Factors Influencing Utilization and Adherence to Prevention of Mother to Child Transmission of HIV/AIDS Services in Rivers State, Nigeria

By

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DEDICATION

This PHD study is dedicated to my parents late Lt. Col. Mustapha M. Jumare and Mrs Furera Isma Jumare who inspired me to be the best I can be since childhood. Thank you mama for your support both financially and morally.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	**Acquired Immune Deficiency Syndrome**
ARV	**Antiretroviral Therapy**
HIV	**Human Immunodeficiency Virus**
ANC	**Antenatal Care**
NGO	**Non-Governmental Organization**
WLWHA	**Women Living with HIV/AIDS**
PMTCT	**Prevention of Mother to Child Transmission**
UNAIDS	**United Nations Program on HIV/AIDS**
UNDP	**United Nations Development Program**
UNICEF	**United Nations Children Education Fund**
USAID	**United States Agency for International Development**
HCT	**HIV Counseling and Testing**
WHO	**World Health Organization**
MTCT	**Mother to Child Transmission**
PMTC	**Prevention of Mother to Child Transmission**

ABSTRACT

Effectiveness of services for Prevention of Mother to Child Transmission (PMTCT) of Human Immunodeficiency Virus (HIV) depends on viable and efficient health systems, adherence to and utilization of services. Despite strategies to provide access to PMTCT of HIV services, utilization of these services remain low in Nigeria thereby increasing child morbidity and mortality from HIV-related causes. Adherence to comprehensive HIV/AIDS care, for both the mother and baby, remain a challenge for HIV positive women. Utilizing the Health Belief Model and Social Support Theory, this qualitative study explores factors influencing utilization and adherence to PMTCT services by mothers living with HIV/AIDS in Rivers State, Nigeria. Purposive sampling procedures were used to select 40 study participants including 20 HIV positive mothers and 20 health care workers as key informants. Findings indicate that high self-perceived susceptibility to HIV influences utilization and adherence to PMTCT services among mothers living with HIV and AIDS in Rivers State. Although utilization and adherence to PMTCT were reported very high among this population, there were however challenges and barriers to optimal utilization of PMTCT. These include unavailability of test kits, antiretroviral medication stock-outs, and inadequate human resources for health. High transport, PMTCT and antenatal care costs were identified as the major socio-economic barriers to PMTCT administration as well as the high financial burden of formula feeding for women that preferred exclusive formula feeding. In addition to increased numbers of health care workers trained in PMTCT service delivery, recommendations for a public health approach to service delivery and a streamlined primary care strategy are proposed. These include social and community activities to address HIV/AIDS stigma, improving awareness of PMTCT facts, addressing gender relations and encouraging male participation. Inter-ministerial collaborations and targeted partnerships are also recommended for expanding coverage and ensuring optimal utilization of PMTCT services.

CHAPTER 1

INTRODUCTION

This chapter presents the background and context to the study including the global HIV prevalence with specific reference to the prevalence among women and children in Nigeria. This is followed by an outline of the National PMTCT guidelines in Nigeria as well as a statement of the research problem. Thereafter, the research aims, objectives and questions are highlighted. The chapter finally discussed reasons why a research of this nature is relevant and clarifies some key concepts.

1.1 Background and Context

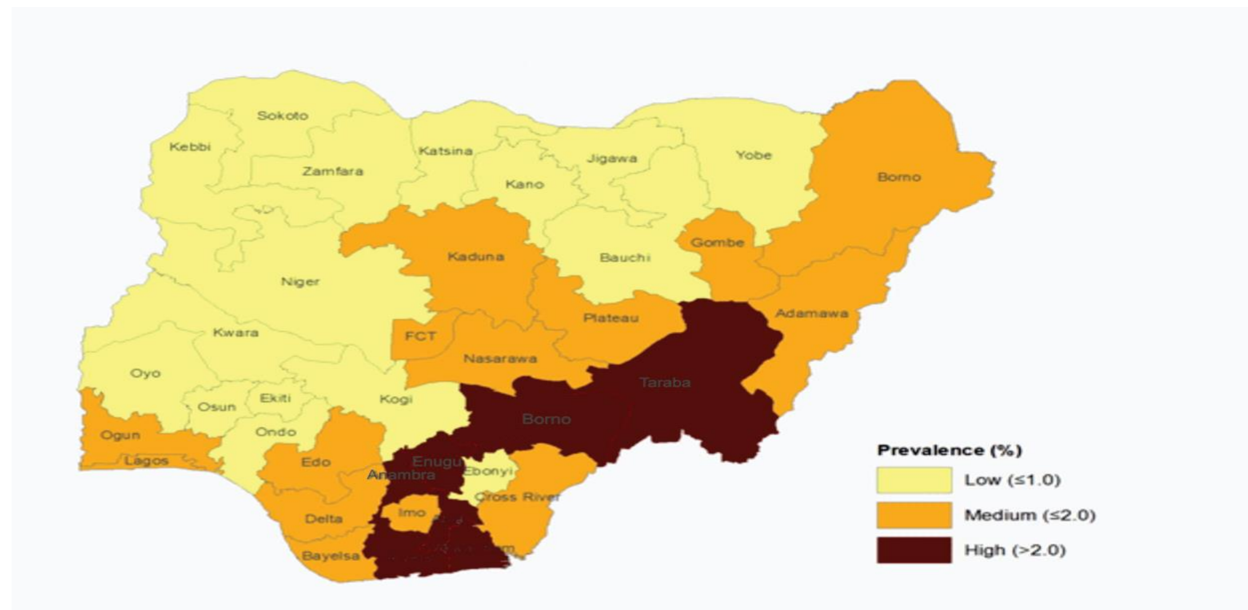
Health development in most of the low- and middle-income countries has been traditionally seen as provision of health care service that is affordable, accessible and of good quality thus improving the health status for the majority of the people (Alubo, 2001; World Health Organization (WHO), 2000). Better health for all has been described as the most important purpose for the existence of a health system. This means that the health system must serve the goals of ensuring better health, responsiveness to the health needs of the people, and achieving fair financing through reduced financial risk to households (WHO, 2000). Health systems are in principle complicated, and varied in practice (Musgrove, 1996).

The spread of the Human Immunodeficiency Virus (HIV) pandemic has been shown to compound the pressure on national health systems by greatly increasing the demand for health services by HIV-infected persons (John-Langba, 2013). HIV has been a threat to social and economic progress of most affected countries and has come to be one of the most serious health and development challenges in the world. As a result of the prevalence of HIV and Acquired Immune Deficiency Syndrome (AIDS) epidemic, modest gains made in maternal and child

survival during previous decades are now adversely being affected (WHO, 2007). In 2017, about 36.9 million people were living with HIV and 1.8 million new infections were recorded worldwide according to the United Nations Program on AIDS (UNAIDS, 2018). About 940,000 pregnant women were living with HIV in 2017 while there were 180,000 children aged between zero and fourteen years who were newly infected in the same year (UNAIDS, 2018). HIV/AIDS is also one of the major causes of disease burden in Sub-Saharan Africa (Dwyer-Lindgren et al., 2017). According to UNAIDS (2018), the region that carries the highest burden of HIV is Sub-Saharan Africa with an estimated 980,000 new HIV infections among adults in 2017. Also, 59 per cent of these new HIV infections in Sub-Saharan Africa in 2017 were women (UNAIDS, 2018).

Nigeria, Africa's most populous country has an estimated 1,900,000 million PLHIV making it the country with the world's highest burden of HIV after South Africa and has a National prevalence rate of 1.4 per cent according to the National Agency for the Control of AIDS (NACA, 2018). According to NACA (2018), females have a significantly higher prevalence rate of 1.9 per cent than men with an estimated 0.9 per cent. The number of new HIV infections was 210,000 in 2017 of which 36,000 were among children. Nigeria comprises 36 states divided into 6 geopolitical zones which have varied HIV prevalence rates as depicted in figure 1.

Figure 1: Distribution of HIV Prevalence by States and Geographic Region



Source: National Agency for the Control of AIDS (NACA, 2018)

The map in figure 1 shows the states with the highest HIV prevalence rates or states with prevalence rates greater than 2 per cent. Based on figure 1, HIV prevalence rates were highest in 7 states namely: Akwa Ibom (5.6%), Benue (4.9%), Rivers (3.8%), Taraba (2.7.5%), Anambra (2.4%), Enugu (2.1%) and Abia (2.1%). There is no regional pattern in these prevalence rates because Akwa Ibom, a state in the South-South region of Nigeria had the highest HIV prevalence rate according to the NACA (2018) followed by Benue State which is in the North Central region. However, NACA (2018) reveals that three states in the South East region are among the 7 states with the highest prevalence rates greater than 2%, while two states were from the South South region with no state from the North West region. These regional divisions reflect varying ecologies and climates, along with differing population characteristics and therefore varied realities of distinct regions, ethnic and religious groups, and a myriad of other factors (Agunwambaet al., 2009).

Heterosexual sexual intercourse which is the leading route of transmission of HIV accounts for about 42 per cent of HIV infections and Mother to Child Transmission (MTCT) accounts for 90 per cent of HIV infections in children (NACA, 2018). With an MTCT rate of 22 per cent in Nigeria, the 2016 National HIV Strategy for Adolescents and Young People 2016-2020 in Nigeria states that MTCT accounts for a fairly high proportion of infections among adolescents aged between 10 and 18 years old (UNAIDS, 2018). Recognizing that based on a UNAIDS (2010) report, an estimated 20% of all global HIV infections and more than 95% of pediatrics HIV transmissions occur as a result of MTCT, the World Health Organization (WHO) developed a comprehensive approach for Prevention of Mother to Child Transmission (PMTCT) of HIV. This is among various tools available to countries for preventing HIV transmission such as condom use, socio-behavioral interventions, blood screening and male circumcision. The WHO guidelines for PMTCT intervention comprise the following services:

i. Antenatal services and HIV testing during pregnancy,
ii. Use of antiretroviral treatment (ARV) by pregnant women living with HIV,
iii. Safe childbirth practices
iv. Appropriate infant feeding,
v. Infant HIV testing and
vi. Other post-natal healthcare services.

Since 2008, the policy and guidelines for PMTCT in Nigeria recommended that pregnant women should be enrolled in early antenatal care where they are offered routine HIV Counseling and Testing (HCT) at the point of registration in antenatal care clinics (Adejumo, Erhunwuse & Oyetunde, 2013). After consenting to PMTCT regimen, women with positive HIV test results are counseled and thereafter enrolled in and offered services like ARV therapy and options for safer

delivery and infant feeding (Adejumo et al., 2013). The mother-infant pairs are then followed from the time of delivery until the baby has reached 18 months postpartum postpartum (Adejumo et al., 2013). With these activities forming the heart of the program, PMTCT was developed in Nigeria and laid down in the National Scale-up Plan towards Elimination of MTCT of HIV, National Policy for HIV/AIDS and the National HIV/AIDS Strategic Plan 2010-2015.

In 2002, Nigeria initiated the PMTCT program in one hospital in each geo-political zone and as at 2012, there were 1352 health facilities offering PMTCT services across the country (NACA, 2013). Table 1 shows some of the guidelines for PMTCT service provision in Nigeria:

Table 1: Guidelines for Comprehensive PMTCT Services in Nigeria

Specific PMTCT Intervention	Guideline
HIV testing and counseling	All antenatal care facilities shall offer HIV testing and counselling for all pregnant women as part of existing integrated reproductive health care services and shall include referrals for family planning counselling and other services when necessary. Testing will be offered routinely with the right to opt-out. **Components of HIV testing include**: i. Pre-test information ii. HIV testing and same day result iii. Post-test counselling iv. Follow-up counselling. **When in labour:** i. Determine HIV test history

	ii. Discuss the benefits of testing and ARV prophylaxis iii. Explain the testing process iv. Offer the test **Post-test counselling for HIV positive pregnant women should include information on the following**: i. Disclosure, partner notification and testing ii. Benefits of PMTCT intervention iii. ARV iv. Nutrition v. Delivery vi. Infant feeding vii. The need for follow-up and adherence
HIV and Infant feeding counseling	All maternity facilities shall provide counselling on risks associated with possible MTCT during pregnancy, delivery and breast feeding and adequate information to limit MTCT if the mother is HIV positive, including referrals for family planning services.All HIV infected mothers should be encouraged to exclusively breastfeed their babies for the first 6 months, after which complementary feeds are introduced and breastfeeding continues for up to

	12 months. Breastfeeding should be accompanied with maternal ART or ARV prophylaxis and infant ARV prophylaxis.
Modification of obstetric practices	When a woman is known to be HIV positive or is diagnosed as HIV positive during pregnancy, her obstetric and medical care will need to be strengthened and modified.
Administration of Antiretroviral (ARV) prophylaxis to mother-child pair	Pregnancy in the HIV positive woman is an indication for ARVs irrespective of CD4, VL or clinical stage The time to commence and ARV choice depend on the clinical setting: **Use of Anti-retroviral drugs for therapy (ART)** ART should be initiated in HIV positive pregnant women based on the following criteria: a. CD4 Count ≤ 350 irrespective of WHO clinical staging b. WHO AIDS Stages III & IV disease, irrespective of CD4 cell count. **Use of Anti-retroviral drugs for prophylaxis** ARV prophylaxis should be provided for HIV positive pregnant women who do not meet above criteria. They include women with WHO Stages I & II AIDS with CD4 of >350cells/ml.

	All infants irrespective of type of feeding should receive: Daily NVP from within 72 hours of birth to 6 weeks of age: For babies with weight <2,500g, give NVP 10mg or 1ml once daily while for babies with weight ≥2, 500g, give NVP 15mg or 1.5ml once daily.

Source: Federal Ministry of Health, (2010, p.7)

In 2016, the PMTCT guidelines were updated to provide for administration of ART to all HIV positive pregnant women irrespective of their WHO clinical stage and CD4+ cell count as opposed to the previous practice of providing ART only for those with CD4 Count ≤ 350 irrespective of WHO clinical staging and WHO AIDS Stages III & IV disease, irrespective of CD4 cell count (Federal Ministry of Health, 2016). The new guidelines have also strengthened the provisions on family planning services to include offering contraception including emergency contraception to all HIV positive mothers in the immediate postpartum period to prevent unintended pregnancy. These PMTCT guidelines also form part of the national strategic plan for HIV/AIDS outlined by Federal Ministry of Health and NACA (2017), particularly the goal that seeks to Integrate PMTCT services by ensuring the provision of one-stop access to ANC, eMTCT, MNCH and family planning services. While the PMTCT guidelines provide specific interventions that must be followed by health facilities, the strategic plan sets out targets and general interventions activities that the guidelines must rely on.

The uptake of PMTCT interventions reflects both capacities of clinics to provide PMTCT services and acceptability of the intervention to clinic attendees (USAID, 2002). This study is

concerned with the demand for and uptake of PMTCT services. Despite improvement in coverage of these services, progress is insufficient because women and children either do not receive the services or are lost to the system before completion of treatment. However, studies have always focused on access to the services without considering their use and adherence by HIV positive women. Some studies have showg that cultural and ideological factors can influence access and utilization of health services (Standing, 1997). Specifically, the most difficult barriers to slowing the spread of HIV/AIDS originate from the negative perceptions about HIV that result in shame or ostracism and the stigma faced by people with HIV/AIDS (Israel & Kroeger, 2003). Due to gender related factors such as inequality, vulnerability and dependency, women are often exposed to social ostracism and marginalization which often restricts their access to much needed information and services (Gupta, 2002). In particular, women's relationships with their partners may affect their abilities to undergo Voluntary Counseling and Testing (VCT) and adhere to infant feeding choices (Israel & Kroeger, 2003). Standing (1997) adds that utilization of health services by women is inhibited by their inability to act freely without permission from their husbands or senior kin and the fact that health needs of women and girls are often under-valued (Key, 1987; Tipping & Segall, 1995, as cited in Standing, 1997).

Research conducted on women's inequality in economic opportunities have provided a useful basis for an enquiry into utilization of PMTCT services such as those conducted by Barret, (1995); Wilkinson (1996) and World Bank (2001). These studies have failed to link the issues of gender with the PMTCT guidelines to track the specific stages where HIV positive women drop out of treatment. Most of the current literature on utilization of PMTCT services consider only aspects of PMTCT instead of providing analysis of PMTCT use and adherence in its totality as provided in the Nigerian Guidelines and Strategic Plans. Furthermore, little attention has been paid

to social support and health belief models as explanatory variables for PMTCT utilization and adherence. For example stigmatization of HIV positive women may cause weakening support which according to Hill, Maman, Grove and Moodley (2015) is an integral health component of the adolescent mother-child pair during pregnancy and postpartum. For example, a woman who plans to cease breastfeeding at 6 months may choose to carry on breastfeeding due to the fear that members of her community will develop negative reaction towards her for rapidly ceasing exclusive breastfeeding at six months (Thorsen, Sunby & Martinsen, 2008).

Given that social support is important for the well-being of HIV positive women, there is need to better understand the crucial role played by partners, families and communities and how they either provide or fail to avail support to HIV positive women during pregnancy or in their postpartum period (Hill et al., 2015).

1.2 Statement of the Research Problem

The distribution of PMTCT services in health care facilities of many developing countries is not wide and in countries like Nigeria, the level of utilization is often low (Ekanem & Gbadegesin, 2004). Among women from resource-poor settings, utilization of PMTCT services is unacceptably low as demonstrated by some research studies (WHO, 2008; Avert, 2009).

Studies have also revealed that utilization of some PMTCT services such as Voluntary Counseling and Testing (VCT) and infant feeding have proved challenging for some women (Israel & Kroeger, 2003). In the 20th international Acquired Immune Deficiency Syndrome (AIDS) conference 2014 held in Melbourne Australia, it was revealed that even in high income countries, a significant proportion of PLHIV continue to present late for treatment, thereby reducing the effectiveness of ART on preventing HIV infection and consequently morbidity and survival. In many circumstances, immediate enrolment in care is hindered because women who are informed

of their HIV-positive status are not adequately linked with appropriate services (WHO, UNICEF & UNAIDS, 2011).

Furthermore, a NACA (2014) PMTCT communication strategy highlighted the barriers to PMTCT service provision in Nigeria which centered on pregnant women's low motivation to use PMTCT services thereby contributing to increase in HIV positive babies, infant morbidity and mortality. In developing countries, governments and donors have invested substantially towards PMTCT implementation but there are still HIV positive women who fail to return to clinics for follow-up visits and others who do not adhere to the ARV drug treatments prescribed for them (Adejumo et al., 2013).

Reliable figures for PMTCT utilization rates in Nigeria are not available but reports have shown that despite adopting PMTCT guidelines stipulated by the World Health Organization (WHO), the percentage of women who were counseled and tested for HIV in 2016 was only 34.7 per cent. Similarly, the percentage of pregnant Women Living with HIV (WLWHA) who received Antiretroviral Treatment (ART) for PMTCT in Nigeria was only 32 per cent (NBS & UNICEF, 2017). Given a corresponding MTCT rate of 22 per cent as reported by (UNAIDS, 2018), an ART enrollment rate of 32 per cent is quite low. Therefore understanding PMTCT service adherence and utilization is crucial especially in the context of Nigeria where discriminatory social structures and stereotypes are entrenched in communities and where women's level of autonomy in seeking health care is often restricted by family members.

1.3 Rationale and Significance of the Study

Policy makers and health practitioners involved in providing PMTCT services are faced with some challenges in implementation of PMTCT guidelines (Nuwagaba-Biribonwoha, 2007; Pai, 2009;

Willan, 2004 & Chopra, 2009). Findings from this study will enable health managers to spot concerns of women who are rejecting PMTCT services and resolve their needs. This will aid in ensuring that PMTCT is integrated into the programming of sexual and reproductive health as well as promote fair distribution of health services in Nigeria (United Nations Children's Fund, 2012). Subsequently, this may contribute to improved maternal health, child survival and support for Nigeria's effort to implement the National PMTCT program of 2010-2015 (Federal Ministry of Health, 2013).

The U.S. President's Emergency Plan for AIDS Relief (PEPFAR), acknowledged that PMTCT is significant for keeping WLWHA alive through treatment, ensuring that the life of their babies are saved and aids in the protection of her other children from becoming orphans (UNAIDS, 2010). This triple benefit characterized by PMTCT, will only be enjoyed by Women Living with HIV/AIDS (WLWHA) who are using and adhering to PMTCT services. Understanding PMTCT utilization and adherence patterns at each stage of the PMTCT guideline would play a large part in maximizing the efficacy of biomedical approaches to HIV prevention. Also, the unmet need for healthcare is a startling threat to WLWHA and their quality of life. As such, health care utilization as a critical element of wellbeing and a component of human capital is of major interest to social development.

1.4 Aim and Objectives of the Study

This study is aimed at exploring factors that influence PMTCT service utilization and adherence by Women Living with HIV/AIDS (WLWHA) in Rivers State, Nigeria. The objectives of this study are to:

1. Understand the nature of adherence and utilization of PMTCT in Rivers State, Nigeria;

2. Examine factors that influence decisions of women living with HIV/AIDS to utilize PMTCT services;
3. Examine factors that influence adherence to the PMTCT services by women living with HIV/AIDS;
4. Identify the barriers and challenges to adherence and utilization of PMTCT services.

1.5 Research Questions

1. What is the nature of PMTCT service adherence and utilization in Rivers State, Nigeria?
2. What are the factors influencing decisions of women living with HIV/AIDS to utilize PMTCT services?
3. What are the factors influencing adherence to PMTCT services by women living with HIV/AIDS?
4. What barriers and challenges do WLWHA face in utilizing PMTCT services and adhering to PMTCT regimen?

1.6 Main Assumptions

This study assumes that the Nigerian society is not culturally liberal. As a result, women experience stigma resulting from radical religious and cultural beliefs. This affects adequate utilization and adherence of women living with HIV/AIDS to PMTCT services. Additionally, it is assumed that women often view themselves as inferior and the involvement of male partners of women living with HIV/AIDS in PMTCT programs is low. This makes the social support systems in Nigeria weak. Also, the beliefs and perceptions of women living with HIV/AIDS about the efficacy of PMTCT and the support they receive from family and community influence their decisions to utilize and adhere to PMTCT services.

1.7 Clarification of Concepts

Human Immunodeficiency Virus (HIV). HIV is a virus that infects the CD4 cells which are certain types of white blood cells and monocytes/macrophages which have important functions in the immune system (Pinsky & Douglas, 2009). This research is concerned with women who have tested for HIV that are found to be positive and when they found out their HIV status.

Acquired Immunodeficiency Syndrome (AIDS). This occurs when HIV causes a pattern of devastating infections that attack and destroy the CD4 cells that have essential functions in the body's immune system (UNAIDS, 2000). This research considers AIDS as the clinical stage of HIV positive women when the disease has progressed to the most advanced stage.

