in all areas of adaptive functioning. There was decreased school attendance and less energy for school work and pleasure reading. Behavioural problems were reported especially attention deficit, deviation and conduct factors. Low CD4 counts were consistently associated with poor health and depression-anxiety symptoms. Communication decline correlated with poor immune functioning in the HIV positive group.

2.11 EFFECT OF HIV ON PUBERTY

Like any chronic illness, HIV infection delays the attainment of puberty and the secondary sexual characteristics (Tanner stages). The median delay in pubertal onset is two years for girls and one year for boys. Tanner stages are delayed by 2.5 years in girls and 1.5 years in boys. The degree of delays depends on level of immune dysfunction. It is important to view abnormal growth and development by understanding what normal development milestones are; this is provided in the table. The table shows four domains; psychosocial, gross motor, fine motor and communication and hearing.

2.12 NORMAL DEVELOPMENTAL MILESTONES - THE FIRST 24 MONTHS OF LIFE

It is important that mothers are taught about the normal pattern of growth and development for an HIV uninfected child. This growth and development pattern should be available in charts and diagrams as training materials for pregnant women attending

PMTCT and EID trainings. Table 2.1 provides the growth and development of a child in the following domains: psychosocial, gross motor, fine motor and communication.

Table 2.1 - Developmental milestones

AGE	PSYCHOSOCIAL	GROSS MOTOR	FINE MOTOR	COMMUNICATION AND HEARING
1month	Follow faces to the midline	Moves all extremities equally. Lifts head when lying on abdomen	Opens hands spontaneously	Startled by loud sounds; cries; quiets when fed and comforted.
3months	Recognizes mother Smiles responsively	Can support head for a few seconds when held upright	Opens hands frequently	Responds to voices Laughs
6months	Reaches for familia people	Rolls from stomach to back or back to stomach Sits with anterior suppor	Plays with hands by touching them together Sees smal objects such as crumbs	Responds to name Babbles
9 months	Indicates wants Waves hand Has stranger anxiety	Can sit withou support Creeps o crawls on hands and knees	Look for a toy takes a toy in each hand transfers a toy from one hand to the other	Responds to sof sounds such as whispers
12 months	Has separation anxiety	Pulls self up to	Points a	Says at least 1 word

	Social interactions are intentional and goal directed	standing position Walks with support	objects with index finger	Makes ma-ma or da da sounds Locates sounds by turning head.
15 months	Imitates activities Finds a nearby hidden object	Can steps or own Can get to a sitting position from a lying position	Can stack one cube on top o another	Able to say mama and dada to respective parents
18 months	Initiates interactions by calling to adult	Walks withou help	Can take of own shoes Feeds self	Says at least 3words
2years	Does things to please others Engages imitative plays	Runs withou falling	Looks a pictures in a book Imitates drawing a vertical line	Combines 2 differen words

2.13 DEVELOPMENTAL RED FLAGS

Table 2.2 provides the red flags for abnormal pattern of growth and development of a child. This table should be reproduced as charts and drawings for teaching pregnant women attending ANC/PMTCT trainings.

Table 2.2 - Red flags in a child

AGE	DEVELOPMENTAL PROBLEM
Birth - 3months	Failure to alert to environmental stimuli Rolling over before 2months Persistent fisting at 3months
4 - 6months	Poor head control Failure to smile Failure to reach for objects by 5months
6 - 12months	No baby sounds or babbling Inability to localize sounds by 10months
12 - 24months	Lack of consonant production Hand dominance prior to 18months No imitation of speech and activities by 16months
Any age	Loss of previously attained milestones

(Copied from Lowenthal and Million, 2006)

The symptoms and signs that mothers see in their HIV-infected children fall into one of the WHO staging**.** This staging is a symptomatic screening tool for determining the intervention necessary and for monitoring of the progression of the disease**.**

2.14 WHO CLINICAL STAGING

All confirmed HIV infection must be staged according to WHSO clinical staging (WHO, 2005). This is very important for monitoring of the clinical progress of the disease. Staging is relevant as part of the decision making for HAART initiation in children older than one year.

Stage 1: No symptoms; persistent generalized lymphadenopathy.

Stage 2: Unexplained persistent enlarged liver and /or spleen; unexplained persistent enlarged parotid; angular cheilitis; minor mucocutaneous conditions (chronic dermatitis, fungal nail infections, or warts, molluscum contagiosum), recurrent or chronic respiratory

tract infections (sinusitis, ear infection, pharyngitis, tonsillitis), herpes zoster and recurrent oral ulcerations.

Stage 3: Moderate unexplained malnutrition, oral thrush (outside the neonatal period), oral hairy leukoplakia, diarrhoea for fourteen days or more, fever for one month or more, anaemia (HB<8g/dl) for one month or more, neutropaenia (<500/mm^3) for one month, thrombocytopaenia (platelets<50,000/mm^3) for one month or more, recurrent severe bacterial pneumonia, pulmonary TB, TB lymphadenopathy, symptomatic lymphocytic interstitial pneumonia, and acute necrotizing ulcerative gingivitis.

Stage 4: Unexplained severe malnutrition, oesophageal thrush, herpes simplex ulceration for one month or more, severe multiple or recurrent bacterial infections two or more episodes excluding pneumonia, PCP, Kaposi sarcoma, extra-pulmonary TB, Toxoplasmosis, Cryptococcal meningitis and HIV encephalopathy.

2.15 PREVENTION STRATEGIES

The focus of international organizations and Government is centred on reduction of HIV transmission from mother to child (PMTCT). This is in accordance with meeting the Millennium Development Goal 4 (reduction of child mortality), 5 (improve maternal health) and 6 (combat HIV/AIDS, malaria and others) (MDG Country Report, 2010). The critical role of South African Government in service delivery along this MDG agenda is commendable. Critical review of provision of HAART for people living with HIV especially efforts to mitigate MTCT have shown the commitment and responsiveness of the South African Government (NDOH, 2010). The HIV & AIDS and National Strategic Plan set an ambitious target of reducing mother to child transmission to less than 5% by 2011. The Government revised the PMTCT guidelines in February, 2008 to include dual therapy and HAART for eligible women. The guideline gave priority to early infant diagnosis of HIV infection at six weeks. The coverage of the services was considered adequate by the Department of Health (more than 90% coverage of primary health care in the country).

The results of the Government effort paid dividends in some provinces: Western Cape recorded over 95% of their pregnant women tested for HIV and two-thirds received PMTCT. This resulted in a decline in the vertical transmission. However, a survey of six-

week old babies tested with DNA-PCR in Kwazulu-Natal province showed over 20% of the HIV exposed infants were infected (failure of PMTCT programme). Surveys conducted by SANAC in 2007 revealed the challenges of the PMTCT programme. They recognized there was slow translation of policy to reality in different parts of South Africa; inadequate coverage of quality maternal and child health services to provide HIV related knowledge on prevention, treatment and care. The challenges were addressed adequately with the hope to see improvement in the statistics.

The Department of Health further revised the guidelines in response to emerging evidence of benefits of early initiation of HAARTs. Violari et al. (2008) in Johannesburg, South Africa showed convincingly the urgency in early treatment of HIV in infants in CHER study; a study that has gone down in history as the landmark scientific evidence in the management of infant HIV infection. Today, the 30% vertical transmission rate can be reduced to less than 2% with the use of antiretroviral drugs. The South African Government once again showed her commitments to the citizen by the changes to paediatric HIV care following the outcome of CHER Study (NDOH, 2010). All children less than one year infected with HIV must be commenced on antiretroviral therapy (NDOH, 2010). The effectiveness of the therapy can only be tested if administered early in eligible infants; therefore the HIV positive infants must first be diagnosed at six weeks follow up visit.

The goal of early infant diagnosis is to identify HIV infected infants prior to the development of symptoms/signs of clinical disease. This will facilitate prompt treatment and follow up (Hassan et al. 2011). HIV exposed but uninfected infant will have the opportunity to appropriate feeding to prevent further infection from breast feeding.

2.16 INFANT HIV DIAGNOSIS

VIROLOGIC TEST: Early identification of HIV DNA using PCR (Polymerase Chain Reaction) obtained from dried blood spot (DBS) is considered as the test of choice in children less than eighteen months. CHER study showed the earlier antiretroviral therapy is initiated in infants before immune suppression starts, the better the chance of survival of the child (Violari et al. 2008). About 40% of perinatal infections can be diagnosed at

forty-eight hours after delivery, 93% can be diagnosed by two weeks and majority of infant infections can be diagnosed by a month in the absence of breastfeeding. PCR directly detects the presence of the virus or products of the virus in the blood. A negative result in a breastfed child does not rule out infection completely because the child could still be infected with further exposure from the breast milk (Wilson et al. 2007). Therefore, breastfeeding babies should be re-tested six weeks after stopping the breastfeeding. Infants younger than six weeks who are symptomatic should be tested for HIV with PCR test, if negative, repeat the test at six weeks of age.

