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Faculty of Community and Health Sciences

Exploring pre-and post-partum barriers to anti-retroviral therapy adherence for HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Master of Public Health at the School of Public Health, University of the Western Cape

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KEYWORDS

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Pre-partum

Post-partum

Option B Plus

Prevention-of-mother-to-child transmission

Zimbabwe

Women



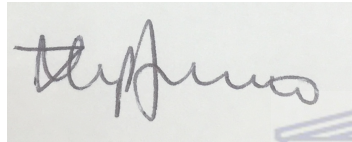
DECLARATION

I declare that this thesis entitled “*Exploring pre-and post-partum barriers to anti-retroviral therapy adherence for HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe*” is my own work. It has not been submitted for any degree or examination in any other university and that all the references I have used or quoted have been acknowledged.

Full name: Lorraine Tanyaradzwa Dube

Date: November 2016

Signed:



LIST OF ABBREVIATIONS

ANC	Antenatal care
ART	Antiretroviral Therapy
CDC	Centre for Disease Control
DHS	Demographic Health Survey
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
HCT	HIV counselling and testing
HIV	Human Immunodeficiency Virus
IMF	International Monetary Fund
MNCH	Maternal, neonatal and child health
MOHCC	Ministry of Health and Child Care
MTCT	Mother-to-Child Transmission
NMTPAC	National Medicine and Therapeutic Advisory Committee
PICT	Provider initiated counselling and testing
PMTCT	Prevention-of –Mother- to-Child Transmission
SAP	Structural Adjustment Program
STI	Sexually Transmitted Infection
TB	Tuberculosis
USA	United States of America
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children’s Fund

VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
ZNNP+	Zimbabwe National Network of People Living with HIV



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ABSTRACT

Background: Zimbabwe has one of the highest HIV prevalence rates in sub-Saharan Africa, with the adult prevalence rate at 15%. The HIV prevalence is highest among adult women, at 18%. Mother-to-child transmission is the second leading cause of HIV in Zimbabwe. Therefore, provision of anti-retroviral therapy to pregnant women is important in reducing mother-to-child transmission. In 2012, the World Health Organisation formally adopted ART guidelines known as “Option B Plus”, where triple therapy is provided to pregnant women for life, regardless of CD4 count. Zimbabwe subsequently adopted Option B Plus in September 2013. However, the success of ART depends on adherence to treatment. Lack of adherence to treatment leads to an increased risk of opportunistic infections and drug resistance, which is costly to treat. The aim of the study was to explore pre-and post-partum barriers to anti-retroviral therapy for HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe.

Methodology: Descriptive qualitative methods were used to explore the barriers to ART adherence for pre-and post-partum HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe. In-depth, semi-structured interviews were conducted in Shona with 20 non-adherent pre-and post-partum HIV-positive women and four key informants who are health workers from two identified health facilities (Edith Opperman Polyclinic and Kuwadzana Polyclinic). The interviews were recorded, transcribed and translated into English. The data was analysed using inductive thematic analysis.

Results: Health facility and individual factors emerged as barriers to adherence. Heavy workload and staff shortages, negative health worker attitude, cost of accessing health facilities, medicine shortages and detrimental health facility policies were all health facility related barriers identified by both key informants and the women. Individual barriers were related to difficulty in navigating the early days after diagnosis and treatment, stigma, intimate partner dynamics and religion.

Conclusion: Despite free, decentralised provision of ART, barriers to adherence still exist. Many of the barriers have been articulated in previous research that focused on prevention-of-mother-to-child transmission regimens, as well as ART regimens for the general population. The fact that the barriers remain suggests that the barriers are complex and

addressing them will require tackling social constraints such as stigma and gender roles that pose a significant barrier to adherence.



CHAPTER 1 INTRODUCTION

1.1 Introduction

This chapter introduces the study. First the study setting is described, including demographics, the economy and the structure and functioning of the health system in Zimbabwe. The provision of antenatal care (ANC) and prevention-of-mother-to-child (PMTCT) services in Zimbabwe is also discussed. The study context is provided. The rationale for adopting Option B Plus by the World Health Organisation (WHO) and subsequently Zimbabwe is discussed. The study aim and objectives are then presented. General challenges regarding Option B Plus and in particular adherence to anti-retroviral therapy (ART) while on Option B Plus are provided. The challenges with regards to ART adherence on Option B Plus provide the basis for the problem statement and rationale for conducting the study. An outline of the thesis is also provided.