CD4+ Cells and CD4 Count. "The CD4 T lymphocytes; a subpopulation of the lymphocytes also known as T helper cells, are coordinators of the body's immune response and provide help to B cells in the production of antibody, as well as in augmenting cellular immune response to antigens" (WHO, 2007). CD4 cell count is "a laboratory test that measures the number of CD4+ T lymphocytes (CD4+ cells) in a sample of blood. It is used to predict HIV disease progression and it is one of the factors used to determine when to start antiretroviral therapy (ART)" (Harvey, 2013, p.1). CD4 count in this research is an indicator of adherence and utilization of ARV drugs for PMTCT. It also includes whether a WLWHA checks her CD4 count and how often she checks.

Antiretroviral (ARV) drug. "ARV drug is used to prevent a retrovirus, such as HIV, from replicating. The term primarily refers to drugs used in the treatment or prevention of HIV" (Harvey, 2013, p.1). The Nigerian PMTCT guideline of 2010 provides that an indication for treatment with ARV is that a HIV positive woman is pregnant irrespective of her CD4 count (Federal Ministry of Health, 2010). This research is concerned with the length of time a WLWHA

has taken ARV drugs, how often she takes it and whether she takes the required doses without skipping.

Antiretroviral Therapy (ART). This refers to the use of a combination of drugs that are preventive and therapeutic to fight off tuberculosis and other diseases which are considered common opportunistic infections that are prone to HIV-infected persons (UNAIDS, 2000). This study applies the Nigerian PMTCT guidelines which provides that when a HIV positive woman is pregnant, ART should be initiated based on the following criteria:

i. "CD4 Count ≤ 350 irrespective of WHO clinical staging

ii. WHO AIDS Stages III & IV disease, irrespective of CD4 cell count while,

iii. ARV prophylaxis should be provided for HIV positive pregnant women who do not meet above criteria. They include women with WHO Stages I & II AIDS with CD4 of >350cells/ml" (Federal Ministry of Health, 2010, p.37). This research is concerned with the length of time a WLWHA has taken ART, how often she takes it and whether she takes the required doses without skipping.

HIV Counselling and Testing (HCT). HIV testing determines the HIV status of a person by carrying out a blood test (Pinsky & Douglas, 2009). HIV counselling is the practice whereby health care providers and clients engage in a confidential dialogue to inform clients with information about HIV and its risks of transmission to enable them make informed decision before getting tested for HIV (Federal Ministry of Health, 2010). This research considers HCT as the first step to PMTCT utilization and an indicator of how informed pregnant women are about their HIV status as well as their ability to take actions that will prevent transmission to their babies. The research also considers whether WLWHA have disclosed their test results to their partners or any family member.

Mother-to-Child Transmission (MTCT). MTCT of HIV is when a child acquires HIV from a HIV-positive mother either at the antenatal, labour, delivery or postnatal stage while breastfeeding the child (Federal Ministry of Health, 2010). In the context of this research, MTCT is an indication of poor adherence to ARV drugs or ART and failure to act on recommendations of health care providers.

*Prevention of Mother-to-Child Transmission (PMTCT***)**. This is the provision of ARVs to pregnant women as either prophylaxis or therapy throughout their pregnancy, during labour and breastfeeding to ensure that their babies are HIV-negative (Federal Ministry of Health, 2010). Infants born to mothers who are not taking ARVs during the breastfeeding period should be administered ARV prophylaxis for one week after all breast-feeding has been ceased (Federal Ministry of Health, 2010). Other important measures outlined by the Federal Ministry of Health (2010) include avoiding "obstetric procedures such as chorionic villus sampling, external cephalic version, early artificial rupture of the membrane, instrumental delivery and episiotomy where possible, as well as active management of the third stage of labor and the use of elective caesarean delivery" (Federal Ministry of Health, 2010, p.3). In addition to these, PMTCT in this study consists of the continuum of care given to a HIV positive woman from the first antenatal care visit, throughout pregnancy and breastfeeding period. These include: HCT, provision of ARV drugs to the mother infant pair at post-delivery stage, exclusive breastfeeding of infant for 6 months as well as infant follow-up until 18 months post-delivery.

Exclusive Breastfeeding. This is when infants are not given any other food or liquid including water during the first six months after delivery with the exception of medicine, vitamin syrup and oral rehydration solution (Khanal, da Cruz, Karkee, & Lee, 2014). In Nigeria, all babies born to HIV-positive mothers are encouraged to be exclusively breastfed and during this period,

the mothers and their babies should be receiving maternal ART or ARV prophylaxis and ARV prophylaxis for the infant (Nigerian Ministry of Health, 2010). Based on this requirement, this research considers exclusive breastfeeding as the length of time a HIV positive mother provided her infant with only breast milk, whether she introduced any food or liquid at some point and when she completely stopped breastfeeding.

Exclusive Replacement Feeding. Replacement feeding means that during the first 6 months after delivery, HIV-positive mothers choose to not breastfeed at all. The infant is only given foods and liquids other than breast milk such as commercial or home-prepared infant formula and micronutrient supplements (Sethuraman, et al., 2011). This research considers exclusive replacement feeding as the length of time a HIV positive mother provided her infant with foods and liquids other than breastmilk and whether she introduced breastmilk at any point.

Mixed Feeding. This is when an infant is initially being breastfed but is soon taking supplementary feeds, water or drinks before 6 months after delivery (Saadeh, Henderson & Vallenas, 2005). Compared to exclusive breastfeeding, this method of infant feeding is said to be associated with a higher risk of HIV transmission to the infant (WHO, 2005). In this research, the length of time of exclusive breastfeeding and the time of initiation of supplementary foods are considered.

Utilization of PMTCT. Utilization of a health service is defined as how much of a particular health service or services are used by a given population in a specific period of time (Pérez-Cuevas, Doubova, Flores-Hernández & Muñoz-Hernández, 2012). This study defines utilization of PMTCT as:

- Visit to health care facility for antenatal care;
- Taking HIV test;

- Health facility delivery.

Adherence. This is referred to as the act of "taking medications exactly as prescribed or following a specific plan of medical care, such as returning for regularly planned follow-up clinic visits. Poor adherence to an HIV treatment regimen increases the risk for developing drug-resistant HIV and virologic failure" (Harvey, 2013, p.1). This study defines PMTCT adherence as:

- Returning to health facility for VCT results;
- Taking prescribed ARVs;
- Returning for follow-up clinic visits;
- Providing antiretroviral prophylaxis for infants born to mothers living with HIV;
- Practicing either exclusive breastfeeding or exclusive replacement feeding.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter provides a review of studies conducted in various settings with varied socio-economic conditions. Many of the studies on HIV/AIDS and PMTCT were related to gender, adherence and utilization of PMTCT services including studies that illustrate the experiences of women. The chapter discussed factors that influenced utilization of PMTCT in the literature and identified gaps in the literature for further research.

2.2 Impact of HIV/AIDS on Women

Women take the brunt of socio-economic effects of HIV infection and their economic, social and cultural dependence on men makes them vulnerable to HIV infection (Albertyn, 2000).Most women living with HIV/AIDS (WLWHA) who are in their child bearing age face difficult choices about child bearing due to the risk of infecting their children. As care givers, women are usually responsible for dying family members and children who have become orphans because of losing their parents to HIV/AIDS (Albertyn, 2000). In addition, the socio-economic stressors faced by women infected with HIV often exacerbate the negative consequences of HIV which can affect their mental and physical well-being. For example, unemployment and inadequate funds to transport and feed themselves are significant obstacles to mothers' access to care and treatment for their HIV infected children.

These challenges are compounded by the feeling which HIV positive women have that they are no longer attractive or desirable because of their HIV status. They feel a sense of social disapproval of their reproductive rights and often feared that if the community became aware of their HIV status, they could lose custody of their children. In a study conducted by Faithfull (1997) as cited in Modeste and Majeke (2010), HIV infected women were faced with the impact of grief

and feared that they might infect their children through casual contact. Women are also vulnerable to HIV infection because they are often economically, socially and culturally dependent on men. They are therefore likely to face economic and social hardship in the event that they are abandoned by their partners or face violent reactions from them (Modeste & Majeke, 2010).

In some instances, women find it difficult to freely undertake VCT or reveal their HIV status because they know they will be blamed for sexual immorality. For example Pashwana-Mafuya (2008) contend that women are accused by their in-laws of avoiding breastfeeding in order to appear or smell attractive to other men. There is also a belief that the new born baby should be given “isicakati” (traditional drink) as their first feed for a couple of days in order to cleanse the gut immediately after birth and improve the baby’s stools (Pashwana-Mafuya, 2008). These cultural influences on infant feeding choices indicate that some babies born to HIV positive women do not receive nevirapine 72 hours after delivery.

2.3 Gender, Health and Socioeconomic Disparities and HIV/AIDS

“Gender inequalities affect women’s experience of living with HIV, their ability to cope once infected, and their access to HIV/AIDS services” (WHO, 2009, p.xii). There is a close link between gender equity and economic structures (Moss, 2002). International organizations such as the World Bank have promoted gender equity because of the evidence of its positive association with lower fertility, better health outcomes and consequently, economic development (Moss, 2002). The reasons most frequently cited to explain the inequality and disadvantaged situation of women vis-à-vis men are related to low levels of education, employment and income (De los Rios, 1993). For instance a study by Hutchinson and Mahlalela (2006) in Eastern Cape, South Africa found that women who had completed secondary education were five times more likely to use VCT services

than women who had little or no education. Similarly, Medly (2004) cites that illiterate women were not as likely to share their test results with their partners as women with higher levels of education. These authors also found that importantly, stigma affects VCT utilization in females considerably more than it affects males.

Shisana, (2004) asserts that men and women are valued differently. This has a direct implication on how much control and access men and women have over the resources available to them for protecting their health and that of their families. For example, a study in Tanzania found that a potential barrier to accessing VCT services by women is created when they are compelled to discuss testing with their partners while the decision made by men to seek VCTis made independent of others (Gupta 2000). Shisana (2004) outlines examples of trends observed in Lesotho and Swaziland noting that a married woman cannot sign contract for a property without permission from her husband because she is considered a legal minor under the guardianship of her husband while an unmarried woman remains under her father's.

In Mozambique, Shisana (2004) states that wives are subordinates to their husbands who are traditionally the heads of households and their properties are held by their husbands. The wife has no right to enter into commercial transactions with her property unless she seeks his authorization. Similarly, the tradition in Swaziland does not permit a woman to inherit from her late husband and she needs either her husband or male relative in order to access land. How then will women access health services or reveal their results from HIV test their partners or parents? This submissiveness and subordination of women in places like the Swazi society put women at a disadvantage in accessing healthcare services including HIV/AIDs treatment. (Whiteside et al., 2003).

The idea that women are less powerful than men in terms of social, economic and political standing gives the impression that women must obey men or their economic support will be withdrawn. In a study conducted in South Africa by Dunkle et al. (2004) women whose partners were controlling were found to be more likely to say they never used a condom. Since women depend more on others for their security in the longer term, “their risk to HIV increases and consequently their lack of access to treatment especially PMTCT increases” (Standing, 1997, p.2). Therefore apart from economic factors, women’s vulnerability to HIV/AIDS is also attributed to cultural practices and expectations (Shisana, 2004). The consequence of inequality between men and women in cultural, economic, social and political spheres is that the chances of taking HIV/AIDS preventive measures are diminished. Due to the presence of harmful traditional practices, passing legislations that seek to foster good gender relations may not be effective enough to end gender discrimination (Shisana, 2004).

2.4 Global Targets and Strategies for PMTCT

Transmission of HIV from mother to child during pregnancy, labor and breastfeeding is considered as the leading cause of mortality for mothers and babies in Sub-Saharan Africa and has been considered a serious global emergency. Several targets have been set globally for PMTCT of HIV. For example, an entire United Nations General Assembly Special Session (UNGASS) which was held in June 2001 was dedicated to HIV/AIDS. Its declaration on HIV/AIDS issues resulted into a commitment to reduce the percentage of HIV/AIDS infections in infants by 50% in 2010 through ensuring access to essential prevention, treatment and care services for 80% of pregnant women and their children to reduce MTCT (Thorne, Malyuta, Ferencic, Mimica, & Eramova, 2011). More recently, a Geneva consultation held in November, 2010 is committed to achieve

significant improvement in maternal, newborn and child survival through elimination of new HIV infections at birth.

Many studies have outlined strategies for reducing MTCT. For example, Tarakeshwar (2008, p.19) states that "usually integrated within a hospital or a community clinic that provides HIV care, Voluntary Counseling and Testing (VCT) enables interested individuals to learn their HIV status, learn more about HIV, and potentially gain access to HIV care and treatment, if available". Also, attention is being focused in the area of expanding access to VCT in order to achieve efficiency in the roll-out of antiretroviral (ARV) therapy for the treatment of HIV disease and prevention of mother-to-child transmission (PMTCT) (Baggaley, 2001). It is therefore no doubt that the UNAIDS has prioritized promotion of VCT and has made it an essential element in its HIV response strategies (Baggaley, 2001). Other strategies that have recorded measurable improvement in the efficiency of PMTCT program are: the opt-out approach to VCT, providing mothers with ARV as soon as they have been diagnosed and early provision of infant dose (Spensley et al., 2009). In addition, Myer et al. (2017) report viral load monitoring as a key component of ART services in lower and middle income countries and is part of WHO (2016) chapter 4.5.1 PMTCT guidelines. These guidelines emphasize the need to scale up access to routine viral load testing at 6 months, 12 months and then every 12 months thereafter.

The results of a review of PMTCT experience in Georgia conducted by Tsertsvadze et al. (2008) showed that among 14 women who were pregnant and participated partially in PMTCT, 2 children were HIV-infected. There was no case of HIV transmission among 12 pregnant women who were given AZT at around 7 months into the pregnancy and among 32 women who received full prophylaxis therapy. Similarly, Mofenson et al. (2011) used Kaplan-Meier methods to estimate the rate of transmission and rate of death from birth until 2 years postpartum. These rates were

then compared among subgroups defined based on the CD4 cell count and viral load of the mother. Their findings provided evidence that in a resource-limited setting, it is safe and feasible to give a triple-antiretroviral regimen for PMTCT to a HIV positive woman from late pregnancy until she has achieved 6 months of breastfeeding. This approach is part of the biomedical interventions mentioned by Tarakeshwar (2008) for preventing HIV/AIDs from being transmitted to babies during pregnancy or at postpartum. As opposed to biomedical interventions, a more public health approach was proposed by Sam-Agudu et al. (2017). This involves structured mentor mother programs to ensure retention in care and viral load suppression for mothers at postpartum. Using logistic regression model, they found that exposure to structured mentor mother support was associated with higher odds of retention and viral suppression at 6-month postpartum than routine peer support.

Administering ART during and after childbirth also promises to produce the greatest prevention success in PMTCT (Hoffman, 2008). Following delivery, uninfected infants remain at risk of HIV infection via breast feeding. Mothers in industrialized countries who are HIV infected are usually advised to practice exclusive formula feeding so that the risk of HIV transmission from breast milk will be totally eliminated (Hoffman, 2008). Arendt (2007) as cited in Hoffman (2008) argued that the most efficacious way of preventing HIV transmission at postpartum is by advising the mother to use ART through-out the breastfeeding period.

In its recommendation, WHO (2009:xii) outlines that where available, HIV-positive mothers especially for women living with violence should be linked with social and legal services, support groups, income generation and food security schemes/initiatives, home and community-based care programmes and orphan care(WHO 2009). A case of successful implementation of HIV/AIDS responses is exemplified in Brazil’s battle against stigma and discrimination. Brazil

prioritized stigma and discrimination in their response to HIV/AIDS and achieved considerable success through government and civil society partnerships (Berkman, Garcia, Munoz-Laboy, Paiva & Parker, 2005). These responses were buttressed by Vrazo, Sullivan and Phelps (2018) who outlined five related strategies for elimination of MTCT of HIV by 2030 which are mostly public health approaches. A notable public health strategy is the implementation of novel service delivery models such as community treatment groups.

In addition rapid scale-up in the free drug program in São Paulo was achieved through a form of universal distribution which allowed for the creation of numerous more access points to treatment. Brazil's capacity to locally manufacture pharmaceuticals paved way for a financially viable program of universal and free access (Berkman et al., 2005). For these reasons, Brazil's program of universal and free access to ART has been recognized as the best internationally known policy and all public health response to the HIV/AIDS epidemic use it as a model ART roll-out program (Galvao, 2008).

Benatar (2004) argues that countries like Brazil, Uganda, and Botswana have so long provided evidence of exemplary leadership on HIV and AIDS which can be emulated by less successful countries. However, it is necessary to note that interventions found effective in one country may not be equally successful in other countries. For example Muko (2004) argues that although the infant feeding guidelines in HIV/AIDS settings provided by WHO and UNAIDS are quite clear, formula feeding may not be economically and socially viable in the context of low income countries because it entails infectious and nutritional health risks in such areas. In essence, the social, behavioral, biomedical and public health interventions outlined for PMTCT may not be culturally transferable to some settings and the level of infrastructure and resources may not be available.

In a South African study conducted by Sibeko (2005), mothers valued the use of traditional herbal preparations (Muthi) for their new born babies thus hindering the ability to practice exclusive breastfeeding. None the less, the WHO (2010) provides that there is a chance of reducing the risk of MTCT down to between only 2 and 5 per cent if modern PMTCT strategies of testing, provision of ARV, modified obstetric and infant feeding practices are adopted. However, while the developed world which has lower prevalence rates has dropped MTCT to less than 2 per cent with the implementation of universal VCT, ARV prophylaxis, elective Caesarean section, and the avoidance of breastfeeding, Sub-Saharan Africa has the heaviest burden of maternal HIV infection and MTCT suggesting that these strategies, are still limited both in scope and reach in most of the less developed world (FMOH, 2003; WHO, 2010).

2.5 PMTCT Policies and Challenges of the Nigerian Health System

In 1998, the Federal Ministry of Health (FMOH) in Nigeria developed the National AIDS Control Program (NACP) which was expanded in 1991 to include sexually transmitted infections (STIs). The new National AIDS and STDs Control Program (NASCP) developed guidelines on key interventions that seek to manage STIs and HIV/AIDS components such as VCT and PMTCT, ARVs administration, including the treatment of opportunistic infections and home-based care (Nasidi, 2006).

Other programmes developed in Nigeria since the restoration of democracy in 1999 such as National Action Committee on AIDS (NACA) did not have specific focus on PMTCT. It was not until 2003 that the first PMTCT program was initiated. In line with global targets, this programme set out to reduce MTCT by 50 per cent. The AIDS prevention initiative in 2003 and 2004 provided support to 5 of the 11 federally established PMTCT sites (Nasidi, 2006). In 2011,

Nigeria endorsed the Global Plan for PMTCT which aims at ensuring a 90 per cent reduction in new HIV infections and 50 per cent reduction in maternal deaths caused by AIDS(Sagay, 2013).

More recently the National HIV/AIDS prevention plan 2014-2015 was developed. This policy states that in order for prevention strategies of countries to be optimally realized, prevention initiatives must be comprehensive and rolled out in such a way that there is access, frequent use and quality on a national scale (NACA, 2013). However, this policy is undermined by the lack of programmatic approaches that increase utilization and adherence rates and not much effort is made by the Nigerian government to track progress in this respect. A lot of emphasis is placed on access and increasing quality while neglecting the issue of utilization and adherence to the HIV/AIDS services. For example, the policy acknowledged that non-adherence to national testing algorithm was a challenge and committed to addressing the risk factors that disproportionately expose women and girls to the HIV epidemic which emanate from social, economic and cultural barriers.

However, this commitment has not been accompanied by practical strategies for ensuring adherence and utilization. Similarly, the National HIV/AIDS Strategic Plan of 2010-2015 paid little attention to utilization rates. Although antiretroviral coverage was mentioned, effort was not made to track its progress from previous years and to know the utilization and adherence patterns among pregnant women living with HIV. These have undermined Policies on HIV/AIDS and PMTC thereby putting Nigeria among the 21 Sub-Saharan African countries that lag behind global targets with 22 per cent MTCT rate in 2016 and among countries that have the highest number of WLWHA in need of PMTCT services (UNAIDS, 2018).

The primary purpose of the national health system of a country is to improve health and this is achieved by all the organizations, institutions, resources and people responsible for managing it (John-Langba, 2013). Three tiers of government are responsible for providing health

care in Nigeria namely: the federal, state, and local government (Adeyemo, 2005). With support from state ministries and private medical practitioners, 774 Local Government Areas provide primary health care at the villages, districts and local government areas (Omoruan, 2009). Secondary health care is primary health care that is managed by states ministries of health who are also responsible for patients referred from the primary level of the health system. Provision of laboratory and diagnostic services, rehabilitation and other services is done at this level of health care (Osian, 2011). The Federal government in conjunction with voluntary, non-government organizations and private practitioners is responsible for the provision of tertiary health care (Adeyemo, 2005). However in Nigeria, the Primary healthcare (PHC) system which is expected to be the foundation of the country's health system is facing difficulties in providing basic healthcare services to the population. This is due to problems of poor budgetary allocation, decaying and poor infrastructure, poor governance structure, poor service delivery and poor health worker performance (Aregbesola & Khan, 2018).

John-Langba (2013) emphasises that a well-functioning health system delivers quality services to all the citizens of a country at any time and place as needed. This includes a well-trained and adequately paid workforce; reliable information on which to base decisions and policies; well-maintained facilities; and logistics to deliver quality medicines and technologies (John-Langba, 2013). A review of the health care system in Nigeria has shown that over the last decade, there has been huge development in the health care sector although there are a lot of gaps and challenges (Adeyemo, 2005; Omoruan et al., 2009). In Nigeria, the process of drugs procurement has been marred by unavailability, inadequate storage facilities, poor transportation and the presence of unqualified personnel thus hindering the system from achieving its goals (Adeyemo, 2005).

One of the most significant obstacles to progress in providing ART in hospitals is capacity. With current staffing levels in Nigerian hospitals, continuing the roll-out of ART to those already on treatment may not be sustainable because most of the treatment is provided through hospitals. Apart from understaffing, medical equipment, buildings and other basic infrastructure are not sufficient to accommodate the number of people seeking HIV/AIDS related care. This translates to reduction in the quality of services provided to persons living with HIV/AIDS thus hindering the achievement of goal of achieving universal access to HIV/AIDS related care.

Another component of well-functioning health systems mentioned by John-Langba, (2013) is a robust financing mechanism. The public healthcare sector in Nigeria has been faced with the challenges of inadequate funding of hospital pharmacies and the problem of medication and hospital materials being out of stock. Other factors are that doctors pay greater attention to their private clinics and refer patients to private diagnostic centers, bribes-demand by hospital staff, diagnostic tests done even when unnecessary and truancy on the part of doctors and other health workers.