The method of testing using PCR involves: dried blood spots (DBS) which can be obtained from the heel, toe or finger –prick or from the veins and placed on DBS card. This method is suitable in all clinics across the country. The other method is whole blood in an EDTA/purple-top tube. Blood samples can be collected into the bottle and shake very well to prevent clots which can interfere with the test. The turn-around time for the PCR test is about two weeks in the local clinics while it takes about 48hours in the hospital. The waiting period of two weeks for results is associated with tension, anxiety and fears of unfavourable outcome. Whether this process impacts negatively on the maternal attitude and consequently, high dropout rate is not known, therefore, the study will find out the attitude of mothers to HIV test in their babies.

The strategy of integrating DNA-PCR test to immunization schedule is brilliant. This is meant to enhance uptake of the service delivery to the HIV positive mother-baby pair (NDOH, 2010). A positive diagnosis of HIV in infant serves as the entry point to comprehensive care for HIV and road to survival. A negative test result means that the child is negative for HIV provided that the child has stopped breastfeeding for more than six weeks before the test.

ANTIBODY TEST: Further testing in infants includes antibody detection with rapid test or ELIZA in children greater than eighteen months. They do not detect the virus itself but antibodies made by the immune cells in response to the virus. However, a positive test needs confirmation with another test. The maternal antibodies are transferred through the placenta to the babies. These antibodies are detectable in the body of the infants after delivery; a gradual decay in the amount of the antibodies occurs. About 50% of the babies

already have negative antibodies by nine months. By fifteen months, the maternal antibodies should not be found in the body of the child. Therefore, a positive antibody test in children under the age of eighteen months is not reliable for diagnosing HIV infection. But the test gives an indication of exposure to the virus which could be useful in cases of abandoned children or mothers that refused HIV test prior to delivery.

2.17 INFORMED CONSENT/CHILD'S RIGHT

The convention on the rights of the child maintains that children have the right to survival, life and development. This position is supported by United Nations Declaration of Commitment on HIV/AIDS. No children should be deprived of their right to quality health services. It is recommended mothers be provided with information to make an informed decision. The client must understand the information provided and the implications of acting on the information. This means infant/child will depend on the parent to take action for him/her (WHO/UNICEF, 2010; South African Children's Act, 2009). Therefore, the maternal knowledge of the importance of diagnosing infant HIV infection early to the survival of the child and ARVs' intervention is crucial to the goal of early infant diagnosis. The attitude of mothers to voluntarily request HIV screening in their babies is paramount to upscaling of early infant diagnosis across the country and the world.

2.18 COUNSELLING OF HIV POSITIVE WOMEN.

There are many awareness programmes on PMTCT across the country and worldwide; the commonest source of information about MTCT of HIV is through the antenatal clinics where HIV positive pregnant women are educated about the risk of MTCT and the how to reduced the transmission. The HIV counsellors in the various health facilities are playing significant roles in empowering women to make informed decision on the reducing the risk of MTCT. They provide pre- and post-test counselling for pregnant women; information about HIV/AIDS, benefits of HAART or dual therapy and risk of transmission to the babies. Is ante-natal counselling adequate? Do HIV positive women need additional counselling at post-natal clinics in order to educate them about the risks of transmission despite HAART or dual therapy and the need for early diagnosis? Should the counselling of pregnant women be re-focused on emphasizing the effect of HIV on

the growth and development and risk of death before the first year birthday if infected? Hassan et al. (2011) showed in their study that the service providers do not have adequate training, knowledge and understanding of early infant diagnosis. They confirmed ante-natal counselling do not focus on the process and core of early infant diagnosis. The knowledge gap in this regards is overwhelming and the present study is relevant to identify what needs to be the focus of post-natal care for HIV-exposed infants.

2.19 IMPACT OF KNOWLEDGE AND ATTITUDE TOWARDS PMTCT

Addo (2005) showed in his study in Ghana the level of awareness of HIV was high (98% among women and 99% among men). The major sources of awareness about HIV/AIDS are: radio, television and churches/mosques. But worrisome in his finding is the lack of knowledge about the transplacental and breastfeeding route of transmission among the pregnant women interviewed (only 51.8% knew about MTCT). Similar study conducted in Thailand by Hyodo et al. (2000) showed 80% of pregnant women do not have proper knowledge of mother-to-child transmission and prevention modalities of HIV. Another study conducted in Ethiopia by Jebessar and Teka (2004) looking at the knowledge and attitude of post-natal women about mother to child transmission in three hundred and eighty four women showed all the women already knew about HIV/AIDS. The major route 82.3% of transmission of HIV; 89.8% knew about mother to child transmission of HIV as compared to only 51.8% in Ghana; 76.8% knew MTCT is preventable; 64.6% knew about the prophylactic effect of antiretroviral therapy and 37.1% knew that abstinence from breastfeeding is protective.

Another study conducted in the Western Cape by Petrie et al. 2007 showed the majority of women in the study demonstrated good knowledge of HIV transmission and mother-to-child transmission. However, they were uninformed about certain aspect of prevention, cure and infant feeding. The attitude of the women in the study towards breast milk or formula milk as a feeding choice was influenced by the HIV status. This study pointed out that health workers are capable of influencing decision of mothers and therefore, very vital to MTCT prevention. The argument that the counselling offered to women during pregnancy, post-delivery and at post-natal clinics are crucial to the success of early infant diagnosis of HIV holds true. The present study will provide the gap on what mothers want

to know about the effect of HIV on the growth and development from conception through infancy to childhood. The study will reflect on the attitude of HIV positive mothers towards learning the status of their newborn early in life and having to cope with the care of HIV infected infants. Without any doubt there is a place in the literature for the present study.

Studies on the influence of knowledge of HIV positive mothers and their attitude toward testing the HIV exposed infants at six weeks (early diagnosis of HIV as against delayed testing till when the child is very ill) is scanty in the literature. There are no sufficient insight into the challenges, fears, and concerns of these women who have to wait for two weeks to get the result of HIV test.

2.20 KNOWLEDGE AND ATTITUDE TO EARLY INFANT DIAGNOSIS

Studies on the influence of maternal knowledge on the attitude to infant HIV diagnosis are very rare in the literature. A Kenyan study explored the service providers and care givers knowledge, attitudes and perceptions (Hassan et al. 2011). The study showed service providers and caregivers (mothers) were aware of vertical transmission through birth and breastfeeding. However, seven of the ten mothers interviewed thought it was impossible for vertical transmission of HIV to occur during pregnancy due to the use of cotrimoxazole prophylaxis, ART or condom. Some mothers reported that HIV can be transmitted through sharing of bathing soaps or cooking for children. Some of these misconceptions may influence attitude to early infant diagnosis.

Most caregivers were not sure of the number, exact time points, or type of test to be done for early infant diagnosis. Nine out of ten of the caregivers said that they had not heard of early infant testing before their children were enrolled for EID care, despite having undergone PMTCT counselling. It is pertinent to mention that the study alluded to the problem of dropout rate which can be influenced by sound knowledge and attitudinal change to embrace early infant diagnosis by mothers of HIV-exposed infants. Only 68% (145) enrolled after two months post-delivery; 65% (139) dropped out before eighteen months, 43% (60) dropped out before two months. The salient factors for drop out were maternal loss to follow up and young maternal age.

This finding put the present study into perspective that mothers who underwent PMTCT training may still not know about early infant diagnosis and the benefits of the test. As reported in the study, all the service providers felt that EID knowledge was not adequately covered during ante-natal and PMTCT training. All the service providers recommended more training on EID and for mothers during ante-natal classes and PMTCT trainings. They acknowledged that mothers need to know about EID, the process of the test and other relevant information as early as ANC/PMTCT trainings so that after delivery; it would be a matter of follow up to demand EID by the mothers.

Hassan et al, 2008 showed in their study that attitude to early infant diagnosis may have a bearing on the knowledge of the process of EID. Caregivers felt their children will be discriminated against in their various schools. Some mothers expressed denial (if the child is positive for HIV). There are concerns about the test being painful to the child and too much blood will be taken from the child. Eight out of ten mothers do not understand the rationale for the test. It has been expressed: 'It is a must for the child to undergo these three tests because he is young and his blood is not enough, so when he is tested three times, that is when he will have grown up'.

The service provider interviewed in the study alluded to misinterpretation of information given to mothers; mothers do not bring their children back if they appear healthy. Service providers confirmed that follow-up on HIV exposed infants occur by chance when the mothers fall sick (they bring the children by chance). Some of the mothers said they were motivated to come back to ascertain the HIV status of their children. The costs of travel to and from the health facilities for follow -up and long waiting period influenced their attitude to EID.

Similar study conducted by Donahue et al. 2012 in Blantyre, Malawi showed similar findings to Hassan et al. 2008. Most women had good understanding of how and when MTCT of HIV takes place. Most of the women were aware of the interventions to prevent mother to child transmission. Almost all the women were aware of the risk of breastfeeding, however, expressed concern about the financial feasibility of early weaning at six months. Some service provider felt that is one of the reasons why

mothers do not come for EID. None of the mothers were aware of the benefit of breastfeeding on preventing respiratory infections and diarrheal diseases. Some of the women expressed that cotrimoxazole will prevent MTCT.

Most of the women were aware of EID services and knew the process involved. However, they had little knowledge of infant ART. They did not understand that early diagnosis is the key to early treatment. The mothers confirmed that other women in the community lack knowledge of early infant diagnosis. One respondent said, 'there are a few people who know the difference between the importance of testing themselves and the importance of testing their babies. They are just staying in the community because they do not know'.

The attitude to early diagnosis from the Malawian study is that of a lost hope. One respondent said, 'what prevents mothers from having their babies tested is that they are scared that once they know that their baby is HIV positive then they have already thrown away their chicken and they might shorten the life of that baby because they are worried most of the time'. "Some people think that they would throw them away and others would give them poison. People tell her, why not get rid of him, he is a child, he will keep you busy".

A South African study conducted by Lazarus et al. 2009 on the hopes, fears, knowledge and misunderstandings of HIV positive mothers to early knowledge of HIV status of the infant is very relevant to the context of the present study. Most participants when asked about their preparation for the result of the infant HIV test; they responded that it can either be positive or negative. One respondent said, 'I told myself just like the soccer game…… I should prepare myself to either win or lose, positive or negative'. The waiting period of two weeks is shrewd in anxiety and stress. "I am now going to be relieved and live like other people. Before, I lived, but I was not ok in my mind". The mothers of HIV negative infants tend to have better knowledge of PMTCT; they know that nevirapine prophylaxis is not 100% protective. They understood the time between

taking nevirapine (NVP) to delivery, maternal CD4 count and viral load may affect outcome.

This contrasts the finding that mothers of HIV positive infants were disappointed and disillusioned about the outcome. They had believed NVP is 100% guarantee to protect MTCT. ‘‘I did everything the right way - I took NVP when I was in labour and when the baby was born, the nurses gave her the syrup, but still she came out positive - so I’m confused”. They however know that maternal viral load and difficult delivery are crucial for MTCT. Both groups were aware of the impact of HIV on the health and development of the child. They accepted that HIV infected infants are more vulnerable than adults. They might die at a young age.

The expectations of their infants differ for the groups; HIV negative infant’s mothers were relieved that they have not given the child disease but life and they can now focused on their own health. The mothers of HIV positive infants felt guilty, sad, disappointed of the infection in their children. They are distressed by the result of the test. They express fears and loss of hope that the child will grow, go to school and become independent. They tend to focus more on short term rather long time hopes for the infected children. Some of the mothers were optimistic of the benefits of ART, however, for how long, and he can still get sick.

Another South African study conducted by Rollins et al. (2009) confirmed the advantages and disadvantages of early diagnosis of HIV status of the infant. Majority of the mothers in KwaZulu-Natal study sites said early testing help you to confirm the status of the infant. About half of the mothers said the test gives opportunities for ART initiation in an infected infant. Approximately a quarter of the mothers were able to link the infant test results to the decision on the best feeding options for the infant. Some responded the test gives them peace of mind. It offers opportunity for initiation of prophylaxis. Only few mothers knew cotrimoxazole prophylaxis. The perceived disadvantages include; breach of confidentiality, reveals mother’s HIV status and the test is frightening or rather too quick to test the child.

Should routine HIV test be introduced at immunization clinics? The study conducted by Rollins et al. (2007) though anonymous unlinked universal test for six week old infants in seven clinics in KwaZulu-Natal province attending immunization clinics. This study showed unequivocally, the benefit of surveillance of infant HIV infection through screening of immunization clinic attendees. This will provide opportunity to identify mothers who were HIV negative during pregnancy but seroconvert along the line and those who did not test for HIV prior to delivery.

Rollins et al. (2009) conducted a study in KwaZulu-Natal Province where they assess the feasibility and the acceptability of universal HIV test at six-week old infants attending immunization clinics. About 90% of the 646 mothers accepted routine HIV screening on their infants at the immunization clinics. But only 56.8% (332/584) of the participants came back for the result. This again corroborates the problem of missed opportunity to intervene and improve the chances of survival of HIV infected infants. Majority of the mothers said they were comfortable with testing of their infants and will recommend it to others.

2.21 CONCLUSION

The epidemiology of HIV worldwide, Sub-Saharan Africa, South Africa and Eastern Cape Province was covered in-depth. The overall effect of HIV on the growth and development was reviewed. The literature on maternal knowledge and attitude to early infant diagnosis was appraised and critique and set the right context for the present study. The next chapter deals with the methodology and the procedure of the study.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

There was a need to embark on this study to establish the knowledge and attitude of HIV positive mothers to early infant diagnosis and to make strategic recommendations to health authorities on how to upscale the services. This chapter explains the steps followed by the researcher in carrying out the study to address the research question. Research methodology provides the road map for guiding a project aimed at solving the proposed research question by emphasizing on the chosen design, possible sample to provide responses for analysis, the analysis and reposting of results (Christensen, Johnson, Burke, Turner and Lisa, 2011). This chapter will provide the design, sampling, data collection and ethical considerations.

The study has generated the following question that will serve as roadmap for the direction to be taken: What is the knowledge and attitude of HIV positive mothers to early infant HIV diagnosis (EID)? The formulated objectives are:

- To assess the level of knowledge of HIV positive mothers on early infant HIV diagnosis.
- To evaluate the attitude of HIV positive mothers to early infant HIV diagnosis.
- To make recommendations based on the findings to the department of health on strategies to address the expansion of early infant diagnosis services.

3.2 SETTING OF THE STUDY

There are many health centres in the King Sabata Dalindyebo Municipality, Eastern Cape Province which run large immunization clinics. Two immunization clinics were chosen which are readily accessible to the investigator. The study was conducted in two immunization clinics in Ngangeliswe and Mbekweni health centres. Ngangeliswe health centre delivers approximately one hundred and fifty babies per month and HIV prevalence of 30.1% (Local statistics, 2010). Mbekweni health centre has a large immunization clinic (average of three hundred attendees per month). The facilities have NIMART trained nurses and lay counsellors who provide support services to HIV positive

clients at the centres. The health centres are accessible to the researcher as well as the mother-infant pair. A private room will be secured in each of the clinics where the interviews will take place; this will guarantee privacy and confidentiality and increase voluntary participation of the eligible participants. Immunization coverage is almost 100% in Mthatha community.

3.3 RESEARCH DESIGN

Research design is the outline, plan or strategy that specifies the procedure to be used in seeking an answer to the research question. It specifies how data should be collected and analyzed (Christensen et al. 2011, pg 232). There are two major types of research designs namely; a qualitative and quantitative study design that can be employed to provide meaningful answers. Qualitative research is an interpretive research approach which makes use of multiple types of subjective data and investigation of people in particular situations in their natural environment.

Qualitative data consist of words, pictures, clothing, documents and other non-numerical information. The researcher focuses on understanding the data from the participants' subjective view. It attempts to provide the insiders' views. The researcher takes the role of an objective outsider and relates the interpretive-subjective data to the research purpose and research question (Christensen et al. 2011). Qualitative study makes use of varieties of methods for data collection. These include interviews with an individual, observation of an individual (s), written documents, photographs and historical information.

It allows triangulation which involves the use of several data collection methods to gain better understanding of the phenomenon. Qualitative research is conducted in the field or the natural settings of the participants. This study design is suitable because it allows multiple methods of data collection (in-depth interview and focus group) which give better understanding of the situation of the mothers. It also, ensures the study is conducted in the immunization clinic which is a familiar territory to the mother-infant pair. Following the understanding of qualitative research, the researcher utilized qualitative research design in order to gain in-depth understanding of the knowledge and attitude of HIV positive

mothers on early infant diagnosis. The researcher made use of qualitative design involving in-depth interview and conducted two focus group discussions.

3.4 TARGET POPULATION AND SAMPLING METHOD

Sampling refers to the process of drawing a section from a population. The sampling technique in a qualitative study is usually purposive sampling. Purposive sampling indicates the researcher specifies the characteristics of the population of interest (eligibility criteria) and then locates individuals who match the needed characteristics (Christensen et al. 2011, pg 159).