Agboghoroma (2013) further summarized the health system challenges faced by the Nigerian government which have affected the provision of PMTCT services. Firstly, the author noted that the PMTCT program in Nigeria was initiated as a pilot program which was to be executed by tertiary institutions with the intention of decentralizing it to secondary hospitals and primary health care facilities. However, the state and local government levels were reluctant to buy-in thereby slowing down the decentralization process. Challenges of weak health systems; limited human resources especially in rural areas and low utilization of maternal and child health care services have relegated the nation’s health system to the background resulting in high mortality rate and low life expectancy (Agboghoroma, 2013).

Furthermore, despite instituting many programs and projects such as The National Strategic Health Development Plan (NSHDP 2010-2015), the National Health Act (2014), Basic Health Social Scheme (BHSS), Primary Health Care Development Agency (PHCDA), National health outcomes in Nigeria continue to worsen. For example, the most recent report from the WHO database states that Nigeria's Maternal Mortality Ratio (MMR) is 814/100,000 live births which makes Nigeria the worst after Chad, Central African Republic and Sierra Leone and against the Sustainable Development Goal (SDG) global target of 70/100,000 live births by 2030. In Nigeria, the proportion of births attended by skilled health personnel is only 35% while child mortality is 108.8 which is very high compared to the SDG target of 25 per 1000 live births. Malaria incidence per 1000 population is 380.8 making Nigeria the highest after Burkina Faso and Mali. With 140, 542 people in need of treatment for neglected tropical diseases, Nigeria scored the lowest in terms of SDG goal 3.3 which seeks to end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases by 2030. These startling statistics are indicative of the poor status of Nigeria's health sector which is fraught with huge disparities in health coverage and outcomes.

Nigeria's health statistics shows that the country ranks low in terms of access to healthcare delivery. Nigeria was placed at the 140th in the 2015 global health care ranking out of 195 countries and territories from 1995 to 2015, which was based on qualification of personal access and quality (The Guardian Newspaper, 2017). Out of 100 points on the healthcare Access and Quality Index, Nigeria reportedly scored only 51 points (Guardian Newspaper, 2017). Despite this, the Nigerian government continues to rely heavily on user charges and NHIS to finance health systems which have significant implications for livelihoods of poor people. Direct charges for health care at the

point of use (user fees) or out of pocket payment (OOP), further limits access to health services and pushes households into poverty.

In addition, evidence has shown that high dependency on out-of-pocket (OOP) payments in the form of user charges and co-payments are regressive as they disproportionately affect the poorest in society (Adeyemi & Nixon, 2013). This therefore challenges the underlying tenets of equity within healthcare system. Consequently, poor health seeking behavior occurs among the poorest quintiles of the population. Therefore, in line with the global health policy agenda, the objectives of equitable access, high quality services, and broader social protection, Nigeria has become under sustained social pressure to develop some urgent measures for protecting poor families from the negative implications of unaffordable health care payments (Chuma & Maina, 2013).

As explained by Mojekwu (2005), the factors responsible for maternal deaths can be related to socio-economic, medical, reproductive and unwanted pregnancy. In many instances, women attend antenatal clinics but choose to deliver at home, church or by traditional birth attendants. These are termed as individual level factors that can be responsible for high mortality as explained by some researchers (Igberase & Ebeigbe, 2007). A study by Muoghalu (2010) found that due to illiteracy, poor knowledge and exposure level of income and nutritional status of many women is being affected. Consequently, this reduces their ability to access skilled birth attendance. There are also situations where women showed up at hospital emergency with numerous complications without ever attending antenatal care (Guerrier, Oluyide, Keramarou, & Grais, 2013).

According to Mojekwu and Ibokwe (2012), low attendance of skilled birth or delivering outside of a health facility have grave implications for PMTCT. Agboghoroma (2013) adds that Nigeria's high MTCT rate is largely due to women's failure to attend antenatal and deliver in

modern facilities and other factors. These women who do not use these services are not aware of their HIV status and are therefore not benefiting from PMTCT services provided. Also, women who fail to deliver at health facilities would not know their children's HIV status and would miss out on life saving antiretroviral drugs for their infants and breastfeeding counselling.

2.6 Barriers and Challenges to PMTCT Utilization and Adherence

Governments are increasingly focusing on strategies to eliminate MTCT. While this is welcome, efforts are insufficient because of the absence of uniform or universal PMTCT programs (Kellerman et al., 2013). A study on evaluation of PMTCT services in Kwazulu-Natal South Africa by Horwood et al. (2010) discovered that the problem with PMTCT interventions is not high coverage during pregnancy and delivery but poor follow-up of mothers and infants.

When PMTCT services are poorly integrated into routine care, barriers to accessing post-delivery services is likely to be created. In some instances, barriers in access are created when health workers are not clear about their roles and record keeping is poor. The Kaplan-Meier survival analysis and the log rank test was used by Deschamps et al. (2009) to describe the PMTCT program in Haiti. Infants who experience early pediatric diagnosis and treatment with ARV are said to have improved survival. In developed countries, significant progress has been made with PMTCT. For example, there has been a dramatic reduction in the rate of MTCT to 1 per cent due to increase in provision of ART to 190 per cent of pregnant women living with HIV (Lazuriaga & Sullivan, 2005).

Several studies have shown that in developing countries, there has been progress achieved in some settings while others are experiencing severe health system challenges which have reduced the effectiveness of PMTCT programmes. For instance Oladokun, Ige and Kikelomo (2013) assessed HIV prevalence in infants and mothers' use of PMTCT services in clinics where routine

immunization is provided in Ibadan, Oyo state in the South Western Region of Nigeria. Using a cross-sectional design, they found that the rate at which infants attending clinics are exposed to HIV is low and HIV testing was received by more than three quarters of women who used conventional health service during their first pregnancies. However, in other settings in Nigeria the effects of PMTCT programmes are sub-optimal. To illustrate, Inegbenebor, Umuemu and Aigbokhai (2012) conducted a study in 30 randomly selected primary health centres in Edo State, Nigeria. The study was retrospective and was aimed at investigating the services provided for maternal health care using data collected through antenatal booking records, maternity and PMTCT services between 2007 and 2010.The authors found no evidence of VCT or PMTCT service provision in an entire senatorial district of Edo State, Nigeria. This is in contrast to South Africa where PMTCT services are offered in all public hospitals.

Furthermore, uptake of VCT constitutes a major challenge to PMTCT implementation. A study conducted by Peltzer, Mosala, Dana and Fomundam (2008) highlighted that despite providing information about HIV and HIV testing to almost all the women, more than half of them (42%) had not been tested and their HIV status remained unknown and only 57% of the HIV-infected women received nevirapine. This was said to be associated with quality of counselling and low encouragement of self-medication with nevirapine tablets at the on-set of labour. In another study conducted by Nigatu and Woldegebriel (2011) in Ethiopia, mothers who were known to be HIV positive and infants who were known to have been exposed to HIV were investigated. It was found that only 53% and 48% respectively received ARV prophylaxis. It was found that there was an 11.6 per cent coverage of ARV among the HIV positive mothers while for their babies, HIV prevalence rate was 8.4 per cent assuming that HIV prevalence was constant.

Another study from the North Central Region of Nigeria was conducted by Anigilaje, Dabit, Ageda, Hwande and Bitto (2013) identified some of the risk factors that are likely to predict MTCT of HIV. Using bivariate and multivariable logistic regression models, they found an independent association of HIV transmission with certain factors such as: Absence of episiotomy at delivery, mothers and their babies receiving ARVs after 72 hours of life, practice of mixed feeding, mothers with high viral load ranging between 1001-10,000 copies/ml and children presenting for the first time when they are at the age of 12 months or more.In a study conducted by Sibeko et al. (2005) in South Africa, mothers valued the use of traditional herbal preparations (Muthi) for their new born babies thus hindering the ability to practice exclusive breastfeeding.

In a cross-sectional qualitative study conducted by Buregyeya et al. (2017), to investigate what facilitates or prevents uptake and adherence to ART by pregnant WLWHA in Uganda. A content thematic analysis approach showed that the major motivator for uptake and adherence was the desire by WLWHA to have babies that are HIV free. WLWHA were found to miss their doses completely and skip clinic appointments although family, peer and partner support greatly improved adherence. Other barriers revealed in the study centered on fear of HIV status disclosure, big size of the ART drug and its side effects as well as HIV stigma which prevented transition from antenatal care to HIV chronic clinics.

A similar study conducted in Kenya by Thomson et al. (2018) explored barriers to utilization and adherence to PMTCT throughout the pregnancy and postpartum periods using focus group discussions and in-depth interviews. The authors found that female participation in PMTCT services is hindered by perceived hazards in the home, community, and clinic environments. This is because before following recommendations of health providers, women have to weigh the risks and benefits of PMTCT interventions in order to maintain confidentiality and their relationships

with partners and community. Another recent study conducted by Omonaiye, Kusljic, Nicholson and Manias (2018) conducted a systematic review to examine the factors that enable or prevent adherence to medication by WLWHA in sub-Saharan Africa. They revealed that the factors that limit administration of ARV medication to WLWHA during pregnancy include stigma, cost of transportation, food deprivation and a woman's disclosure or non-disclosure of her HIV status to a partner, family and the community.

2.7 Factors Influencing Utilization and Adherence to PMTCT Services

So far, research has established that MTCT amongst women living with HIV/AIDS can be reduced through treatment with short-course ARV especially for HIV positive mothers who are breastfeeding. However, Mofenson & Mclntyre (2000) cite that a woman cannot make informed choices about preventative interventions unless she knows her HIV status also stating that while initial acceptance of HIV testing is high, many women fail to return for the results of their tests. Mclntyre et al. (2008) also contend that it has become more difficult to deliver interventions for PMTCT due to key factors like low VCT uptake and MTCT through breastfeeding which continue to drive failure. The reasons mostly cited for women refusing to test for HIV are stigma and discrimination and the fear of being harassed, abandoned or murdered as a result of their HIV status. Also, in some settings, families have to travel long distances to access clinics and with few resources thereby limiting access to ART. It is even more difficult and expensive to access transport to clinics when there is an emergency (Skinner et al., 2005). In addition, these authors cite that infant feeding becomes more complicated for families living in areas with poor infrastructure who lack access to clean water.

One study conducted by Kasenga, Hurtig and Emmelin (2010) sought to explore experiences in the use of PMTCT by rural women in Malawi using a purposively selected sample

of 24 HIV positive women. In-depth interviews showed that willingness for HIV testing depends on perceived susceptibility of the women to HIV and for protection of their children from getting infected. Some women especially those whose sexual partners were aware of their status failed to return for treatment because they were afraid of being economically bankrupt and the potential of facing domestic violence. The study also identified stigma associated with the administration of Nevirapine for babies. It showed that women who didn't return to deliver in the hospital were either sick, too far from the hospital, or lacked support and were afraid of the expenses involved.

Focus group discussions and in-depth interviews were used by AED (2011) to assess peoples' levels of knowledge, awareness and barriers to the use of PMTCT by pregnant women with HIV/AIDS in four regions in Tanzania. Women fail to utilize health facilities or TBAs at the time of labour because of fear of negative attitude from health care staff, delay in receiving treatment, difficulties in transportation to health facilities and related costs. Participants in the study considered breast milk to be nutritious but found exclusive breastfeeding difficult to practice especially for working mothers and those with inadequate milk. There were mothers who viewed that water was supposed to be given to babies for quenching thirst while others were pressured by family members and who could easily stigmatize them as being HIV positive. Non-breastfeeding was not commonly practiced in the study area because of its association with being HIV positive.

Iwelunmor et al. (2014) conducted a review of empirical studies that reported peoples' perceptions towards PMTCT, influencing factors of actions and decisions towards PMTCT service uptake such as availability of enablers/resources as well as the role of families and communities in Nigeria. The findings highlighted that unavailability of accessible and acceptable resources at affordable price have a negative influence on people's decisions and actions towards PMTCT in Nigeria are negatively influenced by lack of available, accessible, acceptable, and affordable

resources. Also, uptake of PMTCT services specifically decisions on whether or not to disclose sero-positive status, family planning and infant feeding choices are influenced by family contexts.

In a cross-sectional study, 52 women who were enrolled in a PMTCT programme were interviewed by Eide et al. (2006) using a structured questionnaire. It was found that the most important consequence of participating in PMTCT program was that women experienced difficulty in breast feeding. Also, women tend to withhold their HIV status from others, meaning that only a few people influence their decision to take part in PMTCT programmes. Okoli and Lansdown (2014) conducted a critical literature review of 12 studies that used primary research to explore why PMTCT in Malawi and Nigeria either failed or did not achieve the desired outcomes. Socio-economic and socio-cultural factors were the most notable barriers found in their review followed by inadequacy of male partner involvement, how PMTCT is organized and inefficiency of health workers.

In order to investigate the operational factors that predict complete breast feeding cessation (CBC) after 24 weeks of Exclusive Breastfeeding (EBF) and its feasibility, Goga et al. (2009) conducted a study in three routine PMTCT sites in South Africa. It was a prospective observational cohort study that used univariate and Kaplan–Meier Survival analyses, logistic and cox regressions to establish that it is uncommon to find CBC by 24 weeks due to lapses in the PMTCT program. Predetermined social, economic, and environmental criteria seem to have no relationship with success. Henry and Carlson (2005) conducted a study to learn why women attending ANC clinics either participate or fail to participate fully in HIV counseling and testing and why those who test positive receive or fail to receive ARV prophylaxis at a health center in Georgetown. Based on review of records from the health facility, observation of clinical practice and in-depth interviews, they found that the most notable reasons why HIV positive women did not receive nevirapine at

delivery were related to inability of the women to arrive at the hospital in time and consistent use of the ANC clinic card system.

Sam-Agudu et al. (2014) in their formative research examined barriers to uptake, access, acceptability and retention of PMTCT service as well as the experiences of mentor mothers providing support for PMTCT clients in rural North Central Nigeria using focus groups and key informant interviews. Money for transportation to PHC, poor attitude of health care providers, irregular supply of drugs and test kits, uncertainty of 24/7 emergency services, non-awareness of clients, confidence in the PHC services available and high level of HIV stigma at the community level were cited as the main barriers to uptake, access and utilization of PMTCT services.

A more recent study by Nabasirye, Mawa and Ayebare (2019) have also explored the level and factors influencing adherence to infant's NVP prophylaxis regimen at six weeks of age. Results from the bivariate analysis and binary logistic regression model showed that maturity of the mother and her perceived benefits of administering NVP to the infant are important positive drivers of optimal adherence. Similarly, Zegeye, Mbonigaba and Dimbuene (2018) used multivariate regression model, Poisson and negative binomial regression models were applied to identify significant factors associated with PMTCT service utilization. They found that the significant factors associated with low PMTCT service utilization are long walking distance, low household income and living in a rural setting. Using exploratory qualitative research, Ankrah (2018) identified the health system factors influencing delivery of EID services and the barriers to the use of EID services among HIV positive mothers. Some of the challenges identified were inadequate staff, transportation challenges, long turnaround time for the return of PCR results, inadequate and frequent breakdown of PCR machine. Availability of DBS cards, adoption of task shifting strategies and positive attitudes of health workers served as facilitators. In addition,

maternal factors such as denial of HIV status, lost to follow up in the EID process, dependency on significant others and consequences after disclosure of HIV status were factors that served as barriers to mother's utilization of EID services for their exposed infants.

2.8 Stigma and Discrimination

Decock et al. (2002) mention that the potential effect increased access to HIV/AIDS care and ARV drugs on improving prevention efforts in Africa has not yet been realized. Yet, it is a topic of international discussion at the high-level. Chopra (2009) notes that this is attributed to avoidable factors at family levels such as delays in seeking care. The reasons why women refuse to seek for care are the fear of being stigmatized or discriminated based on their HIV status. According to Decock et al. (2002, p.68), "stigma emerged universally and early on as a powerful, pernicious force that is an important barrier to prevention efforts".

Similarly, Amuzu (2008) states that people often fail to seek treatment for HIV/AIDS due to fear of being discriminated against. In certain instances, people living with HIV face rejection by friends, colleagues and may even experience eviction by their families. Furthermore, the practice of replacement feeding is stigmatized. Women opting to feed their children through replacement feeding are stigmatized in numerous cultures thereby complicating adherence by women who prefer to feed their children through this means. Identifying them as being HIV positive may result in stigma with consequences such as facing ostracism and expulsion from their family members (Horvath et al., 2010). Having acknowledged the link between stigma and the workings of social inequality, Parker and Aggleton (2003) argue that it is important for countries to consider the broader issues of social exclusion of individuals and how it is created and reinforced in different settings. This will enable them to properly understand stigma and discrimination in HIV/AIDS or issues related to it. For example in some settings, women's fear of disclosing their

serostatus is largely due to the possibility of being stigmatized as promiscuous or as sex workers (Parker et al., 2002).

Additionally, Parker et al (2002) report on a symposium where it was noted that stigma associated with HIV/AIDS is increased through religious doctrines which promote certain moral and ethical positions regarding sexual behavior, sexism and homophobia. They deny the realities of HIV/AIDS and stigmatize those infected as sinners who deserve punishment thereby creating fear of disclosing sero-status to those who are likely to provide support. Families and communities often display their HIV/AIDS-related stigma and discrimination through blaming, scapegoating and even punishing those infected. In some communities, those who are perceived to be infected with HIV are often shunned or gossiped about. In more extreme cases as seen in reports from South Africa, Brazil Thailand and India, violence and HIV/AIDS related murders occur (Nardi & Bolton, 1991 as cited in Parker et al., 2002).

In the context of PMTCT, Peltzer et al. (2018) evaluated the impact a multicomponent, behavioural, prevention of mother to child transmission (PMTCT), cluster randomised controlled trial on HIV stigma reduction among perinatal HIV infected women in rural South Africa. Longitudinal analysis showed that increases in stigma from baseline to 12 months were associated with being unemployed, having been diagnosed with HIV before the current pregnancy, and alcohol use. Lower stigma scores were associated with participation in the intervention, greater male partner involvement, and consistent condom use. In a similar vein, Spangler et al. (2018) explored these issues among self-disclosed couples living in southwest Kenya. Their textual analysis of in-depth interviews showed that stigma continues to restrict full participation in community life and limit access to care by promoting fear, isolation and self-censorship. In another study, Monteiro, Villela, Soares, Pinho and Fraga (2018) analysed how pregnant women living

with HIV/AIDS (PWLHA) experience and cope with AIDS stigma and found that stigma is still predominant despite a non-disclosure law guaranteed by the government. The study therefore suggested that however, the silence surrounding HIV diagnosis perpetuates the psychosocial and structural mechanisms that reproduce stigma.

2.9 Poverty and HIV/AIDS

The situation of women is such that have longer working hours and yet 70% of the world's poor are women. They acquire less education than men and their life expectancy is lower (Gilbert & Walker 2002). These authors outline the situation in South Africa saying that on average, the amount earned by women is between 72 and 85 per centof the amount earned by men who have similar education. The authors also reported that low skilled and low paid occupations are highly pre-dominated by women with only 22 per cent of women having manager positions.

Whiteside (2002) posits that although a simple causal relation has not been established between the epidemic and poverty, HIV prevalence is highly correlatedwith unequal distribution of income. By now it is widely accepted that people, households, communities are impoverished by the HIV/AIDS epidemic. As such household income is affected thereby limiting access to the hospital where HIV/AIDS care and treatment can be received. Horvath et al. (2010) assert that due to poverty, formula feeding and other breastmilk substitutes may not be affordable to many mothers. More importantly, the use of replacement feeding in resource poor regions increases the risk of diarrhoea because clean water may not be accessible in such areas. As such, using formula feeding to protect infants against the risk of infecting HIV may result in placing the same infants at risk of getting sick and dying from other infections (Horvath et al., 2010).

Recent studies have also considered the role that poverty plays in HIV/AIDS service utilization. In the context of PMTCT, Yourkavitch et al. (2018) used qualitative research, to map

out how the effects of poverty, gender, and health systems on women's participation in PMTCT services. They found that the effect of antiretroviral therapy (ART) use, service design and quality, stigma, disclosure, spouse/partner influence, decision-making autonomy, and knowledge about PMTCT tend to influence psychosocial health, which in turn affects women's participation in PMTCT services. In a study by Brittain et al. (2018), disclosure over time during pregnancy and postpartum and the influence of social and economic circumstances was explored using Mokken scale analysis. It was observed that the impact of pregnancy intentions and poverty on disclosure to a male partner is often modified by relationship status. Another study by Achebe et al. (2018), included socio-economic barriers such as poverty and home deliveries as a barrier to retention of mother-baby pairs in PMTCT programs. This is among other factors like long waiting times, stigma and discrimination, insufficient disclosure support, and poor family and/or spousal support as well as other structural and biomedical constraints.

2.8 Conclusion

The studies on PMTCT often focused on utilization and adherence to some aspects PMTCT without considering a holistic view of the entire PMTCT cascade. This presents a substantial gap in available literature because there is a dearth in literature on factors that influence utilization and adherence of PMTCT services at each stage of the PMTCT cascade. Regardless of the methods used, capturing one stage of PMTCT and leaving out the others may not allow the researcher to pin-point the particular stages of PMTCT where WLWHA tend to drop out. This has the effect of limiting the extent of public health solutions that can be proffered to improve utilization and adherence.

Similarly, Most studies conducted on PMTCT have focused on the lived experiences of women who were HIV positive without considering the public health approached that may increase consistency with the use of PMTCT services. Although this aspect of PMTCT research has the

likelihood of revealing salient policy implications, available literature has not considered the factors that can increase compliance with the PMTCT services provided in hospitals including how to ensure that patients attend follow up visits through antenatal to delivery and postpartum. This presents a gap in literature related to policy responses that may enable WLWH use PMTCT services more efficiently.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 Introduction

Sutherland (1976,p. 9) as cited in Wacker (1998, p. 364), defines theory as "an ordered set of assertions about a generic behavior or structure assumed to hold throughout a significantly broad range of specific instances". In other words, theories are important underlying assumptions about a study. Theories provide explanation on why and how specific events are caused by specific relations (Wacker, 1998). This study is guarded on two theories namely health belief model and social support theory. It is expected that these theories will explain how individual characteristics influence women's decisions to utilize PMTCT services or why they fail to use them.

3.2 Health Belief Model

The Health Belief Model (HBM) was developed by a number of social psychologists namely: Irwin M. Rosenstock, Godfrey M. Hochbaum, S. Stephen Kegeles, and Howard Leventhal (Carpenter, 2010; Glanz, Rimer & Viswanath, 2008). The theory was developed in the 1950s making it one of the first models of health behaviour (Glanz & Bishop 2010). In HBM, the main assumption is that the determinants of health behaviour of people are their beliefs about a disease or perceptions of it and the strategies that can be taken to decrease its chances of occurring (Rosenstock, 1974; Glanz, 2008).