There are several sampling methods employed to locate the eligible participants in a qualitative study. These include; maximum variation sampling, extreme case sampling, homogenous sample selection, typical-case sampling, critical-case sampling, negative-case sampling, and opportunistic sampling (Christensen et al. 2011, pg 162). The preferred method to be used in this study is critical-case sampling which allows obtaining meaningful information about the themes of the research. A purposive, critical-case sampling of HIV positive mothers/exposed infants pair was selected for the study.

A minimum of six participants will be chosen to participate in a focus group to deliberate on the main themes of the study. A diverse group of participants will be drawn into focus group discussions (one focus group from each of the study sites); mother-infant pair who are attending clinic for the first time, those who already tested their babies and those who have missed opportunities for testing would be allowed to partake in the discussion. This diverse group of participants with a common denomination of HIV positive status will provide the researcher rich information on the research topic.

All HIV positive mothers attending immunization clinics with their babies will be involved in the research study. Recruitment of eligible participants will be conducted by the senior nurse at each of the centres. Then purposive sampling of HIV positive mothers will be selected for interview. The eligibility criteria are: mothers/caregivers who are 18years and above, self reported HIV positive maternal status; road-to-health card indicating the use of dual therapy or HAARTS in the mother; road-to-health card indicating use of nevirapine in the infant post delivery; and newly confirmed HIV positive status either in

the mother or infant. The selection of the eligible participants will be voluntary and interview will continue until a saturation point is reached when no new information is coming through.

3.5 DATA COLLECTION METHOD

In-depth interviews will be employed which means this is a situation where the interviewer asks the participants series of questions either in face-to-face, on internet or over the telephone. Interviews are good for measuring attitudes and knowledge which is the purpose of the study. It allows probing and posing of follow-up questions by the interviewer. It provides in-depth information about participants' subjective views and ways of thinking. Face-to-face interview allows interviewer to get information from both verbal and non-verbal cues which are relevant to the purpose of the study.

It may be affected by social desirability bias where participants only provide information the interviewer wants to hear. It may be confounded by recall bias. Data analysis may be time consuming; inexperienced investigator might distort the findings. Further validation is needed of the data obtained. With the above strengths and weaknesses borne in mind, the researcher will carefully make provision to conduct two focus groups (one from each centre) to validate the data from the interview (triangulation of data).

Focus group involves a homogenous group of 6 - 12 people who discusses the research issues; session will be audiotaped (Christensen et al. 2011, pg 56). Focus group emphasizes small-group interaction and in-depth discussion among participants. It is relevant for this study to see how participants react to each other, group dynamics and further explore the thoughts and behaviour of the participants.

3.6 MEASURING INSTRUMENT

There are several data collection tools available in the research arena. The most appropriate tool for this study is an interview schedule (see appendix A) which is a set of open ended questions on the research topic; allows free flow of ideas and thoughts. An interview schedule was used to conduct face-to-face in-depth interview with participants drawn from the two centres. The content questions were written in both English and

IsiXhosa. The medium of communication during the interviews and focus group discussions was IsiXhosa to enhance smooth conduct of the interview. The interviews were audio-taped. Verbatim field notes were taken during the course of each participant's interview and the focus group discussions. The interviewer was given opportunity to reflect on her conduct during the interview which could affect the responses from the participants (researcher bias).

3.7 DATA ANALYSIS

Thematic analysis technique was used in the study. Research assistant knowledgeable and competent in theme transcription listened to the recorded interviews and translated them verbatim. Line numbers were used to identify questions asked by the interviewer and responses made by the participants. Themes were developed from what constituted participants' responses on different questions and various issues. The objectives of the study informed the process of themes development. Responses from the participants were categorized into themes. Content analysis was used to interprete the responses from the participants. Line numbers were then used to reference each analyzed response. Themes were colour-coded and those colours were used to shade any response relating to specific themes in the interviews. Field notes taken were compared with the transcribed data.

3.8 LIMITATION OF THE STUDY

The limitation of the methodology to be employed is well documented by Christensen et al. (2011, pg 58 - 59). The process of interview is subject to social desirability bias due to the tendency of interviewees to say what the interviewer wants to hear (reactive effect). The effect of the investigator on the data might be subject to the personal biases and poor interviewing skills. Data analysis might be time-consuming for open ended items. Findings from interviews need validation. The responses from the interviewees may be subject to recall bias. Focus groups are sometimes expensive to put together. The facilitative skills of the moderator determine the success of the discussions and outcome from focus groups. The group dynamics may influence active participation of all the participants.

3.9 ETHICAL CONSIDERATIONS

In accordance with the American Psychologist Association Ethical Standards for Research published in 1953 (amended in Oct., 2002); any research to be conducted on humans must follow certain standards (Christensen et al. 2011)

Institutional Approval: two sets of institutional approval were obtained. The University of Stellenbosch Ethical Research Committee granted approval prior to commencing the study. Another approval was granted by the district manager of King Sabata Dalindyebo Local Municipality which provided the authorization to use the two immunization clinics for the study.

Informed Consent: each participant was empowered to make an informed decision about her participation in the study. This was achieved by providing each participant an information sheet (see appendix B) which stated the following information in written format in both English and IsiXhosa: (1) the purpose of the research, expected duration and procedures, (2) their right to decline to participate and to withdraw from the research during the course of the interview, (3) the consequences of declining or withdrawing from the study, (4) limits of confidentiality/privacy of information (5) whom to contact for questions about the research and research participants' rights, (6) audio-tape recording of their voices and their right to decline or withdraw at any stage of the interview. Written informed consent was then signed by each participant indicating their voluntary participation in the study.

Inducements: There was no financial inducement offered to any research participants.

No form of deception was allowed in the course of recruitment of participants.

Participants had the opportunity to speak with the social worker for debriefing. The investigator provided opportunity to correct misconceptions expressed by the participants.

3.10 CONCLUSION

The chapter provides the roadmap to conduct the study successfully. It covers the design, sampling method, procedure of the study, data collection method and tool, how the data will be analyzed and ethical issues. In chapter four, the researcher will provide the results and findings.

CHAPTER 4: RESULTS AND FINDINGS

4.1 INTRODUCTION

This chapter outlines the result of findings obtained from face-to-face interviews with 14 participants at Mbekweni Health Centre and 10 participants at Ngangelizwe Health Centre. The result obtained was then triangulated with two focused group discussions (one in each centre) to enrich and validate the data. The participants were drawn from the mother-baby pair at the immunization clinics from the two centres. Participants were interviewed until no new information came through (saturation point). The total number of participants interviewed was twenty four. Focus group discussions consisted of two groups; Mbekweni group had six participants and Ngangelizwe group had ten participants.

The interview schedule covered three main domains (see Appendix A for the interview schedule): demographic characteristics of participants (except the names which were not relevant to the objectives of the study); knowledge about infant HIV infection and attitude to early infant diagnosis. The interview schedule consisted of open ended questions with opportunities for probing questions in order to gather as much information as relevant to the objectives of the study. The audio-recording was translated and transcribed to identify the main themes from the interviews. The results were then presented to the focus groups to elicit further information and validation. The group dynamics and interactions were directly observed and field notes were obtained to corroborate the recording on the tape.

4.2 DATA ANALYSIS

The responses to each of the question in the interview schedule were grouped based on emerging themes. The following themes emerged from the field work: (1) knowledge of infant HIV infection, (2) prevention of infant HIV infection, (3) diagnosis and commencement of ARV treatment, (4) symptoms and other effects of HIV infection in infant, (5) benefits of using ARVs in infants, (6) willingness and fears towards infant HIV testing, (7) expectations during waiting period and coming for results, (8) infant mandatory testing, and (9) recommendation of infant HIV test to other mothers. This chapter will present the findings and direct quotes of the participants will be added to validate the results.

4.2.1 Characteristics of the participants

The average age of the participants interviewed was 29 years with youngest being 19 years and the oldest being 45 years. The average age of the participants who participated in the focus group discussions was 27 years with the youngest being 25 years and the oldest being 39 years. Most of the participants have either one or two children alive (7/24); others have three or more children. Few participants have lost one or two children. Half of the participants are in marital relationship while another half consists of single mothers. Only one participant was divorced from the father of the child. Majority of the participants have grade level 6 - 9 education. Only few have tertiary education and the rest have less than grade level 6 education. Nearly all the participants are unemployed (22/24); they collect child grants. Majority of the participants reported that they were diagnosed in the last two years (12/17). Four participants were diagnosed four or more years prior to the study. Half of the participants were already on HAART while the other half has been initiated on ARVs. Most of the participants who are currently on HAART were initiated in the last two years of the study. One participant said she doubted her status and that is the reason for the delay in initiation of HAART. Few participants had the diagnosis of HIV for about five years without the initiation of ARVs.

4.2.2 Knowledge of infant HIV infection

Majority of the participants are aware of infant HIV infection while few felt they did not have enough information because they did not attend the classes. They are aware of the mode of transmission of HIV to infants (mother to child transmission of HIV);

> *'The infant can be infected if the mother is HIV positive and has not been tested'. 'When the mother does not use condom during sex, the infant get exposed'. If the mother does not use pills before giving birth, the new born baby might be infected'.*

Some participants have misconceptions about the mode of transmission of HIV to infants;

> '*An infant is infected with HIV during birth if the mother gave birth through operation since there is a lot of blood involved*'. "*If the mother does not eat*

healthy, the child can be infected". 'Touching HIV positive without using glove can cause infection'. The manner in which the child is infected during birth is not known'. "*All she knew was her HIV status and that of the infant, she was told by ancestors through dreams".*

Most of the participants are in agreement about time of delivery of the baby as a crucial period for HIV transmission;

'*Infection happens during delivery since there is lot of blood'. "Also, through the blood which oozes during birth".*

There are those aware of the risk of HIV transmission during pregnancy but have misconceptions*;*

'The unborn child is likely to be infected since he/she shares everything with the mother'. 'Touching the child by a HIV positive individual might infect the child'.

A participant is aware of the increased risk associated with the disease of the breast during breastfeeding;

'HIV can be transmitted to the infant, If the mother has wounds on her breasts when she breastfeeds the child'.

Some participants have wrong ideas about MTCT;

'*Infections happen during birth when the infant opens the mouth while crying and swallow the mother's blood which oozes during giving birth'. "The infant is infected during birth since the mother's blood can contact the infant's bruises".*

There were some repondents aware of the risk of HIV transmission from the breast milk;

'*Breastfeeding the child when you are HIV positive can lead to child infection*' but are not sure about the facts*; "mixing feeds like breast feeding and formula might lead to HIV transmission". 'Exceeding six months when breastfeeding the infant can lead to infection". 'Since the mother has to breastfeed for six months without*

interruption, changing the method before completing that time make pores inside the child to open and make him vulnerable to infection'.

Few individuals showed knowledge of window period which may give false hope that they were negative*;*

'The unborn baby is also infected as a result of the window period since the mother thinks she is negative'.

Some participants acknowledge the risk of infant HIV infection despite the use of NVP or HAART;

'The unborn baby is infected depending on the type of ARVs the mother takes'. "Breastfeeding when the infant is not taking NVP leads to infant infection".

There was an understanding by some understanding that PMTCT intervention with NVP or ARVs must be commenced early in pregnancy, else the risk of infant infection is high*;*

'When the mother is not treated early, the unborn baby can be infected'.

Some participants understood that failure to adhere to ARVs is a risk for MTCT;

'If the mother does not take treatment while being HIV positive, the infant can be infected'. "If the mother starts visiting the clinic late, the infant can be infected".

There was an awareness of low CD4 count as an important risk factor in MTCT*;*

'If the CD4 count of the mother is very low, the child's chances of infection are increased'.

Overall, majority of the participants have good knowledge of HIV infection in infants. However, some of them have some misconceptions about MTCT and the mode of acquisition of the virus by infants. There were those admitting to have a lack of knowledge of how infants get HIV infection. They confirmed PMTCT classes form the basis of what they know but they do not know enough about HIV in infants.

'*She never got enough coaching from the clinic and she is disappointed'.*

4.2.3 Prevention of infant HIV infection

The knowledge about prevention of infant infection was satisfactorily demonstrated by the majority of the participants. However, the content of the prevention varies across the participants. Majority of the participants understood that protecting the mother from HIV infection is crucial to prevention of infant HIV infection.

> *'Parents should use condom'. 'Wear gloves when helping people in a car accident'. "The mother shouldn't have sex with someone who is not the child's father".*

Majority of the participants were aware of the importance of HIV test in the mother during pregnancy. They understood that diagnosis is the entry point to intervention with dual therapy or HAARTS to protect the mother and the unborn baby.

> *'The mother must go to the clinic in order to test and get treatment'. 'There is a pill called nevirapine available at the clinic which helps in protecting the child and is used by pregnant mother'. 'The mother should visit the clinic and take ARVs before giving birth'. Mothers need to take treatment, AZT before delivery'.*

Most of the participants were aware of the post-exposure prophylaxis effect of nevirapine, given to the infant after delivery. However, few participants mention the duration of treatment with nevirapine.

> *'There are drops the child receives from the clinic'. "The child receives nevirapine syrup".*

Majority of the participants feel strongly against mixed feeding and regard it as dangerous to the health of the child. They understood the additional risk associated with mixed feeding. They acknowledge the prerogative duty of mothers to make a choice on the feeding option (breastfeeding or formula feeding).

> *'The mother must choose between breastfeeding or formula milk and not both'. 'Avoid mixing formula with breastfeeding'. "Breastfeeding should be done alone".*

Some of the participants showed preference for formula feeding as it offers some protection for MTCT. Some of the participants understood that breastfeeding must be exclusive and should be followed with abrupt weaning at six months.

> *'The mother must not breastfeed, if she chooses to; it should be done for six months'. "The mother should breastfeed for six months and after that the baby can receive other foods". "No water and other foods in the first six months of the child".*

Some participants demonstrated the importance of attending follow up clinics.

> *'By taking the child to the clinic so s/he can be tested as soon as possible'. "The child should also test".*

A lack of knowledge was noticeable about ways to prevent infant HIV infection.

> *'She doesn't know the problem about mixed feeding'. "She is not sure of ways to prevent infant infection". 'She doesn't know how mixed feeding leads to child infection'. "She does not know what ARVs are for". "She knows nothing about infant infection prevention since she never got any lesson on this".*

There are some misconceptions demonstrated by the participants about ways to prevent infant HIV infection.

> *"The child should avoid contact with other kids". 'The baby should also test and get the nevirapine'. 'The baby should be breastfed with the permission of the clinic'. "Children should eat pumpkin". 'There should be no sharing of children's toothbrush'.*

4.2.4 Diagnosis and commencement of ARV treatment by infant

The knowledge of participants about where and when HIV test should be carried out was explored in-depth. Nearly all the participants know that the test is done at the clinics.

> '*We can only know the baby's status after taking him or her to the clinic*'.

Only few participants were sure of the appropriate time for infant diagnosis.

"The right time for the child to be tested is when s/he is six weeks".

Some participants do not have any idea of when it is the right time for a child to be tested for HIV.

'*The right time for the child to be tested is when s/he is three to four weeks'. "The right time to be tested is on the day of delivery*". '*The right time for the child is unknown'. "The child can be diagnosed at any time". 'The right time for infant diagnosis is at a very young age, when s/he is less than a month, but not sure.'*

Some feel a child should be tested the day they are born; after the first year birthday; not sure of the right time. Some felt that the child should be tested for HIV as soon as possible but were not aware of six weeks infant diagnosis. The appropriate time of initiation of ARVs in an infant was explored to elicit deeper knowledge of early infant diagnosis. The responses vary widely. Nearly all the participants did not know how soon or the right time for ARVs to be initiated in an infant.

'She doesn't know the time of commencing ARVs; but she prefers that when the child is ready'. "She thinks the child can start ARVs after three years of age but can start nevirapine immediately". 'She doesn't know when the child can commence ARVs'. "The child can start ARVs after two years". 'The right time to start ARVs is unknown'. "The nurses will tell a person the right time for the child to start ARVs". 'She can start ARVs when the CD4 count is low'.

Only few participants said ARVs should be initiated as soon as the results are out. However, it appeared that they do not have the knowledge of the response offered.

'*And they can start ARVs the same day they tested HIV positive'. "S/he can start taking ARVs as soon as s/he tested HIV positive; but is unsure". 'S/he can start taking ARVs as soon as s/he tested HIV positive or skip a week'.*

4.2.5 Symptoms and other effects of HIV infected infant

All the participants are familiar with the symptoms of HIV infection in infants. They mentioned the following symptoms: skin rashes, diarrhoea, loss of energy, body pains,

weakness, loss of appetite, loss of weight, cough, difficulty in breathing, sores in the mouth and body etc.

> "*They develop rash and wounds all over the mouth and body". 'Usually have diarrhoea, looses weight and energy'.*

Other effects of HIV infection on the different aspects of child's development were explored. Majority of the participants understood that HIV affects the rate of growth of the child.

> "*They don't grow properly. They have delayed growth (crawling, walking, talking etc).*

Some participants are aware of the effect of HIV on the school's attendance of an HIV infected child.

> "*They struggle to go to school sometimes".*

There was an awareness the psychosocial development of the child can be affected by HIV.