HBM recognizes four main constructs which are: perceived seriousness, perceived susceptibility, perceived benefits and perceived barriers. These constructs are further explained as follow:

i) Perceived seriousness proposes that individuals who perceive a health problem to be serious are more likely to prevent its occurrence or reduce severity of the health problem (Janz & Marshall, 1984; Rosenstock, 1974; Glanz et al., 2008).

ii) Perceived susceptibility is concerned with the assessment by an individual of the risks associated with a particular health related problem. HBM assumes that when individuals perceive susceptibility to a health problem, they are more likely to engage in behaviours that will reduce their risk of developing the health problem (Rosenstock, 1974).

iii) While perceived seriousness and susceptibility are jointly termed perceived threat, Glanz et al. (2008) posits that perceived benefit relates to assessment by an individual of the value or efficacy associated with a particular health problem. HBM proposes that regardless of the objective facts of the effectiveness of a health behaviour, an individual is likely to engage in that particular health behaviour when he or she has confidence that susceptibility to a particular health problem or its seriousness will be reduced (Rosenstock, 1974).

iv) Perceived barrier is concerned with an individual's assessment of obstacles to health behaviour. In this construct, HBM proposes that barriers may prevent engagement in health promoting behaviour even if the individual perceives that the particular health problem poses a threat and has confidence that the threat will be effectively reduced by that particular behaviour (Janz & Marshall, 1984; Glanz et al. 2008).

Although it is the most widely used theory used to investigate the reasons for people's failure to undertake measures that are health preventative, HBM has been criticized for the limited predictive capacity of its existing variables and small effect size of the variables (Orji, Vassileva, & Mandryk, 2012). Despite this criticism, many studies have used HBM to explain health behaviour. Psychologists have used HBM to provide a better understanding of the reasons why tuberculosis screening programs have experienced a widespread failure and to explain many other aspects of health behaviour such responses of patients to disease symptoms, people's reasons for complying with medical regimens, lifestyle related behaviours such as sexual risk behaviour and

chronic illness (Janz & Marshall, 1984; Glanz, 2008). For example Naghashpour, Shakerinejad, Lourizadeh, Hajinajaf and Jarvandi (2014) examined how an education program on nutrition has effect on female students' knowledge, attitudes and practices (KAP) of dietary calcium. Another study evaluated how community-based health education programmes affect high school students' prevention of injury (Zhi-Juan, Yue & Shu-Mei, 2014). Other studies namely Straub and Leahy (2014) as well as Zhang, Dalal and Wang (2013) have examined pro-environmental behaviour and injury related risk behaviour using HBM.

Workagegn, Kiros and Abebe (2015) used two HBM constructs to find out what predicts utilization of HIV-test by ANC attendees. In this study, the authors found that there was a negative association between HIV-test utilization for PMTCT and negative or low perceived net benefit. Similarly, the relationship between acceptance of HIV tests, receiving results by mothers and belief in susceptibility to vertical transmission of HIV to infants was explained using the perceived susceptibility construct of HBM. Perceived benefits in the context of PMTCT is the belief by mothers that and the knowledge that PMTCT interventions have the benefits of effectively preventing HIV transmission to their babies (Igumbor, Pengpid & Obi, 2006). This study will use HBM to provide a useful basis for an enquiry into the factors influencing PMTCT service utilization by exploring whether a perception of seriousness, susceptibility, benefit or barrier are among the reasons why women fail to use PMTCT services.

3.3 Social Support Theory

Hobfoll and Stokes (1988) as cited in Goodwin, Cost and Adonu (2004), defined social support as "social interactions or relationships that provide individuals with actual assistance or with a feeling of attachment to a person or group that is perceived as loving or caring". Two types of social support have been recognized in the literature; perceived and actual support. The support that is

received by an individual either by saying or giving something to the individual is termed actual support while perceived support is an individual's belief that there is available support (Goodwin et al., 2004).

It is also widely acknowledged that perceived support predicts positive outcomes more often than actual support. As such lack of perceived support means low service uptake and utilization. For example, Uchino (1999) explained social support in terms of how perceived and received support are potentially linked with disease end points. One of his propositions is that positive psychosocial profiles are developed by family environments that are positive from early years. As such it is predicted that there is an association between parental support or less conflict with healthy behavioural choices and adherence to medical regimens.

However, social support theory has its drawback. It is a model that is characterized by reciprocity and quantifies nurturance offered to someone as if a value can be affixed to it on some level when in reality, a value cannot be easily affixed to the gain achieved in assisting someone cared for (Shumaker & Brownell, 1984). Despite its drawback, many studies have linked social support to health outcomes. For example, Anderson, Winett and Wojcik (2007) found that higher social support levels were associated with higher self-efficacy to choose and prepare the most nutritional foods. Through support from friends and family, they obtained information about health eating and developed confidence that enabled them decide on healthy as opposed to unhealthy foods.

The idea of perceived support is also applicable in utilization and adherence to PMTCT services. Results from a study conducted by Busza et al. (2012) found that although pregnant women may be concerned about their status, lack of motivation or self-efficacy may prevent them from accepting testing especially when the logistical arrangement involved is complicated when

they have to provide an explanation for their absence. Also, other studies have shown that male partner involvement in HIV testing and antenatal care means a statistically higher acceptance of ARV prophylaxis by their women, higher health facility delivery and attendance of follow-up visits (Busza et al., 2012). Based on this proposition, this study assumes that the support available to an individual is associated with the ability to seek PMTCT services and utilize them.

In order to identify the level of PMTCT service knowledge and awareness in Ibadan Nigeria, Arulogun, Adewole, Olayinka-Alli and Adesina (2007) conducted 20 individual in-depth interviews with household heads, religious and community based leaders. Knowledge of MTCT and PMTCT was low and community sensitization was low and health care facilities were inadequate. These findings are indicative of little or non-existence of social support mechanisms for PMTCT users. Hill et al. (2015) explored the effects of pregnancy and HIV status disclosure by adolescent women in an urban clinic located in Umlazi, South Africaon the relationships they have with members of their family and sexual partners while paying attention changes in support in the entire time period. In-depth interviews that were semi-structured with 15 HIV-positive and HIV-negative pregnant adolescents or those at the 18 month post-partum stage revealed that closeness with partners during pregnancy was heightened. A few women reported being in close relationships with their partners at postpartum and the support they experienced did not differ based on their HIV status. It is argued that perception of low social support from the general community will impact PMTCT service uptake and adherence to treatment negatively (Kagee 2008; Perez et al., 2004). Results from studies linking social support and PMTCT utilization or adherence have proved this relationship.

Data collected from Ditrame Plus project combined with interviews involving couples and women was used to analyze how decisions concerning the practices of infant feeding options for

HIV prevention are constructed (Traore´ et al., 2009). It was found that knowing that their wives are HIV positive and being involved in program for PMTCT, men are more likely to actively play a role in applying the advice provided. They found that when men know their wife is HIV positive and are involved in the PMTCT project, they play an active role in applying the advice received. However, support from spouse is not always needed by women before undertaking preventative behavior.

Another study was conducted by Psaros, et al. (2014). Interviews completed assessed depression, stigma, social support and structural barriers to PMTCT among 167 women infected with HIV who were enrolled in PMTCT at about 28 weeks of pregnancy. Lower adherence scores were found among participants whose depressive symptoms were elevated. Adherence was not predicted by income or the amount of time taken to reach the clinic thus, there was no basis for examining its moderation with social support. Social support was a significant predictor of depression and people who had lower score of social support had elevated depressive symptoms. Similarly, there is a significant association between stigma score and social support score.

Another study conducted in Jos, Northern Nigeria by Sagay et al. (2006), explored problems relating to HIV status disclosure by sero-positive mothers to their partners in a PMTCT program. 570 mothers were selected from the PMTCT program and administered questionnaires that were previously field-tested. It was found that out of 560 participants, 500 or 89 percent of the women revealed to their partners that they were HIV positive. Of these, 199 or 39.6 per cent were assisted by health workers while 298 or 59.4 per cent accomplished it unassisted. After revealing their HIV status, 430 or 86.9 per cent of the partners reacted in a supportive manner, 5.7 per cent reacted indifferently, 67 per cent quarreled and abused their partners while 1.0 per cent

reacted violently. Since partner support was high in this study, it is expected that utilization and adherence to PMTCT services will be high as found in aforementioned studies.

Nassali et al. (2009) interviewed HIV-positive mothers at postpartum with the aim of determining adherence to PMTCT at the postpartum stage based on the percentage of mothers who attended follow-up appointments after eight weeks postpartum. Focus group discussions were also used for the assessment of influencing factors of adherence to PMTCT at postpartum. One of their findings is that the most important factors motivating mothers to adhere to PMTCT is the availability of social support from their partners.

3.4 Conclusion

In summary, health belief model assumes that patients' decisions to utilize health services or adhere to medication is based on their beliefs about how serious the disease is, or how susceptible they are to complications, the benefits they derive from utilization and adherence as well as the potential barriers they might face. Most of the studies reviewed have revealed that a positive relationship between health belief and utilization means that high perceived seriousness, susceptibility, benefit and barriers will result in high utilization and adherence, vice versa.. It therefore follows in this study that WLWHA who partake in PMTCT services because of their health or the health of their babies are assumed to have high perceived benefit or susceptibility respectively. This implies the need to constantly engage with WLWHA to provide them with knowledge and reminders that will shape their beliefs about PMTCT utilization and adherence.

The social support theory assumes that perceived support is a strong determinant of health service uptake or utilization and adherence. Most of the literature on social support found that high perceived support is associated with high service uptake and vice versa thus indicating a positive

relationship between social support and health service utilization. This link provides a useful basis for the use of hospital coordinated support from mentor mothers or peer mentoring for improvement of utilization of PMTCT services. It therefore follows in this study that WLWHA who were accompanied by their partners or family members during antenatal care or received some form of financial or other support during their pregnancy are assumed to have high perceived support.

CHAPTER 4

METHODOLOGY

In this chapter, the research design, data collection approach, population and sampling techniques, description of study site and scope of the study, data analysis, ethical considerations as well as validity measures were addressed.

4.1 Study Site

The study was conducted in Rivers State Nigeria. Rivers State is located in the South-South Geographical Zone in Nigeria and it is administratively divided into 23 local government areas as shown in figure 2.

Figure 2: Map of Rivers State, Nigeria

Source: Rivers State Ministry of Health, (2013)

Based on the population census carried out in 2006,there was a total population of 2,673,026 males and 2,525,690 females in Rivers State which grew to about 6,429,596 people at the end of 2012 (Rivers State Ministry of Health, 2013). The most recent estimates show that Rivers state had

1,414,511 women of reproductive age (WRA) and the 321,480 pregnant women (Rivers State Ministry of Health, 2013).

Rivers state was chosen for this study because of its HIV prevalence rate of 3.8 per cent making it one of the highest in Nigeria according to the (Federal Ministry of Health, 2016). About 19,289 pregnant women were HIV positive out of the estimated 321,480 pregnant women residing in Rivers State (Rivers State Ministry of Health, 2013) meaning that prevalence rate among pregnant women in the state is 6%.

4.2 Research Design

This study used qualitative design to provide detailed understanding of PMTCT from the point of view of women living with HIV/AIDS as well as the factors influencing its utilization instead of providing an analysis of statistical results (Soiferman, 2010).Each stage of a qualitative research design is like a journey that builds on past experiences (Richards, 2005). According to Creswell (1994), qualitative design is more concerned with processes rather than outcomes. In this study, the qualitative research process is inductive which involves collection of data from the field and generating meaning from it (Crotty, 1998). The qualitative method relevant to this study is phenomenology. This was chosen because it is a qualitative approach that can interpret the existing practices of women living with HIV/AIDS regarding their use and adherence to PMTCT services.

"In qualitative research, the epistemological assumption, philosophical basis, nature and limits of human knowledge is that each individual has a different view of the world and thus it is difficult to generalize findings and draw inferences simply on the basis of quantitative research" (Soiferman, 2010, p. 16). This epistemological assumption is referred to as social constructivism and is relevant to this study because it can easily be applicable in the socio-cultural world. The assumption guiding social constructivism states that "the social world is without meaning prior to

one's experience of it and truth or meaning comes into existence in and out of ones engagement with the realities of one's world" (Crotty, 1998, p.8). Constructivism in this study will be based on empirical research that seeks to gain understanding of the situation as it is through knowledge derived from experiences of WLWHA. This is why open-ended questions are used by researchers in order for participants to share their experiences (Crotty 1998). The ontological stand-point of the qualitative researcher in this study mainly reflects inequality with respect to gender particularly how women's poor economic backgrounds, their inferior roles in the family, radical religious and cultural beliefs and how these affect their use of PMTCT services in relation to more economically advantaged and more culturally liberal women.

4.3 Population and Sampling Techniques

413 health facilities are involved in provision of ANC in Rivers State. Of these, 66 health facilities of make provision for ARVs as part of PMTCT (Rivers State Ministry of Health, 2013). The population in this study comprises three categories of participants in the Nigerian health system: Stakeholders (Health care staff such as doctors, PMTCT nurses and midwives); representatives from HIV/AIDS support groups and Women Living with HIV (WLWH) all of whom are from varied socio-economic backgrounds and with a broad socio-demographic mix.

This study used purposive sampling technique to select participants from the population. Purposive sampling is defined as a sampling method in which participants are chosen based on particular features of the study (Strydom & Delport, 2002). Purposive sampling allows the researcher to select relevant, rich cases which provide in-depth information (Patton, 2002). This method was chosen in order to obtain responses that are relevant to PMTCT service utilization and adherence. However, purposive sampling is prone to bias because it is created based on the judgement of the researcher (Sharma, 2017). This affected the procedure used in choosing health

care providers because the researcher expected the sample to consist of only obstetrics and gynaecologists when in fact, surgeons, general physicians and even paediatricians would have sufficient knowledge of PMTCT guidelines. Despite its limitations, purposive sampling was chosen because not all of the health providers are trained on compliance with PMTCT guidelines and not all HIV positive women have been pregnant in the past. Therefore to reduce the bias caused by the use of purposive sampling, the researcher established a selection criteria which allowed the selection of general physicians, obstetrics and gynaecologists and surgeons who are better trained on PMTCT guidelines than other health professionals. Ten health care providers from a government owned hospital in a sub-urban area and ten representatives from support groups were selected from the Network of People Living with HIV and AIDS in Nigeria (NEPWHAN). This sample size includes five representatives each from two support groups and ten PMTCT health providers from the hospital selected for the study. Similarly, purposive sampling was used to select twenty HIV positive women from the two support groups. The sample size consists of ten HIV positive women from each of the two support groups selected in Rivers State. These respondents were selected based on the following inclusion and exclusion criteria:

Inclusion and Exclusion Criteria

Key informants in this study were selected based on their knowledge of PMTCT services being investigated. They need to be the most experienced health care providers of pregnant WLWHA. The Nigerian Ministry of Health (2010) requires that HIV positive pregnant women should be provided with ARVs either as prophylaxis of therapy during pregnancy, labor and at postpartum during breastfeeding. Therefore only WLWHA who have been pregnant in the last four years were selected in order to obtain information on their immediate postpartum experiences and outcomes.

Women who are currently pregnant were excluded because they can only provide responses related to their antenatal care experience thus neglecting labor and infant feeding experiences.

Recruitment of Key Informants

After obtaining ethical clearance and permission to conduct research at selected PMTCT sites, the researcher met with the clinic managers to collect a list of nurses or midwives, their years of experience and their work schedules to find out their availability and make appointment with them. In each of the PMTCT sites selected for this study, PMTCT nurses or midwives or doctors were identified and approached to enquire about their willingness to partake in the study. The same procedure was carried out to recruit 10 members from HIV/AIDS support groups.

Recruitment of Women Living with HIV/AIDS

After interviewing key informants in HIV/AIDS support groups, each key informant was asked about the characteristics of their members to establish which of them has been pregnant in the last one year and twenty women were identified and their group meeting days. The researcher then attended a support group meeting to meet the women and enquire about their willingness to partake in the study and their preferred language. Once they consented to participate in the s tudy, an appointment was made with them to meet before or after the support group meeting or in a private room with only the researcher and a field assistant who speaks the language of the participant.

4.4 Data Collection Approach

Given the nature of the issue under inquiry, two semi-structured in-depth interview sheets were administered to both key informants and HIV positive women selected from support groups and

PMTCT nurses or midwives and doctors in hospitals. A semi-structured in-depth interview involves the use of an interview guide covering a list of questions usually in a particular order but the interviewer is able to stray from the guide when it is necessary (Cohen, 2006). These involve verbal, open and direct questions to obtain participants' views. In-depth interview of the participants was chosen because it holds more promise in yielding valuable information through interaction with participants and gives room for asking other questions that arise during the interviews. It also allows the researcher to ask for clarification on participants' opinions and to identify new ways of understanding and comparing the different viewpoints on PMTCT utilization challenges. According to Boyce and Naele (2006), in-depth interviews have the advantage of providing more detailed information than what is available through survey data.

Given the diversities in language and culture in Rivers State, some of the women not have knowledge of English language. It is known that most of the people in Rivers State speak or hear English or Pidgin languages. Although the native languages in Rivers State are Ikwere, Ijaw and 23 others, many people can speak or understand Igbo language in the state. Therefore translation of interviews was necessary from English language to the native Igbo language and Pidgeon spoken by indigenes of Rivers State. In doing this, the research adopted the back translation method which involves using one translator in translating a questionnaire into a target language and then using an independent translator who is blinded to the original questionnaire to translate it back into the source language (Sperber, 2004). This method was chosen because it is more likely to ensure that the certain informal phrases or slangs and jargon, or idiomatic expressions and terms which can be emotionally evocative are not lost in the translation process. The following steps were taken in back translation of the study tools (Sperber, 2004):

i. The English version of the interview sheet was translated by trained researchers who are proficient in *igbo* language and pidgin.
ii. The translated *igbo* and pidgin versions of the interview sheets were then translated back to English by another trained researcher who is also proficient in igbo and pidgin languages.
iii. Finally the translated copies were compared to test for accuracy and to ensure that the original interview sheet has not been distorted.

The interviews took place in participants' preferred language with the support of a field assistant who was trained and provided with knowledge about the research, its aims and objectives, as well as ethical issues surrounding the interview process. The interview sheets were pre-tested in order to assess and identify areas that need to be adjusted. The interview sheets were pretested on a pharmacist, an NGO representative and a WLWHA who were purposively selected in Abuja. The pre-test participants were given informed consent forms and the WLWHA was recruited by the NGO representative. After pre-testing, some questions appeared repetitive and were therefore merged.

A pilot study was done in Abuja, the capital city in Nigeria. Conducting a pilot study was necessary because it has the advantage of giving advance warning about the possibility of the main research failing. It could also pinpoint stages where parts of the research protocol may be skipped or adjusted, or whether there is a problem with appropriateness of the proposed methods or instruments or if it is too complicated (De Vaus, 1993). The same interview sheet was administered to key informants and WLWHA. The interview sheet typically contained demographic information about the participant such as participant ID which was numbered to ensure anonymity, age, marital status, occupation and level of education. This was followed by open-ended questions regarding

the seven steps in the PMTCT continuum namely; antenatal care attendance, adherence to voluntary counselling and testing, adherence to ARV medication, labour and delivery practices, infant feeding practice, infant follow up at postpartum and infant adherence to ARV medication. The research used a tape recorder with the permission of participants and the data collected was merely about participants' perspectives regarding the research question on barriers and challenges to PMTCT service utilization. Interview sheets that were used for both key informants and WLWHA are attached in the appendix section.

Table 2: Summary of Participants

Doctors/Nurses/Midwives	10
NGO representatives	10
Women Living with HIV/AIDS (WLWHA)	20
Total Number of Participants Reached	**40**

4.5 Data Management and Analysis

Data collected through in-depth interviews were inserted into Nvivo qualitative data analysis software and analyzed by means of content analysis as described by Tesch as cited in Creswell (1994). In this approach, the researcher looked for patterns and themes in conversations. The themes were then grouped by their relevance to the research question and sub-questions. Tesch as cited in Creswell (1994) provides a description of systematic theme analysis where the researcher uses a step by step method to objectively and systematically organize data. Information obtained from the key informant interviews were also analyzed using Tesch's steps which involve identification of themes and sub-themes by repeatedly reading through, coding and categorizing the interview sources. In other words, each sub-question was reviewed to find consistencies and

differences among interview data and relevant theories. Eight steps involved in Tesch's data analysis procedure were adopted. These include:

1. All transcriptions were read carefully while noting any ideas that the researcher thought were relevant.
2. One interview was selected, read and the meaning of all the relevant information was extracted and written out.
3. The researcher then went through the transcripts and grouped all similar topics into columns which were labelled as: Major topics, unique topics and leftovers.
4. Next the researcher abbreviated the topics into codes and wrote them next to the appropriate segment of each test. Then the data was organized and observed carefully to check for emergence of new categories.
5. The topics were fully described using the most suitable wordings followed by conversion of the words into categories in order to group similar topics together and therefore shorten the total list of categories. The groupings were indicated by drawing lines between the categories showing how the categories are interrelated.
6. Each category was then given a final abbreviation followed by an alphabetical arrangement of the codes.
7. Next was the gathering of all the data material that belonged to each category into a single file then performing a preliminary analysis.
8. Finally, the data was recoded where the researcher though it was necessary" (De Vos, 2002, p. 340).

This method of analysis was selected to enable results derived from interviews to be used in confirming theories relating to how gendered experiences of women inhibit their use of PMTCT

services in Nigeria. Challenges facing women in obtaining ARV drugs, HIV/AIDS counseling and formula milk for infants were identified from the interviews.

Using Nvivo qualitative data analysis software, all interviews were examined by reading through and making notes. Thereafter, all aspects of PMTCT that were relevant to this research were coded and assigned to categories/themes. The categories were then assigned to relevant sentences and paragraphs in order to describe all aspects of the interviews. A summary of coding and responses is included in Appendix 4. Properties of the codes were merged with key concepts then transformed into key variables (namely social support and health belief model) which are the main theories of interest in the study. Due to extensive pre-analysis of various literature sources as well as the PMTCT cascade which were discussed in chapters 2 and 3 of this study, a start list of categories was drawn up and a categorization matrix was developed as described by Elo & Kyngas (2008). Prior knowledge and assumptions from the literature review in chapter two served as a basis for pre-existing nodes that were compared with the responses gathered. The researcher then looked for similarities and differences between the nodes and organized them into a meaningful description of key themes and categories. Finally, the descriptive themes and their associated data were examined in light of the research questions, theories, assumptions and literature sources in order to make inferences on factors influencing PMTCT utilization and adherence. Table 2 summarises the criteria that was used in coding some of the responses based on a pre-determined set of themes.