> *'They can be paralyzed and mentally disturbed'. "The child will lose weight and do funny things".*

The effect of HIV infection on the weight of a child was explored. Majority of the participants knew that HIV infected child will lose weight.

> *"The baby is weak, thin and unable to grow. The child gets sick, lose weight and have kwashiorkor"*.

The effect of HIV on the immune system of the child and the outcome in terms of vulnerability to infection was explored. Majority of the participants knew that HIV infected infant has increased vulnerability to infections and myriads of disease conditions.

> *'S/he develops TB and big tummy, as well as low weight'."They can be paralyzed". 'Skin problems are possible with body temperature being high'*.

The risk of death of infant was explored in-depth. All the participants have witnessed and understood that HIV infected child can die prematurely.

'*Some children die'. "Death eventually comes".*

4.2.6 Benefits of using ARVs in infants

The knowledge of the benefits of ARVs was demonstrated by the majority of the participants. The benefits mentioned by the participants include the following: ARVs help the child to fight the virus; it prolongs the life of the child by avoiding death; it helps the child to have normal growth like other children.

'The child will be strong'. "ARVs fight the virus for the child". 'It protects the child from being vulnerable to other sicknesses'.

Few participants lack the knowledge of the benefits of using ARVs by infants while some were not sure of the benefits.

'She is not aware of the benefits of ARVs'. "She does not know but think ARVs help in improving the child's condition".

4.2.7 Willingness and fears towards infant testing

The attitude of participants to HIV test in infants was explored and observed. The attitude of the participants was evaluated for the following themes: willingness to test; readiness to test; immediate and long term fears and reaction to positive results. Majority of the participants never thought of bringing the child to the clinic for HIV test. One of the participants burst into tears when asked about her willingness to test her child for HIV. Few participants were willing and ready to have HIV test done on their children. Some of the participants who were willing to have HIV test done for their children were not prepared to do the test same day.

"She feels that her baby is still young to be tested". 'She never thought of bringing the child to the clinic for HIV testing, she thought if it happens s/he will be tested later'. *'She never thought of bringing the child to the clinic for HIV testing because she was scared of injection'.*

Few participants who are willing to have the test done understood the benefit of the test.

'*She wishes to see her child tested since she wants her child to grow like other kids'. "She suspects that the child might be positive".*

Only few participants were not willing to have HIV test on their infant.

"She is not willing because the child looks HIV negative".

Nearly all the participants have fears about HIV test in their babies. The main reason for the fear is that they are afraid the child might be positive for HIV. Other reasons expressed by some participants include; embarrassment of having an HIV positive infants, fear of what people might say, fear of HIV, fear that the child will depend on pills, fear of the child falling sick, fear that the child might die and fear of how she would manage to live with HIV positive child.

'The fear relates to the injection as well as the child being positive as young as s/he is".

Few participants did not express any fear about HIV test in their infants.

'*She is not afraid because she already knows her HIV status'*.

The reaction to a positive HIV test was elicited from the participants. The body language of the participants was documented. A participant started crying on hearing if the child is positive for HIV. There was a feeling of guilt while some appeared numb to the result.

"If the child is positive, she would be reaping what she sowed". 'She has doubts'.

4.2.8 Expectations during waiting period and coming for results

The interval between sample collection for DNA-PCR test and delivery of result to the mother is laden with different expectations, thoughts, and proposed line of actions. These expectations were explored from the participants to determine what their attitudes are to early infant diagnosis of HIV. The attitude and motivation towards knowing the results of the test was elicited by asking the mothers if they would return in two weeks to fetch the results.

Nearly all the participants knew there are only two possibilities from the result; it is either positive or negative. Most of the participants demonstrated the tendency to believe that the results would be positive while only few expected a negative result.

> *"She expected the child to be HIV positive and have TB as well". 'She expected negative and positive and wishes for the negative since she had done all that the nurses said she should do'.*

Some of the participants confirmed that they would not be able to sleep during the period of waiting for the result. Other reactions during this period include; being nervous about what might happen, some will question themselves many times about the result, some felt they would be worried while waiting due to fear of incurable disease in their young child.

> "*She will feel destroyed and nervous as she will ask herself many questions. She will not even sleep at night since her baby is too young to be positive".*

The willingness to return for the result was explored. Majority answered that they will return for the result on the appointment date. The motivation to keep appointment date for the result is due to curiousity to know the HIV status of the child for many of the participants while some are desperate to see the result.

> "*She wanted the result so badly". 'She will come for the result on the said date since she is curious'.*

Only few participants doubt whether they would return for the result. No participant said that she would not come for the result.

4.2.9 Infant mandatory HIV testing

The attitude to mandatory HIV test at six week immunization clinics was elicited from the participants to assess the acceptability of the test to the mothers whose infants are at risk of HIV infection. Nearly all the participant agreed that infant mandatory HIV test is beneficial to the child and mother/caregiver.

This will help the parents so that they cannot take the child to where he shouldn't be (traditional healer)'. "This will help in determining whether the child needs treatment in early stage."

4.3 RECOMMENDATION OF INFANT HIV TEST TO OTHERS

The participants were then requested to recommend the test to other children in their community. Majority of the participant feel strongly about recommending infant HIV test to other children in their community. They acknowledge that it will be beneficial to the community.

'*Yes since there are many mothers who do HIV test and choose not to take the results and their babies are having health problems now'. "She recommends it because children are sick and their mothers are careless". 'Generally some women regard testing the infant as a negative thing to do and as such babies suffer'.*

Some participants were not keen to recommend the test to others because;

'*It is not an easy thing when you stay in the rural areas; because they think that you imply that their kids are HIV positive'. "She can't do that since such will require that a person first discloses her status". 'She doubts since she might be forced to disclose her status'.*

Few participants were non-committal to recommend the test to others in their community. The participants were given opportunity to suggest how to reach every child in the community; majority of the participants recommend that the government should take the information to the radio. Some participants suggested that education on early infant diagnosis must start from ante-natal classes.

4.4 CONCLUSION

The main purpose of the chapter was to present the report of findings from the study. The results showed mothers have general knowledge of HIV infection both in adults and children. They have some knowledge of prevention and the role of ARVs. The knowledge of early infant HIV diagnosis and early intervention with ARVs is lacking

among the participants. There is a mixed attitude to early infant diagnosis; some people are willing to have the test but were not ready for the test to be conducted same day and others never thought about HIV test in a young infant. The infant mandatory test is acceptable to the participants but some are sceptical to recommend the test to other children in their community.

Chapter five focuses on the discussion of the findings of the study in perspective of what is already known about the topic. The conclusions of the study and what this study adds to existing knowledge will be presented in the next chapter. The recommendations on how to scale up early infant diagnosis services will be provided in the next chapter.

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter will attempt to appraise the findings from the present study and put them in perspective of existing literatures on the topic of early infant diagnosis of HIV. The conclusions from the study will be presented accurately and form the yardstick for making recommendations. The recommendations will be presented to the authorities at King Sabata Dalindyebo Local Municipality in order to implement and upscale early infant diagnosis. The study has generated the following question that will serve as roadmap for the direction to be taken: What is the knowledge and attitude of HIV positive mothers to early infant HIV diagnosis (EID)?

The formulated objectives are:

- To assess the level of knowledge of HIV positive mothers on early infant HIV diagnosis.
- To evaluate the attitude of HIV positive mothers to early infant HIV diagnosis.
- To make recommendations based on the findings to the department of health on strategies to address the expansion of early infant diagnosis services.

5.2 DISCUSSION AND CONCLUSION

Majority of the participants in the study have high level of awareness about MTCT of HIV. This finding corroborates the result of the study by Addo et al. (2005) which found 98% of the women to have high level of awareness of MTCT. The study conducted by Jebessar and Teka (2004) also concurred with the high level of awareness about infant HIV infection. Majority of the participants demonstrated good knowledge of MTCT; they understood that infection occurs during pregnancy, delivery and from breastfeeding. This finding reflects the facts about MTCT which previous studies have shown (Dunn et al. 1992; Burr et al. 2011).

Few mothers understood the significance of the window period in relation to the risk of MTCT. Majority of the mothers were aware about the role of ARVs in the prevention of MTCT of HIV. Only few participants knew about the small risk of MTCT despite the use of ARVs.

This finding can be compared with the finding in Lazarus et al. 2009 which showed among HIV positive mothers, they were confused and disillusioned; they wanted to believe that NVP guaranteed protection. Some participants alluded to the risk of non-adherence to ARVs, while some other participants understood that ARVs must be started early in pregnancy to achieve protection against MTCT.