Table 2: Themes

Name	Description
Access to CD4 count Services	CD4 count experience, Follow up counts, support,
Antenatal Care Attendance (ANC)	Stage of first ANC visit, how often WLWHA attended ANC, attitude to follow up visits and support received from partners, friends and relatives
Baby testing and treatment	Time of testing, results, follow up test, status of other children, challenges with taking ARV, Support
Effect of Stigma on use and adherence to PMTCT services	reasons for experiencing or not experiencing stigma and discrimination
HIV Testing	Time of first test, knowledge of HIV status, support received, HIV status disclosure
Immediate Postpartum experiences of WLWHA	Provision of ARV to mother and baby, support, challenges, follow up visits with baby
Infant feeding experiences of WLWHA	Reasons for choice of infant feeding, length of time baby was exclusively breast or formula fed, reasons for stopping the mode of feeding, constraints to chosen infant feeding
Key informant recommendations	What can be done to improve ANC attendance and what is the NGO/hospital doing to improve it?

Transcripts of Interviews and responses to open ended questionnaires were analysed using the process described by Tesch, (1990). Responses from both WLWHA and key informants were closely examined to create labels that summarize their experience of PMTCT service utilization and adherence as described in Table 3.

Table 3: Framework for Analysis

Main Themes	**Categories**	**Subcategories**
Reasons for PMTCT service use and adherence	Importance of having a healthy mother and a negative baby	Lives of mother and unborn child
HIV Testing	Knowledge and disclosure of HIV status	Testing late Non-disclosure
CD4 count experiences/ Follow up counts	Quality of hospital services	Unavailability of service at hospitals
Challenges of HAART use and adherence	Institutional, cultural and religious factors	Side effects of drugs, administrative bottlenecks, shortage of drugs supply/stock outs, religious factors, indirect costs, cultural factors
Labour experiences of WLWHA	Skilled birth attendance	TBA attendance, Un-booked cases. Reluctance, un-

		seriousness, hiding, Finance. Too late to go to the hospital
Immediate postpartum experience of WLWHA	Failure to attend follow up visits with baby	Side effects of ARV medication, economic hardship, lack of information about prophylaxis for baby
Baby testing/follow up tests	Inaccurate information	No follow up tests for babies
Infant feeding practices of WLWHA	Acceptance and health of nursing mothers	Confusion about infant feeding choices, poor lactation, inability to cope with EB, working mothers, family pressures, ignorance, poor information about baby's nutrition, latching problems, Acceptance by babies, fear of having cuts
Family and Community Support	Male partner and community / Family involvement	Lack of financial or moral support from partners, relatives and friends
Effects of stigma and discrimination	Non-disclosure of HIV status	Religious sentiments and ignorance

		Discrimination by family or community
Use of family planning services	Prevention of unintended pregnancies	Family size, financial reasons, prevent transmission, spacing pregnancies

4.6 Data Verification Procedures

The process whereby information is checked and confirmed, making sure and being certain is called verification. By verifying, the researcher is ensuring that there is reliability and validity as well as rigor in the study (Morse, Barrett, Mayan, Olson & Spiers, 2002).

Transferability. This is the process of representing different perspectives by establishment of similarities and differences across accounts (Morse et al., 2002 & Slevin, 2002). To achieve this, the findings in this research were supported and compared with verbatim accounts of selected participants which are thought by the researcher to be rich and thick.

Confirmability. This is when personal biases that may have an influence on the findings are accounted for (Morse et al., 2002). The researcher therefore recorded all the data accurately and provided a clear decision trail as well as ensured consistent and transparent interpretations.

Credibility. Krefting (1991) mentions peer review and member checking as ways of ensuring credibility in research. The researcher therefore conducted member checking by contacting the interview participants to clarify any disputed issues on the data collected. This ensured an honest account of PMTCT service utilization. Peer review was done by discussing the research process and findings with experts in qualitative research methods including the researcher's supervisor who has experience in PMTCT research.

Dependability. To ensure dependability, data types and methods are mixed in the form of triangulation as described by Olsen (2004) in order to validate claims that might emerge from a first pilot study. As such data from the information gathered from key informants was assessed against interview data with WLWHA in this study to ensure diverse viewpoints, higher predictive validity and reliability as described by Hunter and Hunter (1984) as cited in Olsen (2004).

4.7 Ethical Considerations

In order to conduct research on human subjects, certain guidelines need to be followed regarding participants' rights as stipulated by the national commission for the protection of human subjects of biomedical and behavioral research 1979. Therefore the standards of research prescribed by this commission in the Belmont report was adhered to by the researcher. The ethical considerations that were addressed include: human participants' protection, informed consent, do no harm and the right to privacy, voluntary participation, anonymity and confidentiality.

Human participants' protection. Ethical approval was obtained from the University of Cape Town's research ethics committee and the Federal Ministry of health in Nigeria. Permission was also sought from the Management of hospitals and support groups in order to conduct key informant interviews.

Informed consent. The participants of the research must know about their entitlement to decline at any stage of the interview for any purpose and to re-claim any data provided by them. Also the Social Research Association provides that no information that has the possibility of affecting the willingness of participants to partake in the study should be withheld. This research therefore obtained written consent from participants which is accompanied by the researcher's proposal and contains an explanation of the purpose of the research and what the process is, any

limitations to participating in the research and information regarding the possibility of risks they may experience.

Anonymity and confidentiality. The researcher guaranteed participants that no attempt is made to identify them in any form and the data gathered including tape recordings will be kept safe with restricted access. Ensuring anonymity means that the data will not be linked in any form to the participants' identities (Social Research Association 2003). To ensure this, only the researcher and participant were present at the interview room. No data regarding personal details of participants was required by the researcher. Names of NGOs were changed into codes as soon as the data was organized. Also, any audio tapes used were preserved in a safe and well protected place, inaccessible to anyone but the researcher and supervisor. The tapes will be erased after one year.

*Protection from harm and the right to privacy. T*he interview was conducted in a private place where no-one else will listen to the conversation. In order to further protect participants' rights to privacy, the researcher focused only on the questions relevant to the research objectives.

Voluntary participation. Participants were informed that partaking in the study was absolutely voluntary and participants were assured that should they decide not to participate, their decision will not affect their existing or subsequent relationship with the supervisor or service provider in any way. The researcher informed participants that if for any reason, they do not want to continue the interview, the interview will be stopped, no questions asked and that they possess the right to stop or terminate the interview at any stage without facing any consequences.

4.8 Limitations of the Study

The researcher's presence during interview, which is unavoidable in qualitative research, may have affected the reliability of responses of PMTCT care givers who may feel the need to provide

socially desirable answers. The women living with HIV/AIDS were reluctant to divulge information especially when they became emotional. This affected the adequacy of their responses in addressing the research questions in the study. Another limitation of the study is the reluctance of key informants to accept recording of the interviews due to heavy work load in health facilities. As a result, they were allowed to fill in the interview sheets in the presence of the researcher. Although open-ended questions were asked, some key informants provided responses either in the affirmative or negative without responding to the probe questions. To curtail the effects of this, the researcher asked additional probe questions to explain the rationale behind the questions. However, this was not possible for all key informants because some inexperienced key informants did not have enough information about PMTCT while others simply did not have time to respond adequately to all questions.

Given the nature of the topic HIV/AIDS, a more rigorous methodology would have been to interview PMTCT mothers and health care providers from resource poor settings but this was outside of the scope of this research. The extensive ethics procedure for a highly sensitive topic such as HIV/AIDS led to delays in obtaining the necessary permissions to conduct interviews in state owned clinics. As such, only one Federal Government owned and one private hospital were selected. Although the findings are broadly representative of prevailing PMTCT practices in Nigeria, caution should be exercised in generalizing findings to other geographical settings. The research found that some WLWHA mixed breast feeding with other liquids because the mother's milk was not enough and baby was not satisfied. However, the researcher expected to find more of cultural practices regarding exclusive breast feeding such as the need give traditional medicines to their babies.

4.9 Reflexivity

The researcher was drawn to the topic on PMTCT because a woman known to the researcher for many years found out she was HIV positive only two weeks before she died. If she had received antenatal care during pregnancy, she could have known her HIV status. Perhaps her baby died because of MTCT. This prompted the researcher to find out why women fail to use PMTCT services. Furthermore, the researcher shares similar gender experiences with participants coming from a culture where women are always regarded as inferior compared to their male counterparts and the health needs of women are often neglected. These similarities enabled the researcher to approach participants from an objective point of view while sharing experiences and being empathetic in interactions with them.

CHAPTER 5

PRESENTATION AND DISCUSSION OF FINDINGS

This chapter presents findings from in-depth interviews conducted with 20 WLWHA, 10 NGO representatives and 10 doctors on their experiences and perceptions of the use and adherence to PMTCT services in Rivers State. The chapter begins with a description of demographic profile of respondents. It follows with an in-depth presentation of major findings of the research. Drawing on the theoretical assumptions offered by social support theory and health belief model, the study investigates the extent to which WLWHA's decision to use and adhere to PMTCT services is shaped by these variables. The broad themes that emerged were organized based on the Nigerian PMTCT cascade/guidelines.

5.1 Socio-demographic Profile of Respondents

As shown on table 4, participants from WLWHA comprise 6 women from Rivers State, 5 women from Imo, 3 from Abia State, 2 from Anambra State and others from Ebonyi State, Delta, Niger and Benue States. This means that most of the respondents came from the South South and South Eastern parts of Nigeria, the regions with the highest HIV prevalence as discussed in chapter 1 of the study. Over half (11) of the respondents speak Igbo language, 3 speak Ikwerre while others spoke either Kalabani, Ogoni, Urhobo or Odoma language but all respondents had fair or average command of the English language thus they did not require a translator. It is also evident from table 1 that all the respondents were married except one who indicated that she was a widow. The maximum age of WLWHA interviewed was 46 while the minimum was 30 years old although most of the women were in their 30s. The average age of WLWHA was 36 years. Since 95 per cent of the WLWHA were married the researcher therefore expected to find that there is optimum support received by WLWHA from partners and relatives.

Table 4: Socio-demographic Profile of Women Living with HIV/AIDS (WLWHA)

Participant Category	Age	State	Ethnic Group	Marital Status
WLWHA 1	33	Abia	Igbo	Married
WLWHA 2	36	Rivers	Ikwerre	Married
WLWHA 3	38	Rivers	Ikwerre	Married
WLWHA 4	35	Imo	Igbo	Married
WLWHA 5	41	Imo	Igbo	Married
WLWHA 6	34	Rivers	Kalabani	Single
WLWHA 7	46	Rivers	Ikwerre	Married
WLWHA 8	44	Ebonyi	Igbo	Married
WLWHA 9	37	Abia	Igbo	Married
WLWHA 10	37	Abia	Igbo	Married
WLWHA 11	30	Rivers	Ogoni	Married
WLWHA 12	30	Rivers	Christianity	Married
WLWHA 13	30	Niger	Edo	Married
WLWHA 14	34	Anambra	Igbo	Married
WLWHA 15	34	Delta	Urhobo	Married
WLWHA 16	33	Anambra	Igbo	Married
WLWHA 17	34	Imo	Igbo	Married
WLWHA 18	36	Benue	Idoma	Married
WLWHA 19	40	Imo	Igbo	Married
WLWHA 20	38	Imo	Igbo	Married

Of the 21 key informants interviewed, majority (17) were from Rivers State. Majority of them spoke either Ijaw (7) or Igbo (6) languages while the remaining 7 key informants spoke either Ogoni, Ikwerre, Tsekiri or Efik languages. Almost all the key informants had bachelor's degree with only 1 Master's degree holder, 1 Diploma and 1 respondent with no degree at all. This indicates that the literacy level in Rivers State is quite high. In addition, half of the respondents or all the health care providers interviewed were either medical doctors or Obstetrics and gynecologists while the NGO representatives or half of the key informants were either counsellors nurses, social workers, data entry clerk or volunteers.

This profile indicates that there is a high caliber of health care providers working at the health facilities meaning that WLWHA should be receiving high quality information on PMTCT and survival strategies for their babies. The average age of key informants was 35 years. Of the 21 key informants, only 6 females were interviewed with only one female doctor out of 11 indicating that either males were more willing to be interviewed than their female counterparts or there were more males in the sample selected.

Table 5: Socio-demographic Profile of Key Informants

Participant Category	Age	State/ Ethnic Group	Education	Occupation
Dr 1	35	Rivers/ Ijaw	MBBS	Obs & Gynae
Dr 2	41	Rivers/ Urhobo	MBBS, Consultant	MD, Obs & Gynae
Dr 3	28	Rivers/Igbo	MBBS, MWACS	Obs & G, Senior Registrar
Dr 4	30	Rivers/ Ijaw	MBBS	MD, Gynae
Dr 5	32	Rivers/ Igbo	MBBS	MD
Dr 6	37	Rivers/ Ijaw	MBBS	MD
Dr 7	39	Rivers/ Ijaw	MPH, MBBS	MD

Dr 8	30	Rivers/ Ijaw	MBBS	MD
Dr 9	34	Rivers/ Ogoni	MBBS	Medical practitioner
Dr 10	33	Rivers/ Igbo	MBBS	O & G Registrar
Dr 11	34	Rivers/ Ogoni	MBBS, MSc	Public health physician
NGO 1	40	Ebonyi/Igbo		M & E officer
NGO 2	44	Rivers/ Ikwere	BSc	Social worker
NGO 3	25	Abia/Igbo	BSc	NGO representative
NGO 4	49	Delta/ Itsekiri	BSc	Graduate volunteer
NGO 5	37	Rivers/ Efik	BSc	Counsellor
NGO 6	28	Rivers/Igbo	BSc	Nurse
NGO 7	35	Imo/Igbo	BSc	Volunteer
NGO 8	22	Rivers/ Efik	Diploma	Data entry clerk
NGO 9	45	Rivers/Ijaw	SSCE	Social worker
NGO 10	28	Rivers/ Ogoni	BA	Data entry clerk

5.2 Reasons for PMTCT Service Use and Adherence

Most of the WLWHA attended ANC at a health facility from 12 weeks according to the instructions provided at the health facility. All participants responded that they attended at least 4 ANC visits and even more throughout their pregnancy mostly because it is expected to be a monthly routine visit. Contrary to the NACA (2014) PMTCT communication strategy that highlighted pregnant women's low motivation to use PMTCT services this finding indicates high utilization among the WLWHA interviewed. This may be due to the fact that most of the women

were informed of their HIV-positive status at the time of antenatal care and are therefore adequately linked with appropriate PMTCT services.

Importance of Having a Healthy Mother and Negative Baby.

When the theme reasons for utilization of PMTCT services and adherence was explored, most of the respondents noted that they attended all their antenatal care appointments. This was confirmed by key informants as evident in the following excerpt; *Mothers occasionally miss their appointments but adherence is good (Public health physician, age 34)*. WLWHA unanimously stated that they used the services because they wanted to stay healthy and to have HIV negative babies; *Yes. I attended because the life of my unborn child was very important to me (Mother of 2, age 33).* Another WLWHA states; *Yes. I followed all instruction given me because I wanted to live long (Mother of 2, age 33).*This is supported by a third WLWHA who states that she adhered to PMTCT; *To ensure that the baby is HIV negative (Mother of 5, age 36).* These responses are indication that many women are aware of the health benefits of PMTCT and are ready to use and adhere to instructions of health care providers as far as possible.

These findings are consistent with the assumptions of perceived susceptibility in the health belief model which assumes that when an individual has confidence that the susceptibility to the disease will be reduced (Rosenstock, 1974), they are more likely to engage in a healthy behaviour in this case, utilize PMTCT services. However, it was observed that the price of booking for antenatal care can hinder some women from attending ANC as noted by a key informant; *the price of booking is a concern* (*M&E officer, age 40)*. This is especially a problem for WLWHA who attend private health facilities. According to the perceived benefit in health belief model as described by Glanz et al. (2008), this perceived barrier did not reduce the level of utilization or

adherence to PMTCT because of their assessment of the value or efficacy associated with PMTCT to their health and their babies'.

5.3 HIV Testing

Mofenson & Mclntyre (2000) stated that a woman cannot make informed choices about preventative interventions unless she knows her HIV status. All the WLWHA interviewed in this study accepted HIV counselling and testing services even though some WLWHA did the test before pregnancy and already knew their HIV status before the first ANC visit.

Knowledge of HIV Status and Disclosure.

Generally, HIV testing was accepted by WLWHA given that most hospitals practice provider initiated HIV testing with the opt-out approach to ensure that every patient who presents for ANC is tested. This is evident in the following statement made by a key informant; *Women on ANC visits do not resist testing and WLWHA are compliant with their medications as they believe it will help the baby from contracting the disease (Gynaecologis/Obstetrician, age 41).* Most of the WLWHA find out their HIV status at the first stage of ANC while a few find out even before getting pregnant. These categories of respondents utilized PMTCT services. Two respondents reported that they found out their status during their earlier pregnancies and did not benefit from PMTCT services at the time;

> I discovered I was HIV positive when I was pregnant with my second child. My husband was also tested and confirmed positive for the virus. We were, thereafter placed on drug therapy (*Mother of 2, age 33*).

Another respondent states;

No I never knew I was positive, No, I only did testing during second pregnancy *(Mother of 2, age 28).*

A third woman only found out her HIV status after giving birth, making the risk of transmission to the baby very high. In these cases, their oldest children were therefore found to be positive thus indicating the importance of early knowledge of HIV status. As one of the WLWHA who discovered her HIV status late stated; *my first was positive but the other two are negative (Mother of 3, age 34).*

Furthermore, most women reported that they disclosed their status to their partners even though the partners were barely seen with them at the hospitals as stated by a key informant. *I have not seen their partners (Medical Practitioner, age 34*). This statement is confirmed in the response of a WLWHA. *No. the only time my partner accompanied me for a test was when we were about getting married (Mother of 5, age 36).* Others chose to disclose their results only to their partners to avoid stigma as evident in the following statement while another tested in church all of which can lead to non-adherence to PMTCT services. *Yes. I disclosed it to my partner alone*". *"I tested in church (Mother of 3, age 44).* These statements indicate lack of support to WLWHA by their partners during pregnancy. Also those who did not disclose their HIV status to anyone other than their husbands may not have any source of support since no friends and family members understand their situation. This finding does not conform to the theory of social support which assumes that more support indicates more utilization. In this study, more utilization was associated with less support. For example, it contradicts the finding of the study conducted by Busza et al. (2012) which showed that male partner involvement in HIV testing and antenatal care means a

statistically higher acceptance of ARV prophylaxis by their women, higher health facility delivery and attendance of follow-up visits.

Regarding baby testing, respondents were asked whether WLWHA tested their babies at 6 weeks and at 18 weeks. Generally, their responses were positive mainly due to maternal interest and to check the health status of their babies. However, it was observed that after testing at 6 weeks and baby is negative, some women did not bother to return for the second test at 18 weeks with many responses like; *No, just at birth* (*Mother of 2, age 33*). *Its been up to a year and some months (Mother of 2, age 28)*. With the babies who were tested and found positive, it is difficult to treat the babies especially when they are too young to understand their status. It is evident that there is a perceived barrier that is consistent with the health belief model based on the quote from a WLWH who states that;

> He keeps asking why he is the only one taking the drugs and I keep telling him that I want him to be healthier than others but I have not told him the truth about his condition. I intend to do that at some point in time (*Mother of 3, age 34)*.

5.4 CD4 count experiences/follow up counts

Like ANC and HIV testing, CD4 count check and follow up were also well utilized by WLWHA although some challenges were discovered.

Quality of Hospital Services.

WLWHA recounted their CD4 count experiences. They expressed willingness to check their CD4 count and follow up counts as evidenced by the following statement made by a WLWHA; *6 months*

in order to know how im doing (Mother of 3, age 30). Another WLWHA states; *Every six months to know if ART is working or not. I followed it as instructed (Mother of 3, age 34)*. These statements were confirmed by a key informant who stated that; *It is generally accepted as most people wish to know their CD4 as an assessment of improvement or decline (Public health physician, age 34).* These responses also indicate that perceived susceptibility and perceived benefit played a role in utilization of CD4 count services by WLWHA.

However, concerns were raised over the ability of hospitals to provide CD4 count services. A key informant noted that; *materials and machines are not readily available (Public health physician, age 34)* while some respondents cited *laboratory logistics* as a factor inhibiting utilization of CD4 count services. Others cited *cost and long waiting list* as factors as well as *delays in getting the result, unavailability of reagents and faulty machines*. For the patients attending private hospitals, key informants mentioned *financial problems* as a challenge for women seeking to check their CD4 count. These responses were verified by WLWHA who cited difficulty in accessing CD4 count services as evident in the following statement made by a WLWHA;

> My recent experience was not so good. I was referred to some other places because their machines were faulty at the hospital I registered *(Mother of 2, age 33).*

Another respondent made a statement regarding cost of CD4 count services. *Regularly/ I have been doing it every time they ask when I have money (Mother of 4, age 37).* These statements are indication of the low quality of CD4 count services provided in hospitals and that economic barriers may inhibit utilization of CD4 count services.

5.5 Provision of HAART

The literature by Kasenga, Hurtig and Emmelin (2010) revealed that some women especially those whose sexual partners were aware of their status failed to return for treatment because they were afraid of being economically bankrupt and the potential of facing domestic violence. Contrary to this finding from literature, this study discovered that acceptance of ARV for treatment and prophylaxis was very high with all women and key informants in the study confirming that WLWHA took their medication regularly.

Side Effects of Drugs, Health System Constraints and Socio-Cultural Factors.

Although key informants unanimously mentioned that there is sufficient use and adherence to HAART throughout pregnancy, it was discovered that there are a few gaps. As mentioned by Mofenson & Mclntyre (2000) in the literature section of this study, ability to find out HIV status early is a great determinant of whether WLWHA will use PMTCT services. A WLWHA states; *No, I knew my status after my delivery (Mother of 3, age 44).* A WLWHA in this situation is very likely to transmit HIV to her baby because no measure was taken for PMTCT throughout the pregnancy. Some women are said to experience strong side effects from the medication thus posing perceived barriers as described in the health belief model which assumes that adherence will be reduced in these situations.

At the health facility level, key informants reported that there are issues like *administrative bottlenecks, shortage of drug supply* and the fact that some women have to buy medication whenever it is not available. *Sometimes we don't have certain medication. If we don't have, they need to go and buy (NGO representative, age 25).* When asked about their challenges, a key informant mentioned; *Yes most women still go to TBA to have their child* (*Data entry clerk, age 28).* For these women, they are not likely to find out their HIV status hence, facing high risk of

transmitting HIV to their babies. Some key informants mentioned that the need to swallow tablets every day and too many tablets to swallow are also factors hindering effective administration of HAART. For example a key informant mentioned factors like; *Delay in decision making, patients in denial and side effect of drugs (Medical doctor, age 32)*. Other responses were hospital related difficulties such as volume of clients and funding. One notable response by a key informant is that; *there are some that resist us with excuses like they have been prayed for (M&E officer, age 40).* This means religious factors can hinder the use of medication by WLWHA.

As evident in the response from another key informant, payment for antenatal care by WLWHA is a factor that can hinder adherence even when HAART is provided free. *The HIV medication are free but they paid for medication like the antenatal and that is done by the client(Data entry clerk, age 28).* Therefore payment for other PMTCT services may lower the gains achieved in providing free medication to WLWHA. This claim was confirmed by a WLWHA who states; *it is free, but the transportation to get the medication is expensive (Mother of 3, 33 years)*.The responses by key informants were confirmed by WLWHA when most women complained about the side effects of HAART. One WLWHA said; *previous dosage was once every morning and evening but now the dosage has been changed to just every evening and the drug seem more potent (Mother of 2, age 33)*. Other WLWHA who also experienced high perceived barriers reported feeling dizzy and having dry lips while another woman narrates her experience in the following statement;

> At the onset I usually forget or feel reluctant. I sometimes mix it into my meal to enable me take it. But after a while, I became consistent and now it feels natural to me *(Mother of 3, age 34)*.

Another WLWHA said;

I have to eat a lot. The pills are very large and I have to take two

(Mother of 4, age 34).

5.6 Experiences of WLWHA during Labour and Delivery

Most WLWHA delivered in a health facility with a few exceptions and some WLWHA who were termed un-booked patients attended another health facility for ANC but showed up at a different health facility for delivery where their HIV statuses were unknown. In these cases, doctors would have no prior information about patient's history putting the baby at risk of MTCT.

Un-booked Patients.

Responses from both key informants and WLWHA revealed that most women who deliver in health facilities arrive at the first or second stage of labour. A few WLWHA noted that there was no time to get to the hospital so they delivered at home with the help of a midwife. *No. it was late and I could not go to the hospital, so a hospital staff help me deliver at home (Single mother, age 34).* When asked whether there are women who show up at the health facility for the first time during labour, some of the key informants mentioned that there are un-booked patients who did not attend antenatal care due to ignorance. *Yes. Some do clinic elsewhere but want to deliver here because of safe delivery (Graduate volunteer, age 49*). Another key informant states; *Im aware that most do not go for ANC (Public health physician, age 34).* One respondent further explained that this happens due to finance and the patients are usually worse off. *Yes un-booked. They have poor outcomes (Medical Practitioner, age 34). They attend traditional birth attendants where they are not screened and do not know their status (Public health physician, age 34).* Another key informant states;

> Yes. I think it is un-seriousness and some are just afraid that their partners would find out/ not taking it seriously/feel reluctant / some are hiding so the husband will not know *(NGO representative, age 25).*

In such cases, the WLWHA may not know her HIV status and there may be no time to carry out such test when she is at the final stage of labour. Consequently the babies will be at risk of being exposed to the HIV. Key informants noted that women usually prefer vaginal delivery to caesarean delivery as evident in the following statements by a key informant. *Most women here are not keen on CS and most women prefer natural delivery irrespective of viral load (Public health physician, age 34*). Another challenge expressed during labour as suggested in this theme is the absence of viral load machines. A key informant confirms this saying; *we don't have viral load machine (Social worker, age 45).* When asked about her viral load at the time of delivery, a WLWHA further corroborated this statement by stating that; *I didn't know then because no such test was conducted but I know now (Mother of 4, age 34).*

5.7 Immediate Postpartum Experiences of WLWHA

At postpartum, WLWHA are expected to receive Nevirapine for their babies for up to 6 weeks and septrin for 3 months while the mother is to continue taking ARV. Thereafter, the mothers are to attend follow up visits with their babies until the baby is 18 months based on the Nigerian PMTCT guideline by the Federal Ministry of Health (2016). At the post-delivery stage, WLWHA and key informants noted that mothers continued taking their ARV medication and babies are usually administered prophylaxis to prevent transmission of HIV. This aspect of PMTCT was also highly utilized and adhered to but some mothers were said not to return for follow up visits with their babies because they believed that their babies were negative.

Attendance of Follow-up Visits.

It was found that some WLWHA do not attend follow up visits even though adherence to ARV medication is very good. Key informants disclosed that no actual numbers of women returning for follow up was recorded and expressed concern that many patients are faced with economic hardship that might have affected their abilities to attend follow up visits. A key finding in this theme is that there are WLWHA who test their babies at birth and discover that baby is negative but they make no further effort to attend follow up visits to check baby's status. When asked whether she attended follow up visits, a WLWHA responded thus; *Not anymore/only at birth because he was discovered to be HIV negative (Mother of 2, age 34).* Another woman who attended follow up visits twice mentioned that her baby was not given nevirapine prophylaxis because her baby was ok. These have severe consequences for PMTCT. This finding conforms to the health belief model that perceived susceptibility of transmission of HIV to the baby has significantly reduced which translates to significant decrease in attendance of follow up visit after 6 weeks postpartum.

One of the challenges faced by WLWHA after caesarean delivery is that they are instructed not to eat immediately they are out of the theatre. This presents a difficulty because they cannot take the ARV medication without eating some food as evident in the following response; *I had to take the drug on an empty stomach since I delivered by CS and could not indulge in heavy foods even though the drugs require it (Mother of 3, 34 years).* Inability to eat after a caesarean section is a perceived barrier which prevents mothers from breastfeeding immediately after delivery and the baby may starve in the absence of supplementary food. When this happens, the aim of exclusive breastfeeding may be defeated.

5.8 Infant Feeding Practices of WLWHA

Many WLWHA understood the importance of exclusive breastfeeding and preferred it but some women stopped exclusive breastfeeding before 6 months against the recommendation of WHO and PMTCT guideline of the Federal Ministry of Health (2016). Others opted for exclusive formula feeding because of the information they received from health care providers about the high risk of MTCT.

Reasons for Choice of Infant Feeding.

Respondents in the study were well aware of the benefits of exclusive breastfeeding for PMTCT. When asked about their preferred choice of baby feeding, most WLWHA were said to prefer exclusive breastfeeding because it is affordable and because of the information provided to pregnant women during their ANC talks as suggested in the following; *Yes, it makes the child healthier and cuts my expenses on baby food (Mother of 3, age 38)*. In these cases, perceived benefit and perceived susceptibility assumptions of the health belief model played a role in determining infant feeding choices of WLWHA. A key informant supported this finding by stating that; *It is less likely for one to get confronted about their baby feeding practice if they are breastfeeding (Social worker, age 44)*. This finding conforms to the literature cited by Eide et al. (2006) that the most important consequence of participating in PMTCT program was that women experienced difficulty in breast feeding.

However, key informants noted that mixed feeding is common among WLWHA because it is difficult to keep up with. As suggested by a key informant; *they find it strenuous* (*Public health physician, age 34).* Another mentioned p*oor lactation and believe that breast milk alone is inadequate (Obstetrician and Gynecologist, age 35)*. Others mentioned that; *some of the women*

work (Obstetrician and Gynecologist registrar, age 33). A key informant summarized the issues in the following quote;

> Family pressures to add supplementary feeds, ignorance and poor flow of breast milk especially in the first few days after delivery *(Medical Doctor/Obstetrician and Gynecologist, age 34).*

These factors are common even among HIV negative mothers and have made it extremely difficult to achieve the goal of exclusive breastfeeding for the first 6 months. These issues were also confirmed by WLWHA in the following quotes; *I added water to the breastfeeding so that he will be more satisfied (Mother of 2, age 33*). This quote indicates that the respondent was misinformed. Another quote from a WLWHA shows that community pressure is also a factor that hinders utilization of PMTCT services;

> Certain persons expressed their concerns and suggested I switch to other food options but I stuck to breastfeeding *(Mother of 2, age 33).*

> A WLWHA adds that;

> Sometimes people suggest that I give him something else but I stuck to breastfeeding *(Mother of 1, age 35).*

Another challenge is that even though WHO recommended that breast milk and other foods should be given between 6 months and 1 year, many WLWHA reported that they stopped breastfeeding at 8 or 9 months giving reasons like the baby will bite them and become infected. While some women decided to give only formula to their babies for the first 6 months because of

the fear that baby will become infected as depicted in the following quote; *Exclusive formula feeding. We were informed that breastfeeding has a 50% chance of infecting the child and I did not want to take that risk(Mother of 3, age 34).* Other women were simply advised by their doctors to choose formula feeding as evident in the following quotes; *Doctor recommended baby formula* (*Mother of 4, age 36).Baby Formula. Doctors recommend one type of feeding practice (Mother of 4, age 34). I was instructed to buy NAN baby formula (Mother of 3, age 33).*

For WLWHA who chose exclusive formula feeding, they had to contend with societal pressure from those who are unaware of their HIV status. *The neighbors wanted to know why I was not breastfeeding. I excused myself from the argument with a sound excuse (Mother of 3, age 34)*. This response conforms to the finding in the literature that the practice of replacement feeding is stigmatized. Women opting to feed their children through replacement feeding are stigmatized in numerous cultures thereby complicating adherence by women who prefer to feed their children through this means. Identifying them as being HIV positive may result in stigma with consequences such as facing ostracism and expulsion from their family members (Horvath et al., 2010).

Other WLWHA were faced with the problem of low milk supply and were forced to stop exclusive breastfeeding from as early as 3 months while one woman had a cut in her nipples which prompted her to stop exclusive breastfeeding at 3 months. *Yes I stopped on my own because of difficulty of getting the milk out (Mother of 4, age 34). After three weeks the baby was not suckling properly so my doctor advised me to stick with infant formula* (*Mother of 1, age 41*). *I had a cut in my nipples (Mother of 3, age 37).* The aforementioned responses regarding mixed infant feeding by WLWHA confirm the literature cited by AED (2011) that mothers found exclusive breastfeeding difficult to practice especially for working mothers and those with inadequate milk.

The same study cited mothers who viewed that water was supposed to be given to babies for quenching thirst while others were pressured by family members and friends who could easily stigmatize them as being HIV positive. Also similar to this study was the finding by AED (2011) that non-breastfeeding was not commonly practiced in the study area because of its association with being HIV positive.

5.9 Effects of Stigma and Discrimination

When the theme effects of stigma and discrimination was explored, most women stated that they did not feel discriminated based on their HIV status.

Non-Disclosure of HIV Status.

Similarly, Amuzu (2008) states that people often fail to seek treatment for HIV/AIDS due to fear of being discriminated against. Contrary to this literature source, WLWHA in this study did not feel discriminated based on their HIV status. This is mostly because they did not disclose their status to any other family member except their partners. For example a WLWHA affirmed the following statement; *No, because I kept the information between my partner and the hospital staff (Mother of 2, age 33).* Another woman who feared stigma and discrimination disclosed;

> Yes, I was living with someone before marriage and I didn't want the person to find out so as not to get stigmatized and driven out of the house *(Mother of 3, age 33).*

This response is also evident in the finding by Amuzu (2008) that in certain instances, people living with HIV face rejection by friends, colleagues and may even experience eviction by their families. In addition, a key informant stated; *Yes RVD patients usually avoid ARV clinics close to*

their locality due to stigmatization (Obstetrician and Gynecologist, age 35). Some responses were related to *religious sentiments and ignorance (Obstetrician and Gynecologist, age 35)* while others mentioned that some women *do not want to be publicly seen in ARV clinics* (*Medical Doctor/gynaecology, age 30*).

Other responses were; *stigma reduces support from relatives and community (Medical doctor, age 32). They cannot come out openly and say their problems (Medical doctor, age 39).* The level of stigma and discrimination in health facilities plays a significant role in whether women return to the hospital for PMTCT. It was found that WLWHA are stigmatized by health workers' attitudes as mentioned by two WLWHA who stated that they experienced stigma from attitude of health workers to the extent of making them switch facilities in order to remain anonymous. For example, a key informant stated that; *some people decide against certain facilities (Social worker, age 44).* Another respondent noted that;

> when they come for antenatal and they are tested positive, they sometimes go elsewhere to register and some of the negative women would be looking at them with unease and that can make them not to show up for antenatal *(NGO representative, age 25)*.

In situations where only one family member knows, the death of that member means that support for WLWHA has been cut off.

5.10 Family and Community Support

Partners of WLWHA did not feel the need to accompany their wives at the early stages of pregnancy but during the latter stages, many WLWHA reported being accompanied by their partners and relatives. They also reported that they received financial support at the time of labour and were accompanied by either their partners or relatives.

Male Partner Involvement and Family/Community Support.

Although all the women stated that their partners were aware of their HIV status, most of the women attended antenatal care and other PMTCT services alone. A key informant noted that it is *very rare to see partners (Public health physician, age 34)*. Another stated; *based on statistics, most come alone (Social worker, age 45)*. These statements were confirmed by WLWHA who corroborated that they went alone to the hospitals for antenatal care and HIV tests as well as CD4 count. For example a woman stated that she attended *most times alone (Mother of 4, age 40)* while another woman mentioned that her husband accompanied her *only once (Mother of 1, age 35)*. Of greater concern is the acceptance that there is no place for the man in the PMTCT process. A statement made by a WLWHA affirmed this *there was no need for him (Mother of 1, age 41).* This statement is an indication that men are made to believe that their only traditional gender role is to provide financial support for their families thus making it difficult for them to perform non-financial roles. Unlike in the earlier stages of PMTCT, many of the WLWHA were accompanied by their partners or relatives to the hospital for labour. It is evident that during delivery, they also received financial support from their partners and relatives based on the following response *No, my cousin and my mom paid (Single mother, age 34).*

5.11 Use of Family Planning Services

Key informant interviews on the use of contraceptives by WLWHA revealed that acceptance of contraceptives by WLWHA is very high with no resistance.

Reasons for Use of Contraceptives.

The views of key informants were consistent with WLWHA who adhered to the use of family planning services giving reasons such as the need to prevent transmission, planning for healthy pregnancy, regulating family size and prevention of unintended pregnancies. These views are

supported by some of the responses of WLWHA such as; *to plan and build my CD4 count for the next baby (Mother of 3, age 30). Modern because its more secured. Yes because im through with child bearing (Mother of 2, age 28). Modern, Not sure of partner's faithfulness (Mother of 4, age 34).* In all these responses, perceived susceptibility in the health belief model played a greater role in the choices of WLWHA to use family planning services offered to them.

A key issue in this theme is that some of the WLWHA were not using any contraceptives even though they do not plan to have any more children as evident in the following responses; *No this would be the last (Mother of 2, age 33).* Having mentioned that she was not using contraceptives, a WLWHA states; *And I don't want more children. No im ok (Mother of 4, age 37).* Another WLWHA stated that she was not using contraceptives because she believes it fails even though she was not planning to have any more children. *No I don't. im ok with 3(Mother of 3, age 37).* The consequence of this is that where contraceptives fail and a WLWHA gets pregnant, she may not find out about her pregnancy early enough to partake in PMTCT to save her baby.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

In chapter one, the questions guiding this research centered on the influence of social support and health belief model on utilization and adherence to PMTCT services by HIV positive women in Rivers State, Nigeria. The guidelines on PMTCT as laid down by the Nigerian Ministry of Health served to provide the scope of defining the various components of PMTCT listed in chapter one. These PMTCT components include: Antenatal Care Attendance (ANC), HIV Counselling and Testing (HCT), provision of Highly Active Anti-Retroviral Therapy (HAART) and infant feeding counselling and support, labour and delivery, Baby testing and treatment as well as family planning services.

This chapter addresses the extent to which the research objectives were met by discussing the findings related to each objective. Recommendations were also formulated with regard to future applications of the research findings and their implications on social development and policy. This will provide the Ministry of Health with information on the assistance and guidelines that can be given to health care providers to enable them to implement the PMTCT program based on an understanding of the plight of WLWHA. It will also provide WLWHA with the necessary information on the need to adhere to PMTCT. Finally, the chapter discussed limitations to this research.

6.1 Conclusions

The first objective of this research was to explore the nature of PMTCT service utilization and adherence in Rivers State, Nigeria. Responses from both key informants and WLWHA revealed that utilization and adherence were very high. There were hardly any WLWHA who dropped out in the PMTCT process.

The second and third objectives which were to explore the factors influencing utilization and adherence of PMTCT services were captured in the reasons most frequently cited for WLWHA returning to health facilities for antenatal care, HIV tests and follow up. Even though the research revealed low social support for WLWHA especially at antenatal care, it appeared that social support was not the major reason for high PMTCT utilization and adherence. It was found that these factors are related to the belief that their babies will be negative and they will also live longer. These conform to the main tenets of health belief model described in chapter two. Specifically, perceived seriousness and perceived susceptibility were the major influencing variables for utilization and adherence of PMTCT services.

The fourth objective which sought to discuss the challenges facing WLWHA attending PMTCT programs was captured in all the themes that emerged. It appeared that health system constraints, were the major factors hindering health care providers from effectively providing PMTCT services such as unavailability of test kits, ARVs stock-outs, staff shortage was also a challenge resulting in patients waiting long hours to be attended to. Another challenge revealed in the themes discussed was socio-economic factors. It appeared that despite having a legal plan and framework to ensure that PMTCT services are available and free, the study revealed transport costs, payment for CD4 count and antenatal care as major socio-economic factors hindering HAART administration as well as the financial costs of formula feeding for women who would have preferred exclusive formula feeding.

The influence of these factors results in costs being imposed on HIV positive women and is made worse by financial dependence on their partners and family. Again, these factors did not affect the willingness or ability of WLWHA to seek and adhere to PMTCT services because of

their perceived seriousness and perceived susceptibility. These factors barely influenced utilization and adherence because WLWHA believed that they and their unborn babies were highly susceptible to HIV and were therefore more likely to take preventative measures. It therefore follows that perceived barrier in the health belief model did not influence PMTCT utilization and adherence.

The realities confronting WLWHA as suggested in this research provided examples of instances where fear of stigma, discrimination and abandonment resulted in lack of disclosure of HIV status even though this did not affect the use of PMTCT services. The main socio-cultural factors in this study were more likely to influence PMTCT use and adherence and have potential outcomes such as social isolation. Inevitably, cultural beliefs are said to influence infant feeding choices and the use of contraceptives which lead to high risk of transmitting HIV to the new born.

6.2 Recommendations

It is recommended that further research on PMTCT should look into what the priorities should be for an effective PMTCT program. In the researcher's opinion, efforts should be made by the Nigerian Ministry of Health to train more health care staff for PMTCT services such as HCT in public health facilities. This will eliminate long queues in clinics and reduce the burden of health care staff that are responsible for both PMTCT service provision and other health care needs of clients.

Varga, Sherman and Jones (2006) mention that social and community factors such as addressing HIV/AIDS stigma, improving awareness of PMTCT facts, addressing gender relations and encouraging male participation are particularly important for improving utilization to PMTCT services. This requires stronger efforts by nurses and midwives to co-ordinate meetings with HIV positive women who are faced with similar situations. In this way, they can share their experiences

and coping strategies therefore, becoming more confident in relating with their partners and families. Campaigns could be organized by community organizations and the media could be used to create community awareness on some of the factors hindering PMTCT utilization. This will generate support for HIV positive women who are threatened by stigmatization.

Poverty reduction is also considered as a gender sensitive factor in this research and it is important because it is one of the main factors and consequences of HIV/AIDS as mentioned by Whiteside (2002). Therefore, directly tackling poverty should remain one of the primary goals of public policies thereby enabling women to afford food and transport costs for visiting health facilities (Tladi, 2006; van Donk, 2002; Barnett & Whiteside, 2007). In this respect the researcher recommends partnership through communication with community organizations, Ministry of Social Development, Ministry of Health and National Agency for the Control of AIDS. This will ensure access to social grants for women in resource poor settings and allow policy makers to explore the possibility of bringing PMTCT services closer to the under resourced communities. Further research is needed to explore intensely into them. For reasons of practicality and to get the most experienced health care providers and NGO representatives, purposive sampling was used. A wider sample may have generated more varied results.

Since perceived susceptibility and seriousness play the greatest roles in PMTCT utilization and adherence, it is recommended that the Nigerian government should more attention to public health approaches such as the structured mentor mother programs proposed by Sam-Agudu et al. (2017). This will ensure retention in care and viral load suppression for mothers at postpartum and will complement on-going biomedical approaches to ensuring optimal utilization and adherence to PMTCT services. In line with this, other recommendations deduced including those made by key informants for strengthening PMTCT practices in Nigeria are:

- WLWHA at postpartum regardless of babies' HIV status should be required to attend scheduled follow up visits with their babies up to 18 months until doctors have certified the babies negative to ensure that the babies born to WLWHA remain negative.
- For pregnant women who appear in the health facility for the first time at the time of labour, effort should be made to find out their antenatal history from the initial health facility in order to know if there are any complications and HIV status including viral load.
- CD4 count and viral load machines should be procured and provided to all government owned health facilities and effort should be made to ensure that private health facilities comply with this standard.
- In order to address the issue of side effects of ARV medication, it is necessary to prescribe the brands that are taken only once daily because WLWHA feel these are more potent than those taken 2 or 3 times daily.
- Male partner and community support during early stages of pregnancy should be encouraged in addition to support provided at the time of delivery to ensure that WLWHA follow instructions made by health providers.
- To ensure that all WLWHA exclusively breast feed for 6 months, certified, trained lactation consultants should be made available and accessible to WLWHA at the time of delivery and nurses should inform and encourage them to attend consultation sessions. This will enable WLWHA address any issues they face with breast milk supply.

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APPENDICES

Appendix 1: Ethics Approval Letters

University of Cape Town Departmental Ethics Review

Original to Bryn

UNIVERSITY OF CAPE TOWN
Department of Social Development: ETHICS REVIEW FORM

ETHICS REVIEW FORM : JOINT STATEMENT BY STUDENT & SUPERVISOR
This form is filled in jointly by the student and the supervisor.

PROCESS:
Student and Supervisor need to read the UCT/FACULTY ETHICS GUIDELINES on the WEBSITE. The ethics pertaining to the profession of Social Work also needs to be taken cognisance of in relation to social work students/candidates carrying out research with human participants.

Once this ethics review form has been completed it is submitted to the Departments' Ethics Review Committee which according to the Guidelines laid down should consist of no less than three academics who will do the reviewing. In our instance the HOD as well as the designated committee members should assess the proposal/ethics.

Once the Department approves the proposal/ethics then only is it sent through to faculty.

This form should be completed by the research student and then co-signed by student and supervisor: Tick the YES or NO box, and write in details where appropriate. Please read the UCT Ethics Guidelines involving Human Subjects before completing the form. Ask your supervisor for clarification and help if needed.

Student researcher Name: ~~Farida~~ Jumare Fadila Jumare
Student number:

Title of research project: **Factors influencing Utilization and Adherence to Prevention of Mother to Child Transmission (PMTCT) of HIV in Rivers State, Nigeria**

Course Code: SWK 6002W

Degree: HD001 (PHD in Social Development)

Supervisor :Name: Dr Johannes John-Langba

11. Are there any foreseeable risks of harm to UCT or to other institutions that might result from or occur in the course of the research? e.g., legal action resulting from the research, the image of the university being affected by association with the research project, or a school being compromised in the eyes of the Education Ministry. If your answer is YES, give details and state below why you think the research is nonetheless worthwhile.	YES	NO ✓

12. Are there any other ethical issues that you think might arise during the course of the research? (e.g., with regard to conflicts of interests amongst participants and/or institutions) If your answer is YES, give details and say what you plan to do about it.	YES	NO ✓

Signed:
Student:

Co-signed:
Supervisor: pp

Date handed to the Dept Review Committee: Jan 2016.