The knowledge of prevention of MTCT was high among the participants. However, there were misconceptions among the minority of the participants. The participants understood the primary prevention of MTCT; protect women from HIV through condom use, wearing of glove when dealing with blood and maintain mutual faithfulness in relationship. The participants encourage HIV test to diagnosis and intervene in MTCT. The findings on the knowledge of prevention of MTCT are similar to studies by Jebessar and Teka et al. 2004 which revealed that 76.8% knew that MTCT is preventable.

These findings are in agreement with the National Department of Health policy guideline on PMTCT (2010). The participants are aware that maternal ARVs are preventive for the child. They are familiar with the benefit of the nevirapine issued to infants to protect against HIV in the child. The prophylactic effect of ARVs was mentioned by 64.6% of the participants in the Ethiopian study by Jebessar and Teka, 2004. The participants recognized the danger of mixed feeding. Majority showed preference for formula feeding because of the fear of HIV transmission through breast milk. Some of the participants were aware of the risk of diarrhoea if hygiene is not maintained. They emphasized the importance of attending follow up clinics to get help. However, minority of the participants lack the knowledge of prevention of MTCT. These participants had misconceptions about the ways to prevent MTCT.

Majority of the participants acknowledged they need to know more about HIV in infants. This finding corroborate the result of a Kenyan study by Hassan et al. 2011 which found the knowledge of EID was not adequately covered during ante-natal and PMTCT training by the service providers.

The knowledge about early infant diagnosis was unsatisfactory. All the participants knew where such service can be obtained; however, majority of the participants did not know the right time to bring a child for HIV test. This finding showed the focus of ante-natal and

PMTCT training needs to be expanded. The knowledge about early ARVs is poor among the participants. Majority of the participants had no idea when ARVs should be initiated in HIV positive infant. Some of the mothers were worried about having to care for an infant on medications for the rest of his/her lives.

The knowledge of the effect of HIV infection on the health and development of infant was high. The effects cut across various domains; rate of growth of infant, skin infections, vulnerability to illnesses, poor school attendance and death were mentioned by the participants. This finding is similar to the findings from Lazarus et al. 2009 which confirmed the higher vulnerability of HIV positive infants to infections.

The knowledge about the possible outcome from HIV test of the infant is not doubtful. Nearly all the participants knew that the results can only be positive and negative. This agrees with Lazarus et al. 2009; “I told myself that just like in soccer …….. I should prepare myself to either win or lose, positive or negative”.

The attitude to the mention of positive result generated numbness, guilt and cries. This again is similar to the findings of Lazarus et al. 2009 which reported that mothers go through mental preparation to receive the results. ‘The HIV positive infants’ mothers were ‘badly affected, upset, disappointed, really hurt, feeling sad or bad……..’ Majority of the participants have not thought about carrying out the HIV test in their child at the time of the study. This attitude reflects the poor health seeking behaviour of most mothers towards the care offered to their children when they are obviously at risk of HIV infection. The level of knowledge varied from one participant to the other. Majority of the participants wish to know more about infant HIV infection and EID.

The knowledge of the benefits of ARVs is good among the participants. Though the level of knowledge vary from good to lack of knowledge; majority of the participants have good knowledge of the benefits of using ARVs. Only few demonstrated poor knowledge of ARVs in infants.

The participants were willing to test their child for HIV though on another day. The reactions to waiting for the result include being unable to sleep, feeling very nervous and asking themselves many questions about the possibilities. This finding is similar to findings from

Lazarus et al. 2009. Nearly all the participants were willing to come for the result if the child were to be tested immediately. They pointed to their curiosity and desperation to know the status of their children as the motivation to return on the appointment date. However, the reality of what happens following the PCR test in infant suggest that high percentage of mothers do not come back to fetch results (Meyer et al. 2007; Hassan et al. 2010).

Majority of the participants recognized that it is beneficial to test children early. They were willing to recommend the test to other children in the community. However some women do not feel strongly about recommending infant diagnosis in their community because people might perceive that they are HIV positive or they might be implying that the other children are HIV positive. The fear of community members knowing their status is the reason for not choosing to tell others about early infant HIV diagnosis.

5.3 STRENGTH AND LIMITATION OF THE STUDY

The research study focused on exploring the knowledge of mothers to HIV infection in infants, early HIV diagnosis in infant, intervention with ARVs and attitude to knowing the status of their children. The process of the research and the findings demonstrated a well conducted qualitative study. The study made use of in-depth interviews and the result was then triangulated with two focus group discussions to validate the findings. The strength of this study is supported by the fact that it is one of the pioneer studies on this topic from Eastern Cape, South Africa. The study provides insight to the challenges of the early infant diagnosis programme in South Africa. The study highlights the direction for the integrated approach to PMTCT/EID programme. There is urgent need to expand PMTCT training and ante-natal counselling to accommodate EID.

The limitations of qualitative study with regards to representivity and generalizability of findings to other population is well understood by the researcher. There can be no doubt that necessary precautions were taken to reduce bias through variation in the conduct of the interviews (interviewer's bias) or reactive effect of the participants.

5.4 RECOMMENDATIONS

Recommendations are made against the objectives that were formulated to assist the study to focus on the propose problem statement.

5.4.1 PMTCT training - early infant diagnosis

The National Department of Health, Provincial Department of Health and Local Health Authorities need to review the curriculum of PMTCT training to inculcate the training on the early infant diagnosis. The study confirmed most mothers attend ante-natal care and PMTCT training. This is an opportunity to empower women during pregnancy, post-delivery and at post-natal clinics. Mothers have fears about open disclosure of their HIV status through HIV test of their children. This fears need to be addressed through EID trainings. The time of EID, benefits of the test, need for early initiation of HAART and benefits of follow up clinics are themes that must be covered in a new look PMTCT training.

5.4.2 Training of counsellors

The study showed the PMTCT counsellors are crucial to the success of any information and education programme. The counsellors in every health facilities across the country need refresher courses on the content of EID curriculum. EID curriculum must be inculcated into the practice of counsellors. They must be supported with drawings, charts, and evidence of the benefits of early diagnosis.

5.4.3 Training of nursing staffs

Every HCW involved in the management of pregnant woman and the newborn should undergo training on EID. Every HCW must be an agent of change in identifying HIV exposed infant and bring them for test. The government must invest in awareness campaign on EID all over the country**.** HCWs must be empowered to make the difference wherever they may be working.

5.4.4 Community mobilization

The study revealed the reluctance of mothers to lead the battle of community mobilization towards universal coverage of early infant diagnosis. Therefore, strategic decisions are

urgently needed to mobilize the community towards recognizing the benefits of early infant diagnosis. One of the participants recommended that the Government should take the lead to empower the community with information leading to change of attitude.

5.4.5 Integration of infant diagnosis to immunization schedule

There are pointers indicating that the integration of HIV test to the six week immunization schedule is the direction to go in identifying all HIV exposed and infected infants. These infants can be followed up through comprehensive package of care for the HIV positive and nutritional support for the HIV negative. The integration of the two programmes is the pathway to the promise land of achieving zeros of infection and mortality of infants from HIV related illnesses.

5.4.6 Expansion of infrastructure

Early infant diagnosis programme require investment from the department of health and health authorities. More personnel and equipment will be needed to deal with the large population of HIV exposed infants across the country. Media outlets should be utilized to create the public awareness. Mobile units should be constructed to reach the nooks and crannies of the country where there are no health facilities.

5.4.7 Development of point of care test for EID

There is urgent need for science to develop same-day technique of diagnosing HIV in infants. Similar to the rapid test in adults, the dropout rate associated with DNA-PCR can be reduced to 0% if there is a point of care (same-day) test. This is a future direction for paediatric HIV care.

5.5 CONCLUSION

The objective of this study is to assess the knowledge and the attitude of HIV positive mothers to early infant diagnosis with a view of making strategic recommendation on how to expand the services. This qualitative study explored the in-depth knowledge and attitude of mothers to knowing the status of their babies. The findings from this research corroborated a number of studies on related issues and brought to the fore the inadequate knowledge of

mothers about early infant diagnosis. The findings from this project provide a framework to strategize on dealing with diagnosing all cases of infant HIV infection before the onset of clinical events. The research findings satisfactorily answered the research question. The study, however, did not find out how much maternal knowledge of infant HIV infection will lead to behavioural change in attitude of the mothers towards accepting early infant diagnosis.

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APPENDIX A: INTERVIEW SCHEDULE FOR MOTHERS (ENGLISH VERSION)

OPENING

After providing each participant with information sheet written in Xhosa, I shall arrange the interview sessions on the selected participants. The interview will cover three main themes:

A. Demographic details (except the name)
B. Knowledge about early infant HIV diagnosis
C. Attitude to early infant HIV diagnosis

The interview should take 30 to 40 minutes.

The interview will be semi-structured, guided by the following kinds of questions:

A. **DEMOGRAPHIC DETAILS:**

1. Age of the mother and the child
2. Number of children alive and dead
3. Marital status of the mother
4. Level of education
5. Employment status
6. Time of diagnosis of HIV in mother and HAART initiation.