Date of Review Meeting: Only will be reviewed when academic year starts. Reviewed 29/2/2016 by Dr C O'Brien. no reservations concerning the ethics of his study [15 minutes]

6

Scanned by CamScanner

Actual Time spent on review.. 15 minutes per Review.

Departmentally approved (YES/NO) if yes then passed on to Faculty if NO then returned to supervisor OR sent to Faculty Ethics Committee for further assessment.

Date forwarded to Faculty for approval.................... NOT deemed necessary.

Dr Kubeka's comments; Fine

Chair: Dr O'Brien

This ethics form scrutinised 26 February 2016 by Dr. Kubeka + Dr. O'Brien

Letter of Approval from the National Health Research Ethics Committee of Nigeria

National Health Research Ethics Committee of Nigeria (NHREC)

Promoting Highest Ethical and Scientific Standards for Health Research in Nigeria

Federal Ministry of Health

NHREC Protocol Number NHREC/01/01/2007-25/05/2017
NHREC Approval Number NHREC/01/01/2007-02/06/2017
Date: 02 June, 2017

Re: Factors Influencing Utilization and Adherence to Prevention of Mother to Child Transmission (PMTCT) of Human Immonodefiency Virus (HIV) Services in Rivers state, Nigeria

Health Research Committee assigned number: NHREC/01/01/2007
Name of Student Investigator: Fadila Jumare
Address of Student Investigator: Doctoral Degree Board
University of Cape Town
Masingene Building
Private Bag X3, Rondebosch,7701
Date of receipt of valid application: 25/05/2017
Date when final determination of research was made: 02/05/2017

Notice of Expedited Committee Review and Approval

This is to inform you that the research described in the submitted protocol, the consent forms, advertisements and other participant information materials have been reviewed and *given expedited committee approval by the National Health Research Ethics Committee.*

This approval dates from 02/05/2017 to 01/05/2018. If there is delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval of the study.* In multiyear research, endeavour to submit your annual report to the HREC early in order to obtain renewal of your approval and avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the Code. The HREC reserves the right to conduct compliance visit your research site without previous notification.

Signed

Professor Zubairu Iliyasu MBBS (UniMaid), MPH (Glasg.), PhD (Shef.), FWACP, FMCPH
Chairman, National Health Research Ethics Committee of Nigeria (NHREC)

Department of Health Planning, Research & Statistics
Federal Ministry of Health
11th Floor, Federal Secretariat Complex Phase III
Ahmadu Bello Way, Abuja

Tel: +234-09-523-8367
E-mail: chairman@nhrec.net, secretary@nhrec.net, deskofficer@nhrec.net,
URL: http://www.nhrec.net

Appendix 2: Transcript of Interviews

Transcript of Interview for WLWHA at Postpartum

Introduction: My name is Fadila Jumare. I am a PhD student at the department of social development in University of Cape Town, South Africa.

Interview Protocol: I would like to obtain information from you about your use of and adherence to PMTCT services during your pregnancy and after you have delivered your baby. The interview will not be longer than one hour and you have the right to withdraw from participating for any reason without consequences. Any information you provide will be kept in the strictest confidence and your identity or that of your NGO will not be revealed in any way. Do you have any questions?

Recording: I would like to record the interview so that I will not have to take lots of notes while we talk. Would that be a problem for you? I assure you that only the researcher and supervisors will listen to the recording. Please speak clearly so that we can hear what was said on the tape.

Thank you for agreeing to participate in this interview. I really appreciate the opportunity.

DEMOGRAPHIC INFORMATION

Participant ID: …………WLWHA 1…..………..

Age: ………33years………………………………

State and Local Government Area: …*Abia…State*.. Place of residence: *Port Harcourt, Rivers State.*

Language: ………Igbo…………………… Tribe or ethnic group: ……*Igbo Etche*…………...

Place of birth: ………*Abia…State*…………………………………

Date of birth of your 1st child: …*14th July, 2008*…………

Where was your last baby born? ……*28th March, 2015*……

Interview Guide

(**Probe**:

- Are you married? *Yes*
- Are you living with your partner? *Yes*
- Is this your first pregnancy? *No*
- If No, how many other children do you have? *2 Boys*
- ___*I previously had a miscarriage in October 2016, but I am currently pregnant. So my children are two in total now*._________

1. Tell me about your visits to the clinic during pregnancy (Antenatal Care (ANC). When did you attend your first ANC visit?

   (**Probe**:

- How many weeks pregnant were you then?*2 months (8 Weeks)*
- How old were you at the first visit? *30*
- How often did you attend? *Weekly (every Saturday)*
- Did you attend at least four times during your pregnancy? Why? Or why not?*Yes. I attended because the life of my unborn child was very important to me*

- Did you follow all the guidelines given by the instructors? Why? Or why not? *Yes. I followed all instruction given me because I wanted to live long.*
- Did your partner accompany you to antenatal care visits? *Yes*
- ____*I discovered I was HIV positive when I was pregnant with my second child. My husband was also tested and confirmed positive for the virus. We were, thereafter placed on drug therapy.*____

2. Next, I want to ask about HIV testing. Did you test for HIV during your pregnancy?

   (**Probe**:

   - When did you do the HIV test during antenatal care visit?*At my first visit (my registration visit)*
   - Is this the only time you've tested for HIV? *Yes*
   - Was that when you knew your status?*Yes*
   - Did the doctors recommend any further tests? Did you do them? *No, the doctors did not recommend any further tests*
   - Did you know before then? No
   - Did you go with your partner? If No, who accompanied you? Yes
   - Did you disclose the results with your partner or anyone close to you? Yes
   - Do you know your partner's HIV status? Yes
   - Does he know yours?) Yes

3. Next I want to ask about CD4 count. When did you get your CD4 count? *Six Months after registration*

(**Probe**:

- What were your experiences in accessing CD4 count services? My Recent experience was not so good. I was referred to some other places because their machines were faulty at the hospital I registered
- Were you referred to go somewhere else? Yes
- Did you go? Yes
- How often did you test for CD4 count? Did you go for follow up counts? Why or why not? Every Six months
- What was the result of the first count? 500+
- Who went with you to get the CD4 count? Did your partner accompany you? My Partner/yes
- Did they recommend HAART for life? Yes, they did
- ____

4. When did you start taking your PMTCT medication (HAART for life)? Immediately it was issued

(**Probe**:

- Did you take it throughout your pregnancy? If No, why? Yes
- For how long did you take it? Throughout the pregnancy
- Did you take the recommended dosage? Yes
- Did you take it as you were told? Yes

- What was the dosage? Once every morning and evening
- Did you have to take it every day? yes
- Did you receive support to take it every day? By who? If no, why not? yes
- Who paid for it? Free
- What challenges did you encounter while taking HAART medication? No
- ______Previous dosage was once every morning and evening but now the dosage has been changed to just every evening and the drug seem more potent ____
  ____

5. Let's talk about labour. Did you deliver at a health facility? Why or why not? Yes

   (**Probe**:

- When did you arrive at the health facility?Labour started at 1am and I went to the hospital at 4am but I put to bed at about 9-10am.
- Did you receive the ARV prophylaxis drug during labour or delivery to save your baby?
- What was your viral load at the time of delivery? I didn't know then (because no such test was conducted) but I know now.
- Did you deliver through Caesarean section? Who paid for the delivery?No I delivered normally/My partner
- Who went with you to the hospital for delivery? Did your partner accompany you? My partner and my siblings

6. Next, I would like to discuss what happened after you delivered. Was the baby injected with the ARV medication after delivery? If no, why? Yes, the baby was injected immediately it was delivered

(**Probe**:

- Are you taking PMTCT drugs after delivery? Why or why not? Yes/to maintain my health
- Is your baby also taking? For how long? Not anymore/only at birth (because he was discovered to be HIV negative)
- Who pays for the drugs? Do you have any support from the community or any one close to you?
- What challenges do you encounter while taking the medication? No
- How do you resolve them?
- Did you attend follow up visits through delivery to 18 months? How many times? No, but he was tested at birth.

  ______________ child was tested once at birth and found negative at birth but no or only one follow up visit was attended to check baby's status. ____ ______________________

7. Please tell me your experience during the first six months of infant feeding. Did they recommend any particular infant feeding practice? Did you follow the instruction? I breastfed for six months.

(**Probe**:

- Are you doing exclusive breast feeding, exclusive formula feeding? Why? I added water to the breastfeeding so that he would be more satisfied
- Did you follow through with your choice? Why or why not? yes
- Did you breastfeed following delivery? yes
- Did you stop exclusive feeding at 6 months? Why? If no, when did you stop? Who told you to stop? Your husband or is it an instruction from the hospital? I stopped breastfeeding after nine months on the instruction of the hospital.
- Will you continue exclusive feeding? Why? Yes, when I deliver again
- How old is your baby now? 2 years old
- Did you breastfeed after six months? Why? Yes, because the child desired it
- What major constraints did you face while exclusively feeding your baby?) Certain persons expressed their concerns and suggested I switch to other food options but I stuck to breastfeeding.

  ________________breastfed after 6 months against WHO recommendation____

  ____

8. Next, let's talk about baby testing. Has your baby been tested? If no, why? Yes

   (**Probe**:

   - When was the baby tested? At Birth
   - What was the result? Negative
   - Did you do the second test after 18 months? If no, why? No, just at birth (only after 6 months)
   - What was the result?

- What is the status of your other children?) Negative

9. Next I want to ask about HIV medication for the baby who tested positive. Is the baby on HAART drugs for life? If no why?

   (**Probe**:

   - Is it easy to get the medication?
   - What are some of the challenges you encounter in getting the medication? Is it always available?
   - Do you get any support from the community or anyone close to you while trying to access the medication?
   - Is your baby accepting it?
   - Who pays for it?)

10. Are you using any family planning? If no, why?*No but we plan on stopping at the third*.

    (**Probe**:

    - Why are you using family planning?
    - Are you using modern or traditional methods? Why?
    - Do you plan to have any more children? Why? Or why not?) *No, this would be the last*
    - ____
      ____

11. Do you experience any form of stigma and discrimination based on your HIV status?*No, because I kept the information between my partner and the hospital staff.*

(**Probe**:

- Do you think this has affected your use and adherence to PMTCT services? How?

No stigma experienced because status has not been disclosed to other family members____

____

____

12. Observation:

- ____

____

____

12. General Comments:

13. ____

______

Thank you for your time and the information you have shared with me.

Transcript of Interview for Key Informants from NGO Representatives

Introduction: My name is Fadila Jumare. I am a PhD student at the department of social development in University of Cape Town, South Africa.

Interview Protocol: I would like to obtain information from you about the factors influencing utilization and adherence of PMTCT services. The interview will not be longer than one hour and

you have the right to withdraw from participating for any reason without consequences. Any information you provide will be kept in the strictest confidence and your identity or that of your clinic will not be revealed in any way. Do you have any questions?

Recording: I would like to record the interview so that I will not have to take lots of notes while we talk. Would that be a problem for you? I assure you that only the researcher and supervisors will listen to the recording. Please speak clearly so that we can hear what was said on the tape.

Thank you for agreeing to participate in this interview. I really appreciate the opportunity.

DEMOGRPHIC INFORMATION

Participant ID: ………NGO 1…………………………………..

Age: ……………………40……………………………………

State: ………Ebonyi…………………………………………………….

Place of residence: …………Port Harcourt, Rivers State…………………………………

Local Government Area: ………Etchet………………………………

Place of work: ……………………Health of the Sick Hospital……

Language: …………………Igbo…………………………………..

Tribe or ethnic group: …………Igbo………………………………

Interview Guide

1. Can you tell me about yourself?

   (**Probe**:

   - What is your level of education?
   - What are your qualifications?
   - What is your occupation? M & E Officer
   - How many years of experience do you have in the HIV/IDS sector/program? 15 Years
   - For how long have you been working in this NGO? 8 years
   - ____ ____ _______

2. Please tell me about the attitude of WLWHA towards antenatal care attendance?

   (**Probe:**

   - When do most WLWHA attend their first ANC? Some come early and some late
   - At how many weeks of pregnancy do most WLWHA begin ANC? Like I said, some come early and some come later
   - How often do most WLWHA attend ANC?

- Do most WLWHA attend at least four times during their pregnancy? Why? Or why not? Every Friday is ANC in this Hospital and some like to come every Friday, some twice a month or once a month but it is always more than four times.
- Do the partners of most WLWHA accompany them to antenatal care visits? Some partners do
- What can be done to improve ANC attendance? Price of the booking is a concern
- Is the NGO doing anything to improve ANC attendance? Yes, we enlighten them on the importance of it

Not all women attend antenatal care 4 times. Some attend even more than 4 times. Price of antenatal care may prevent some women from attending____

____

______

3. What are your views about uptake/ of HIV Counseling and Testing (HCT) by WLWHA. (**Probe:**
   - Do most WLWHA accept the HIV test? Yes
   - Do most WLWHA return for their test results? Yes
   - When do most of the WLWHA find out their status? Some find out here while some already know. HIV test for pregnant women is mandatory here.
   - Do most WLWHA already know their status before ANC? Some know while some don't.
   - Do most WLWHA go for HIV tests with their partners? If No, who accompanies them? We tell them to bring their partners

- Do the partners of most WLWHA take the HIV test? We encourage it and they respond to it
- If no, do they disclose the results with their partners or anyone close to them? Some disclose it themselves but in case they are afraid to, we invite their partners and take them through counselling where we expose the result to them
- Do most WLWHA know their partners' HIV status? Yes, but with the permission of the partner
- What can be done to improve HIV testing utilization and adherence? There is no issue with the testing nor is there any issue with compliance from the people.
- What is your NGO doing to improve HIV testing utilization and adherence?
- ________We are doing a lot to make them take the test ____ ______________

4. Next, I want to talk about CD4 count.What is your view about the general uptake with CD4 count by WLWHA?

   (**Probe**:

   - Do most of the women go to receive their CD4 count?
   - What are the challenges with accessing CD4 count? Sometimes we run out of reagents
   - Are they referred to other facilities for CD4 count services? Yes, they are

- What should be done to improve CD4 count services? They have to ensure the reagents are always available
- ______________________hospital related difficulties____

5. Tell me about the use of HAART for life. What are the current recommendations for initiating HAART for pregnant WLWHA? As soon as they are tested, they start taking the drug

   (**Probe**:

   - Do most WLWHA take their medication throughout their pregnancy? If No, why? They take it throughout their life time
   - What are the challenges? None in this hospital
   - For how long on average do most WLWHA take their medication? A lifetime
   - Do most WLWHA take the recommended dosage? Yes
   - Do you experience any resistance from WLWHA in administering the medication? There are some that resist us with various excuses like they have been prayed for.
   - Who pays for medication for most WLWHA? The government
   - Do most WLWHA receive any support from their partners or community in accessing the medication?
   - Is the medication readily available? Yes, it is
   - What are the problems hindering effective administration of PMTCT medication? None
   - Have these problems always been there?

- Are there any improvements?
- What can be done to improve the problems?
- What is the NGO doing to address the problems?)

_____religious factors can hinder the use of medication____________________

6. Let's talk about labour. Do most WLWHA registered in your NGO return to the hospital for labour and delivery? Why or why not?

   (**Probe**:

   - At what stage of labour do most WLWH arrive at the clinic?
   - Do you know of WLWHA who are seen for the first time at the time of delivery or at postnatal stage? Why do you think this happens? Yes, there are. I think it is a poverty thing
   - Do most WLWHA with high viral load accept Caesarean section at delivery? Why or why not? CS is by choice
   - Do most WLWHA with low viral load accept natural delivery? Why or why not?)
   - ____
     ____

7. Next, I want to discuss what happens after WLWHA have delivered. Are their babies injected with ARV prophylaxis medication immediately after delivery? Yes, as soon as a HIV positive woman delivers, we give the baby medication for six weeks (Nevirapine syrup for 6 weeks, test after 6 weeks)

   (**Probe**:

- Do most mothers continue taking PMTCT medication after delivery? For how long? Yes
- Are the babies of most WLWHA also taking PMTCT medication? Yes
- For how long?
- Do most WLWHA take the recommended dosage?
- Is there resistance in uptake of the PMTCT medication?
- Has this resistance always been there?
- Are there any improvements in uptake of PMTCT medication?
- What can be done to improve uptake of PMTCT medication by WLWHA?
- What is the NGO doing to address the problems?
- Do postpartum WLWHA attend follow up visits through delivery to 18 months? How many times?)

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8. Tell me your experience with exclusive infant feeding practices of WLWHA.

   (**Probe**:

   - What is the recommended infant feeding practice by the health providers in this state? We recommend six months exclusive breastfeeding
   - Do most WLWHA adhere to it? Yes
   - What is the most common infant feeding practice? Why do you think it is common? Some do formula feeding and some do breastfeeding
   - Do most WLWHA breastfeed following delivery? Yes

- Is mixed infant feeding common among WLWHA? Why is it so? Yes, in cases where the women complain they cannot cope with just breastfeeding
- Do they stop exclusive infant feeding at 6 months? Why? We recommend it so they can add other things to the baby's food catalogue. Poverty
- When do most WLWHA stop exclusive infant feeding?
- Do you find WLWHA still doing exclusive infant feeding after 6 months? Why?
- What major constraints do you encounter in ensuring that they exclusively feed their infants for 6 months? Ignorance, mostly

________We encourage them to feed the baby with breast milk up till one year since there is no fear of contracting the virus

____

________________________________this is not a WHO recommendation___

9. Let's talk about baby testing. Do most WLWHA get their babies tested for HIV after delivery? Why or why not? Yes, after six weeks

   (**Probe**:

   - Do most WLWHA return for the results? Why or why not? Yes
   - Do most WLWHA test their babies at 18 months? Why or why not? Yes, to be sure the bay is actually free

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10. Next I want to ask about HIV medication for babies with positive results. Do you place them on HAART medication for life? Why? Yes

    (**Probe**:

    - How much does the medication cost? It is free

- Do you experience any resistance from the mothers buying the medication? None
- Are the babies accepting it? Yes
- Is there any resistance in the uptake of PMTCT medication by babies born to WLWHA?
- Has this resistance always been there?
- Are there any improvements?
- What can be done to improve uptake of PMTCT medication for the babies?
- What is the NGO doing improve uptake of PMTCT medication?)

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11. Next, I would like to discuss about the use of family planning by WLWHA.

    (**Probe**:

    - Do you recommend family planning to WLWHA? Why or why not? Yes
    - Do most WLWHA opt for modern or traditional methods? That's personal to them
    - Do most WLWHA adhere to their chosen method? Yes

12. Do you think WLWHA are experiencing stigma and discrimination? They do but we try to encourage them

    (**Probe**:

    - Do you think that is affecting adherence and use of PMTT services? How? Yes

13: Observation:

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13. General comments

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Thank you for the time and information you have shared with me.

Transcript of Interview for Key Informants from Health Care Providers

Introduction: My name is Fadila Jumare. I am a PhD student at the department of social development in University of Cape Town, South Africa.

Interview Protocol: I would like to obtain information from you about the factors influencing utilization and adherence of PMTCT services in your clinic. The interview will not be longer than one hour and you have the right to withdraw from participating for any reason without consequences. Any information you provide will be kept in the strictest confidence and your identity or that of your clinic will not be revealed in any way. Do you have any questions?

Recording: I would like to record the interview so that I will not have to take lots of notes while we talk. Would that be a problem for you? I assure you that only the researcher and supervisors will listen to the recording. Please speak clearly so that we can hear what was said on the tape.

Thank you for agreeing to participate in this interview. I really appreciate the opportunity.

DEMOGRPHIC INFORMATION

Participant ID: …Dr 1..………………………………………..

Age: ………………………34 years old………………………

State: …………………Rivers State…………………………….

Place of residence: ………………Rummuobiakani……………

Local Government Area: ………Port Harcourt…………………

Place of work: ………………Health of the Sick Hospital………

Language: ……………………………English…………………..

Tribe or ethnic group: …………Ogoni Rivers State………………

Interview Guide

1. Can you tell me about yourself?

(**Probe**:

- What is your level of education? Postgraduate
- What are your qualifications?MBBS, MSc University of Port Harcourt
- What is your occupation?I am a Public Health Physician
- How many years of experience do you have in the HIV/IDS sector/program?3 years in HIV/AIDS Started with AHNI as a volunteer then FHI 360 USAID under SIDHAS project then AHNI Global fund project. For how long have you been working in this clinic/hospital?I have been with the NGOs for the past 3 years.
- ____

2. Please tell me about the attitude of WLWHA towards antenatal care attendance?

(**Probe:**

- When do most WLWHA attend their first ANC? Most women register between the 2nd -3rd trimester. More volunteers to reduce time spent in clinic. At how many weeks of pregnancy do most WLWHA begin ANC? On the average 16-20 weeks after they feel sure they are pregnant and the pregnancy is stable.
- How often do most WLWHA attend ANC? Most women attend monthly ANC here.
- Do most WLWHA attend at least four times during their pregnancy? Why? Or why not? Yes though working with mothers occasionally miss their appointments but adherence is good.
- Do the partners of most WLWHA accompany them to antenatal care visits? No very rare to see partners.
- What can be done to improve ANC attendance? More incentives for women.
- Is the clinic doing anything to improve ANC attendance? Yes they are doing well in trying to provide staff but the gap is not closed yet.
- ____

3. What are your views about uptake/ of HIV Counseling and Testing (HCT) by WLWHA.

(**Probe:**

- Do most WLWHA accept the HIV test? The test is still being accepted with scepticism
- Is there any improvement in HCT acceptance?
- Do most WLWHA return for their test results? Yes they do.
- Is that when most of the WLWHA find out their status? Same day result is practiced here.

- Do most WLWHA already know their status before ANC? A few of them already know.
- Do most WLWHA go for HIV tests with their partners? If No, who accompanies them?No they usually come alone.
- Do the partners of most WLWHA take the HIV test?Only after persuasion.
- If no, do they disclose the results with their partners or anyone close to them? Yes they do
- Do most WLWHA know their partners' HIV status? Most do but a few do not continue
- What can be done to improve HIV testing utilization and adherence in your clinic?
- What is the clinic doing to improve HIV testing utilization and adherence?)
- __Provider Initiated Counseling and Testing (PICT) with the opt out approach ensuring that everyone who steps in for ANC is tested____

4. Next I want to talk about CD4 count. When do you usually reveal the result of their first CD4 count?

(**Probe**:

- What is your view about the general uptake with cd4 count by WLWHA?It is generally accepted

- Do most of the women go to receive their CD4 count? as most people wish to know their CD4 as an assessment of improvement or decline.
- What are the challenges with accessing CD4 count?Materials and machines are not always readily available.
- Do you refer them to other facilities for CD4 count services?Yes they are referred to the closest center with CD4 machine eg Obio cottage, military hospital, etc.
- What should be done to improve CD4 count services? _Ensuring that men and materials are available at all time.____

  ____

5. Tell me about the use of HAART for life. What are the current recommendations for initiating ARV medication for HIV pregnant WLWHA?

(**Probe**:

- Do most WLWH take their medication throughout their pregnancy? If No, why? Yes they do. Occasional misses are noted especially due to TDF 600mg side effects.
- If no what are the challenges?
- For how long on average do most WLWHA take their medication? They take them throughout the period of pregnancy
- Do most WLWHA take the recommended dosage? Yes
- Do you experience any resistance from WLWHA in administering the medication? Not much only in starting treatment.

- What are the problems hindering effective administration of PMTCT medication?
- Who pays for medication for most WLWHA?NGOs pay.
- Do most WLWHA receive any support from their partners or community in accessing the medication?Not much support I would say.
- Is the medication readily available? Yes it is with few gaps.
- Have these problems always been there?
- Are there any improvements?
- What can be done to improve the problems? More adherence counselling
- What is the clinic doing to address the problems?) Yes ongoing adherence at every point been emphasized. Yes use of mentor mother's and…
- ____
  ____

6. Let's talk about labour. Do most WLWHA registered in your clinic return for labour and delivery? Why or why not?

   (**Probe**:

   - At what stage of labour do most WLWH arrive at the clinic? Most come at the second stage of labour.
   - Do you give them ARV prophylaxis drug during labour or delivery?Yes
   - Do you know of WLWHA who are seen for the first time at the time of delivery or at postnatal stage? Why do you think this happens?Im aware that most do not go

for ANC. They attend traditional birth attendants where they are not screened and do not know their status.

- Do most WLWHA with high viral load accept Caesarean section at delivery? Why or why not?Most women here are not keen on CS
- Do most WLWHA with low viral load accept natural delivery? Why or why not?)
- __Most women prefer natural delivery irrespective of viral load____

7. Next I want to discuss what happens after WLWHA have delivered. Are their babies injected with ARV medication immediately after delivery?

(**Probe**:

- Do most mothers continue taking PMTCT medication after delivery? For how long? They are given Nevirapine.
- Are the babies of most WLWHA also taking PMTCT medication? For how long?Yes they are, 6 weeks then DBS then Septrin.
- Do most WLWHA take the recommended dosage?
- Is there resistance in uptake of the PMTCT medication? No there is no resistance
- Has this resistance always been there?
- Are there any improvements in uptake of PMTCT medication? Yes they are improving
- What can be done to improve uptake of PMTCT medication by WLWHA?Constant monitoring of women

- What is the clinic doing to address the problems?Ensuring that they pick up their drugs when due
- Do postpartum WLWHA attend follow up visits through delivery to 18 months? How many times?)

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8. Tell me your experience with exclusive infant feeding practices of WLWHA.

(**Probe**:

- What is the recommended infant feeding practice by the health providers in this state? Breastfeeding
- Do most WLWHA adhere to it? Yes
- What is the most common infant feeding practice? Why do you think it is common?they prefer breastfeeding
- Do most WLWHA breastfeed following delivery?Yes
- Is mixed infant feeding common among WLWHA? Why is it so? YesIndecision about infant feeding before delivery
- Do they stop exclusive infant feeding at 6 months? Why? When do most WLWHA stop exclusive infant feeding? Most before 6 months say it is stressful at 3 months
- Do you find WLWHA still doing exclusive infant feeding after 6 months? Yes a few Why?Inadequate information
- What major constraints do you encounter in ensuring that they exclusively feed their infants for 6 months?)They find it strenuous

9. Let's talk about baby testing. Do most WLWHA get their babies tested for HIV after delivery? NoWhy or why not? No test kits

(**Probe**:

- Do most WLWHA return for the results? Why or why not? Yes they return for results
- Do most WLWHA test their babies at 18 months? Why or why not?)Most test of DBS are done at 6 weeks and after that if positive most do not bother to repeat. 18 months testing is rather rare because of DBS

10. Next I want to ask about HIV medication for babies with positive results. Do you place them on HAART medication for life? Yes Why?

(**Probe**:

- How much does the medication cost? Free courtesy of NGO
- Do you experience any resistance from the mothers buying the medication? No
- Are the babies accepting it? Yes
- Is there any resistance in the uptake of PMTCT medication by babies born to WLWHA? NO
- Has this resistance always been there? NO

- Are there any improvements? Yes
- What can be done to improve uptake of PMTCT medication for the babies? Availability is the problem
- What is the clinic doing improve uptake of PMTCT medication?)Improving our supply

____

11. Next, I would like to discuss about the use of family planning by WLWHA.

    (**Probe**:

    - Do you recommend family planning to WLWHA?Yes contraceptiveWhy or why not?For prevention of transmission
    - Do most WLWHA opt for modern or traditional methods?Traditional methods
    - Do most WLWHA adhere to their chosen method?)

12. Do you think WLWHA are experiencing stigma and discrimination?

    (**Probe**:

    - Do you think that is affecting adherence and use of PMTT services? How?Customs and tradition

13: Observation:

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13. General comments

Thank you for the time and information you have shared with me.

Appendix 3: Interview Information and Informed Consent Forms
Informed Consent Forms

RESEARCHER'S DETAILS	
Title of the Research Project	**FACTORS INFLUENCING UTILIZATION AND ADHERENCE TO SERVICES FOR PREVENTION OF MOTHER TO CHILD TRANSMISSION OF HIV IN RIVERS STATE, NIGERIA**
Investigator's Details	FADILA JUMARE
Address	NO 13 ADAMU HUSSAINI STREET DANTATA ESTATE, KUBWA, ABUJA
Contact Telephone Number	+2348096387247
Email	fjumare@gmail.com
INTERVIEW INFORMATION	
Aim	• The researcher is studying to: explore factors that influence utilization and adherence to PMTCT services by HIV positive women in Rivers State, Nigeria

	The information will be used for PhD thesis.
Procedures	Structured in-depth interviews will be conducted with participants. Verbal, open and direct questions will be used to obtain participants' views on factors influencing and utilization and Adherence to PMTCT services by WLWHA
Risks	There are no risks involved as a result of participating in this study.
Possible Benefits	The information collected is geared towards improving PMTCT services.
Anonmity	Participants' identities will not be revealed in any discussion, description or scientific publications by the investigators.
Confidentility	All information collected will be strictly confidential. The data will be secured, password, coded and only accessible to the researcher, the supervisor and the field worker.
Voluntary Participation/ Refusal/ Discontinuation/Privacy	Participation in this study is voluntary and any decision whether or not to participate will in no way affect their present or future

	relationship with the supervisor/service provider. Even if you have decide not to participate, you have the right to terminte at any time without jeoprdising your reltionship with you supervisor/service provider. The interview will be conducted in a private place where noone else will listen to the converstion.
Please Answer the Following Questions by Circling your Responses:	
Have you read and understood the information about the above study?	YES NO
Have you been able to ask questions about the study?	YES NO
Have you received enough information about this study?	YES NO
Do you understand that you are free to withdraw your participation in this study at any time without giving any reason and without any effect on your relationship with your supervisor/ service provider?	YES NO
Do you understand that your responses will be made anonymous before they are analyzed?	YES NO

Do you give permission for the research supervisors to have access to your anonymous responses?	YES	NO
Do you understand that your participation in this study will not result in any risk?	YES	NO
No pressure was exerted on you to consent to participation in this study.	YES	NO
Do you agree to take part in this interview?	YES	NO

I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE INTERVIEW OF THE ABOVE-MENTIONED STUDY:

Signed/confirmed at……………………………………….. on

2017

Full Name and Signature of Participant

Thumb Print of Participant	I hereby confirm that I have explained the information given in this document to the undersigned participant and was encouraged and given ample time to ask questions.
	Full name and Signature of Researcher

Application to Conduct Research: Clinic/Hospital Manager

Letter of Invitation to clinic manager

My name is **FADILA JUMARE**, and I am a PhD student at the University of Cape Town, South Africa. I am conducting research on **factors influencing utilization and adherence to Prevention of Mother to Child Transmission (PMTCT) of HIV services in Rivers State, Nigeria**under the supervision of **Dr Johannes John-Langba**. I wish to invite you to consider taking part in this study. The study has met the requirements of the Research Ethics Committee of the University of Cape Town.

Aims of the Study

The study aims to:

1. Understand the nature of adherence and utilization of PMTCT in Rivers State, Nigeria;
2. Examine factors that influence decisions to utilize PMTCT services by Women Living with HIV/AIDS;
3. Examine factors that influence adherence to the PMTCT services by women living with HIV/AIDS;
4. Identify the barriers and challenges to adherence and utilization of PMTCT services.

Significance of the Study

The study is significant in the following ways:

- Aid in the integration of PMTCT into sexual and reproductive health programming and promote fair distribution of health services in Nigeria.
- Contribute to improved maternal health, child survival and support for Nigeria's effort to implement the National PMTCT program.
- Maximize the efficacy of biomedical approaches to HIV prevention.

Benefit of the Study to the Clinics

- Enable health managers to spot concerns of women who are not utilizing or adhering to PMTCT services and resolve their needs.

Research Plan and Method

Structured questionnaire survey will be administered by the researcher to healthcare staff providing PMTCT services in your clinic. Verbal, direct questions will be used to obtain participants' views on how cultural practices and economic statuses affect women's utilization of PMTCT services. Participants will not be required to provide any personal details. To gain access to the participants, permission will be sought from the participant prior to their participation in the research. The researcher will make appointment with only those who consent. The interview will take place in a private room with only the participant and the researcher present and will not be more than one hour long. A tape recorder will be used only for the purpose of data analysis. All information collected will be treated in strictest confidence and neither the clinic nor individual staff will be identifiable in any reports that are written. Participants may withdraw from the study at any time without any consequence. The role of the clinic is voluntary and the clinic manager may decide to withdraw the clinic's participation at any time without consequence. The data to be collected is merely about participants' perspectives regarding the issues, data will not be sensitive in nature and no harm or risk is faced by any participant or by the clinic. The research is to obtain a PhD. It is not for a government program or anything else and therefore data will not be sent anywhere and will only be used for completing this degree.

Clinic Involvement

Once I have received your consent to approach healthcare staff to participate in the study, I will:

- Arrange a time with your clinic staff for interview to take place.

- Arrange for informed consent to be given to participants and obtain completed informed consent forms from participants.

Attached for your information is a copy of the Participant Information Statement and Consent Form.

Invitation to Participate

If you would like your clinic to participate in this research, please complete and return the attached form.

Thank you for taking the time to read this information.

FADILA JUMARE

University of Cape Town, South Africa

Clinic/Hospital Manager Consent Form

I give consent for you to approach clinic staff who are responsible for implementing the PMTCT program to participate in the research titled: **Factors Influencing Utilization and Adherence to Services for Prevention of Mother to Child Transmission of HIV in Rivers State, Nigeria**

I have read the project information statement explaining the purpose of the research project and understand that:

- The role of the clinic is voluntary.
- I may decide to withdraw the clinic's participation at any time without consequence.
- Clinic staff who are responsible for implementing the PMTCT program will be invited to participate and that permission will be sought from them.
- Only clinic staff who consent will participate in the project.
- All information obtained will be treated in strictest confidence.
- The purpose of this study is to obtain a degree and not for official government or other use.
- The staffs' names will not be used and individual staff will not be identifiable in any written reports about the study.
- The clinic will not be identifiable in any written reports about the study.
- Participants may withdraw from the study at any time without consequence.
- A report of the findings will be made available to the clinic.
- I may seek further information on the project from FADILA JUMARE on +2348096387247.

__________________________ __________________________

Clinic Manager Signature

____

Date

Application to Conduct Research: NGO Representatives

Letter of Invitation to NGO Representative

My name is **FADILA JUMARE**, and I am a PhD student at the University of Cape Town, South Africa. I am conducting research on **factors influencing utilization and adherence to Prevention of Mother to Child Transmission (PMTCT) of HIV services in Rivers State, Nigeria**under the supervision of **Dr Johannes John-Langba**. I wish to invite you to consider taking part in this study. The study has met the requirements of the Research Ethics Committee of the University of Cape Town.

Aims of the Study

The study aims to:

1. Understand the nature of adherence and utilization of PMTCT in Rivers State, Nigeria;
2. Examine factors that influence decisions to utilize PMTCT services by Women Living with HIV/AIDS;
3. Examine factors that influence adherence to the PMTCT services by women living with HIV/AIDS;
4. Identify the barriers and challenges to adherence and utilization of PMTCT services.

Significance of the Study

The study is significant in the following ways:

- Aid in the integration of PMTCT into sexual and reproductive health programming and promote fair distribution of health services in Nigeria.
- Contribute to improved maternal health, child survival and support for Nigeria's effort to implement the National PMTCT program.
- Maximize the efficacy of biomedical approaches to HIV prevention.

Benefit of the Study to the NGO

- Enable NGO management to spot concerns of women who are not utilizing or adhering to PMTCT services and resolve their needs.

Research Plan and Method

Structured questionnaire survey will be administered by the researcher to the NGO staff relating with WLWHA in your clinic. Verbal, direct questions will be used to obtain participants' views on how cultural practices and economic statuses affect WLWHAs' utilization of PMTCT services. Participants will not be required to provide any personal details. To gain access to the participants, permission will be sought from the participant prior to their participation in the research. The researcher will make appointment with only those who consent. The interview will take place in a private room with only the participant and the researcher present and will not be more than one hour long. A tape recorder will be used only for the purpose of data analysis. All information collected will be treated in strictest confidence and neither the clinic nor individual staff will be identifiable in any reports that are written. Participants may withdraw from the study at any time without any consequence. The role of the clinic is voluntary and the clinic manager may decide to withdraw the clinic's participation at any time without consequence. The data to be collected is merely about participants' perspectives regarding the issues, data will not be sensitive in nature and no harm or risk is faced by any participant or by the clinic. The research is to obtain a PhD. It is not for a government program or anything else and therefore data will not be sent anywhere and will only be used for completing this degree.

NGO Involvement

Once I have received your consent to approach NGO staff to participate in the study, I will:

- Arrange a time with your NGO staff for interview to take place.

- Arrange for informed consent to be given to participants and obtain completed informed consent forms from participants.

Attached for your information is a copy of the Participant Information Statement and Consent Form.

Invitation to Participate

If you would like your clinic/hospital to participate in this research, please complete and return the attached form.

Thank you for taking the time to read this information.

FADILA JUMARE

University of Cape Town, South Africa

NGO Representative Consent Form

I give consent for you to approach NGO staff who are responsible for implementing the PMTCT program to participate in the research titled: **Factors Influencing Utilization and Adherence to Services for Prevention of Mother to Child Transmission of HIV in Rivers State, Nigeria**

I have read the project information statement explaining the purpose of the research project and understand that:

- The role of the NGO is voluntary.
- I may decide to withdraw the NGO's participation at any time without consequence.
- NGO staff who are responsible for implementing the PMTCT program will be invited to participate and that permission will be sought from them.
- Only NGO staff who consent will participate in the project.
- All information obtained will be treated in strictest confidence.
- The purpose of this study is to obtain a degree and not for official government or other use.
- The staffs' names will not be used and individual staff will not be identifiable in any written reports about the study.
- The NGO will not be identifiable in any written reports about the study.
- Participants may withdraw from the study at any time without consequence.
- A report of the findings will be made available to the NGO.
- I may seek further information on the project from FADILA JUMARE on +2348096387247.

____________________________ ____________________________

NGO Manager Signature

____

Date

Appendix 4: Summary of Coding and Responses

Examples of Participants' Responses	**Concept/Category**	**Variables/ Main themes**
• *Yes. I attended because the life of my unborn child was very important to me* • *Yes. I followed all instruction given me because I wanted to live long.* • *Yes. To ensure that the baby is HIV negative* • *Mothers occasionally miss their appointments but adherence is good* • *Yes so as to get the medication*	Reasons for PMTCT service use and adherence ANC attendance/attitude towards follow up visits	Lives of mother and unborn child

• *Price of the booking is a concern*		
No I went alone *Very rare to see partners* *No they usually come alone, I have not seen their partners. This is still low. They go alone mostly. Some come with their house helps, wasn't married but he didn't go with me*	Male Partner Involvement	Lack of support from partners
No only my husband *No community support* No I do everything myself	Support received from friends and family	Lack of support from relatives and friends
No I did not experience any because only me and my partner know	Effects of Stigma and Discrimination	Non-disclosure of HIV status
Materials and machines are not always available, laboratory logistics, cost,	CD4 count experiences/ Follow up counts	Unavailability of service at

long list of those waiting, delays in getting results, (it takes 4 -7 days), and hospital related difficulties.		hospitals/quality of services provided
He keeps asking why he is the only one taking drugs No because I already know their status which was negative, No because he was free from the virus	Time of baby testing/follow up tests/Challenges	Inaccurate information about when to test Concern that baby will know the HIV status
A few of them already know, 1st visit to ANC, some know before, some at antenatal. I did the test four years ago, No I never know I was positive, they tested me but I knew since 2011, at 4 months, yes after the first child, yes to only my partner, yes I disclosed to my partner	Knowledge of HIV status,/Time of first test, HIV status disclosure	Testing late Non-disclosure

alone, No after my first child		
Not up to 18 months,they are referred to pediatrics and given prophylaxis yes four times, some come without the baby, mostly economic hardships most patients are faced with. Not anymore/ only at birth because he was discovered to be HIV negative, No he was ok and wasn't given, still low so wasn't taking, Dizziness.	Immediate postpartum experience of WLWHA(Provision of ARV to mother and baby, support, challenges, follow up visits with baby)	Failure to attend follow up visits with baby, side effects of ARV medication, economic hardship, lack of information about prophylaxis for baby
They prefer breastfeeding, because it's affordable, yes indecision about infant feeding before delivery, most before 6 months say it is stressful at 3 months. Yes a few because of inadequate information.	Infant feeding experiences of WLWHA (Reasons for choice of infant feeding, length of time baby was exclusively breast or formula fed, reasons for stopping the mode of feeding, constraints to chosen infant feeding)	Confusion about infant feeding choices, poor lactation, inability to cope with EB, working mothers, family pressures, ignorance, poor information about baby's nutrition,

They find it strenuous, some of them work, 4 months, 5 months, yes to supplement child energy demand, money, they don’t usually like breastfeeding, most of them opt for infant formula because its cheap, it is less likely to be confronted about their feeding choices if they are breastfeeding, some men do not want to compromise at all so they insist on formula feeding. Few, some say I wont give at all. I add water to the breastfeeding so that he would be more satisfied, certain persons expressed their concerns and suggested I switch to other food options but I stuck to		latching problems, Acceptance by babies, fear of having cuts

breastfeeding. I stopped breastfeeding at about 8-9 months. 8 months. After 6 months I stop. 9 months I still breastfed after 6 months but I introduced other fluids. Exclusive formula feeding. We were informed that breastfeeding has a 50% chance of infecting the child and I didn't want to take the risk. The neighbors wanted to know why I was not breastfeeding. I excused myself with a sound excuse. Exclusive breastfeeding because its economical. I couldn't continue due to low milk from my breast. I was instructed to buy NAN		

formula. Baby formula. I gave milk to the child up to 2 years of age. Exclusive breastfeeding although it didn't come out immediately. Exclusive breastfeeding. It makes the child healthier and cuts my expenses on baby food. Sometimes people suggest that I give him something else but I stuck to breastfeeding. After three weeks the baby was not suckling properly so my doctor advised me to stick with infant formula, I was given milk at the hospital to give my baby but I also gave her breastmilk. They told me to breastfeed and give food also. I did exclusive for 3 months and		

stopped myself. I had a cut in my nipples.		
Second stage of labour, im aware that most do not go for ANC they attend TBAs where they are not screened and do not know their status. Most women prefer vaginal delivery regardless of viral load. Yes no ANC registration. First stage. Unregistered cases for ANC (Ignorance). Those on ARV usually continue taking. No majority don't return because of finance. Yes. Some do clinic elsewhere but want to deliver here because of safe delivery. We don't have a viral load machine. I didn't know then because	Labour experiences of WLWHA (Time of arrival at hospitalViral load at the time of delivery, normal or cesarean delivery)	TBA attendance, Un-booked cases. Reluctance, un-seriousness, hiding, Finance. Too late to go to the hospital

no such test was conducted. There was no viral load test in that facility at that time. 550 doctor said I should do CS to be on a safer side so they booked me. CS. I paid myself. My husband paid. No. it was late and I could not go to the hospital, so a hospital staff help me deliver at home.		
Yes a few misses are noted especially due to TDF side effects. Not much support I would say. Delay in decision making, patients in denial, side effects of drugs, too many oral tablets to swallow or swallowing tablets on a daily basis, volume of clients. Some resist us with	Challenges of HAART use and adherence	Side effects of drugs, administrative bottlenecks, shortage of drugs supply/stock outs, religious factors, indirect costs, cultural factors

various excuses like they have been prayed for, religious factors can hinder the use of medication. The HIV medication are free but they paid for antenatal. Sometimes we don't have certain medication. If we don't have, they need to go and buy. Previous dosage was once every morning and evening but now the dosage has been changed to just every evening and the drug seem more potent. Feeling dizzy, No I just set reminder on my phone. At the onset I usually forget or feel reluctant. I sometimes mix it into my meal to enable me take it. But after a while, I became		

consistent and now it feels natural to me. I have to eat a lot. The pills are very large and I have to take two. It is free, but the transportation to get the medication is expensive. Continuous temptation from recommendation of herbal drugs makes it difficult to continue with the HAART medication. Side effects such as dizziness and dry lips. It sometimes shortens my period. Carelessness. Just the normal drag from suddenly taking drugs daily, some dizziness even. I did not like it at first but now, am used to it. I knew my status after delivery		

To properly plan for pregnancy in health. Yes to regulate family size. Yes, to prevent transmission of resistant strains. Yes, for prevention of infection and unintended pregnancies. so they do not have children they cannot take care of. Yes, in order to pace out pregnancies. No, this would be the last. No And I don't want more children.To plan and build my CD4 count up for the next baby. Yes because im through with child bearing.Modern method because I believe it is safer. No, the economy is not favorable to that. Modern, Not sure of	Use of family planning services (Reasons for use of family planning, reasons for choice of family planning method)	Family size, unintended pregnancies, financial reasons, prevent transmission, spacing pregnancies

partner's faithfulness. No, I prefer to be natural "No three is ok for me" No it fails. No I don't want. "im ok with three".		