B. **KNOWLEDGE QUESTIONS**:

1. How much do you know about HIV infection in children?
2. How can HIV infection in children be prevented?
3. What could be the effect of HIV infection in children if not treated early?
4. How can we know that a baby is having HIV infection?
5. When should HIV infection in children be diagnosed and why?
6. When should anti-retroviral drugs be commenced in children and why?

C. **ATTITUDE QUESTIONS**:

1. Have you ever thought about bringing your child to the clinic for HIV test?

2. Are you willing to do HIV test on your child now?
3. Do you have any fears about doing HIV test on your child?
4. What will be your expectations in the next two weeks while waiting for the HIV result of your baby?
5. Will you be returning for the result of your baby's HIV test in two weeks from today?
6. HIV exposed children attending immunization clinics at six weeks should undergo mandatory testing for HIV; rate your attitude to the issue of early infant HIV test on Likert Scale:

1. Strongly disagree

2. Disagree

3. Indifferent

4. Agree

5. Strongly agree

UDLIWANO NDLEBE NO MAMA (XHOSA VERSION)

INGCUKACHA NGAWE:

1. Iminyaka kamama neyomntwana
2. Inani labantwana abaphilayo nabaswelekayo
3. Utshatile okanye awutshatanga
4. Ufunde waphela kwibanga lesingaphi
5. Uyaphangela okanye awuphangeli
6. Uzazi kowuphi unyaka ukuba unesandulela ngculaza

ULWAZI

1. Lungakanani ulwazi onalo ngesandulela ngculaza ebantwaneni?
2. Singathintelwa njani isandulela ngculaza ebantwaneni?
3. Ingayintoni iziphumo zokunganyangwa kwangoko kwesandulela ngculaza ebantwaneni?
4. Singayazi njani ukuba umntwana unesandulela ngculaza?
5. Leliphi ixesha elivumelekileyo umntwana angahlolwa ngalo isandulela ngculaza?
6. Leliphi ixesha umntwana angaqala ukunikwa izithomalalisi zesandulela ngculaza, khona ibe iyintoni izizathu zokunikwa kwazo?

INDLELA OZIVANGAYO

1. Wawukhe wakucinga ukuzisa umntwana wakho kwiziko lezempilo ukuzo kuhlolwa isandulela ngculaza?

2. Ingaba uyakungwenela ukuba umntwana wakho ahlolwe isandulela ngculaza ngoku?

3. Ingaba unalo uloyiko ekuziseni umntwana wakho azohlolwa isandulela ngculaza?

4. Ingaba zintoni oyakube uzilindele kwiveki ezimbini oyakube ulinde ngazo iziphumo zesandulela ngculaza zomntwana wakho?

5. Ingaba uzobuya uzokuthatha iziphumo zesandulela ngculaza zomntwana wakho ukusukela namhlanje ukuya ezivekini ezimbini?

6. Bonke abantwana abahamba uthintela abasemngcuphekweni wokosuleleka sisandulela ngculaza kufaneleke ukuba bahlolwe isandulela ngculaza? Ingaba uziva njani ngalonto?

- Ungqinelana nayo kakhulu
- Uyala
- Awuyihoyanga
- Uyavuma
- Awunqinelani nalonto kakhulu

Elovala: ungakucebisa ukuhlolwa kwesandulela ngculaza kubantwana benginqi ohlala kuyo?

APPENDIX B: PATIENT INFORMATION LEAFLET (ENGLISH & XHOSA)

Dear Participant,

RE: MATERNAL KNOWLEDGE AND ATTITUDE TO EARLY INFANT HIV DIAGNOSIS

In partial fulfilment of the requirements of the Master of Philosophy Degree in HIV/AIDS Management from the Africa Centre for HIV/AIDS Management at Stellenbosch University. I am carrying out the study with the above title. The information you will provide is for academic purposes. All information obtained in the course of the study will be treated with privacy and confidentiality.

The study will assess the level of knowledge of HIV positive mothers and their attitude to the diagnosis of HIV infection in their children as early as six weeks of life. The study will be conducted with in-depth interview and focus group interview. I intend to find out if mothers have adequate knowledge about early infant diagnosis of HIV infection and if more counselling sessions are needed to encourage voluntary testing of infant of HIV positive mothers. The study will find out whether mothers are aware of the benefits of early diagnosis versus late diagnosis and appropriate time of diagnosis of HIV infection in children. The study will assess the attitude of the participants and the demographic characteristics that may predict good or bad attitude toward early infant HIV diagnosis.

The aim of the study is to establish the level of maternal knowledge and attitude to early infant HIV diagnosis in Mthatha, South Africa in order to gain in-depth understanding of how to formulate strategies on expanding early infant diagnosis of HIV.

The objectives of the study are**:**

1. To assess the level of knowledge of HIV positive mothers on early infant HIV diagnosis.

2. To evaluate the attitude of HIV positive mothers to early infant HIV diagnosis.

3. To make recommendations based on the findings to the department of health on strategies to address the expansion of DNA-PCR test.

Please feel free to contact me should you have any questions or you need clarification.

Thank you.

Yours sincerely,

18/06/2012

_____ _____

Signature of Investigator **Date**

Xhosa Version

Molo mthathi ngxaxheba,

KUJONGWA: ULWAZI NENDLELA ABAZIVA NGAYO OMAMA NGOKUHLOLWA KWANGOKO KWESANDULELA NGCULAZA KUBANTWANA ABASELULA

Esi sisifundo esingaqgibekanga ngokupheleleyo sokubaselungelweni lokufumana imfundo enomsila (Masters) kwindlela yobom neyokulawula isandulela ngculaza ne ngculaza uqobo embindini we Afrika, yenzelwa indlela yokulawula ingculaza kwisikolo samabanga aphakamileyo e Stellenbosch. Ndenza esisifundo phantsi kwesisihloko singentla. Zonke ingkcukacha oyakundinika zona ziyakusetyenziselwa izifundo eziphakamileyo kuphela. Zonke ingkcukacha oyakuthi uzibuzwe zizakuhlala zikhuselekile yaye zifihlakele.

Esisifundo sizojonga ubungakanani bolwazi nendlela abaziva ngayo omama abanesandulela ngculaza ngokuhlolwa kwangoko kwesandulela ngculaza ebantwaneni abaselula, abaneveki ezintandathu kuphela bezelwe. Isifundo sizokwenziwa ngokuba kuqhutywe uphando nzulu ngodliwano ndlebe, nodliwano ndlebe neqela lomama. Ndizimisele ukufumanisa ukuba ingaba omama banolwazi olwaneleyo na ngokuhlolwa kwesandulela ngculaza kubantwana abaselula, Nokujonga ukuba ingaba isikolo sokulungisa ingqondo yabo siyafuneka na ukubakhuthaza omama abanesandulela ngculaza ukuba bahlole isandulela ngculaza kubantwana babo beselula. Isifundo sizofumanisa ukuba ingaba omama bayawaqaphela na amaqithiqithi okuhlola umntwana kangoko eselula nokumhlola kade sele-emdala, sijonge nokuba bayaliqaphela na ixesha elilungileyo lokuhlola isandulela ngculaza emntwaneni. Isifundo sizakuvavanya indlela aziva ngayo umthathi ngxaxheba nobume bakhe, obuzoncedisa ekuqikeleleni indlela elungileyo nengalunganga aziva ngayo ngokuhlolwa kwesandulela ngculaza emntwaneni eselula.

Injongo yesifundo kukufumanisa ubungakanani bolwazi nendlela abaziva ngayo omama ngokuhlolwa kwesandulela ngculaza kubantwana beselula kwi sixeko sase Mthatha, kwiphondo lase South Africa ukuze sifumanise ulwazi ngokunzulu lokuba zintoni ezingenziwa ukwandisa ukuhlolwa kwesandulela ngculaza ebantwaneni beselula.

Injongo zesifundo zezi zilandelayo:

1. Ukujonga ubungakanani bolwazi komama abaphila nesandulela ngculaza ngokuhlolwa kwesandulela ngculaza kubantwana beselula.

2. Kuvavanywa indlela abaziva ngayo omama abanesandulela ngculaza ngokuhlolwa kwesandulela ngculaza kubantwana beselula.

3. Ukucebisa ngokuthathela kwiziphumo, kwicandela lezempilo ngezinto ezinokwenziwa ukwandisa ukuvavanywa kwe DNA-PCR.

Zive ukhululekile ukundithinta xa unombuzo okanye kukhona into ofuna ukucaciselwa kuyo

Enkosi,

Ozithobileyo,

.....

Dr Adeniyi, O.V. (Umphandi)