1.2 Study setting

Zimbabwe is a landlocked country located in Southern Africa. A 2012 census estimates Zimbabwe's population at 13 million, with 6.2 million men and 6.8 million women (ZIMSTAT, 2012). Harare, the capital city where this study was conducted has a total population of just over two million, with 48.3% males and 51.7% females (ZIMSTAT, 2012). Zimbabwe's population is young, with 41% of the population aged below 15 and only about four percent aged 65 and above (ZIMSTAT, 2012). These demographics are important when considering the need to provide specific health services such as ANC and PMTCT.

Zimbabwe's economy is largely dependent on agriculture and mining (ZIMSTAT & ICF, 2012). However from 2000, the Zimbabwean economy experienced severe economic decline, with negative gross domestic product (GDP) growth between 2001-2006 (UN Zimbabwe, 2016). According to the United Nations (UN), in 2011 72.3% of Zimbabweans were poor (UN Zimbabwe, 2016). This means that 72.3% of Zimbabweans were unable to pay for basic food, clothing, health services, transport and education (World Bank, 1995).

As a result of the economic decline, unemployment levels are high in Zimbabwe. However, it is difficult to obtain official unemployment figures. The World Bank reports that Zimbabwe's unemployment rate in 2014 was just over five percent (World Bank, 2015). This is because the World Bank definition of unemployment includes people working in the informal sector, who form the majority in Zimbabwe (Luebker, 2008). On the other hand, the government reported in their 2013 election manifesto that unemployment was 60% (AfricaCheck, 2014). The opposition party claims unemployment is at 85% (AfricaCheck, 2014). It is therefore difficult to ascertain the true level of unemployment in Zimbabwe.

1.2.1 Zimbabwean Health Sector

Zimbabwe has numerous health care facilities, including primary health care clinics (usually operated by local municipalities), hospitals, reproductive health centres and individual surgeries. These facilities are operated by government, private companies, churches, individual doctors as well as traditional healers (Munyuki & Jasi, 2009). In order to fully understand the structure and functioning of the Zimbabwean health sector, one needs to take into account the socio-economic developments that occurred post-independence from 1980 to 2000 (Munyuki & Jasi, 2009).

Post-independence, from 1980 to 1990, the Zimbabwean government invested heavily in public sector health facilities. Health care was free to anyone earning less than Z\$150 a month (Sanders, 1990). The expansion in healthcare was supported by training more workers and upskilling community health workers. This investment in health led to improved health indicators such as 89% antenatal coverage by 2000, compared to 20% at independence (Munyuki & Jasi, 2009; Sanders, 1990). In the 1990s, Zimbabwe implemented the International Monetary Fund (IMF) led economic Structural Adjustment Programs (SAP) that led to cuts in public sector health expenditure and the introduction of user fees (Chisadza, Maponga, & Nazerali, 1995). These SAPs also resulted in an increase in private health facilities while public health facilities either remained the same or decreased (Munyuki & Jasi, 2009).

The period from 2000 saw the country experience rapid economic decline which led to a general decline in the quality of healthcare in the public sector (Munyuki & Jasi, 2009). Perhaps

one of the most adversely affected areas in the health sector is human resources. In 2009, it was estimated that on average, 20% of health personnel such as doctors, nurses and pharmacists leave the country on a monthly basis, for better pay and working conditions overseas or regionally (Munyuki & Jasi, 2009). The public sector has been most affected by human resource shortages as shown in the table below:

Table 1.1 Numbers of health professionals in Zimbabwe

Category	National Total	No. employed in the public sector	% of required public sector posts filled
Doctors	1634	772	28.7
Nurses	16407	7636	55.6
Pharmacists	524	129	18.7

(Source: Munyuki & Jasi, 2009)

In its 2009-2015 National Health Strategy, the Ministry of Health and Child care (MOHCC) reported that the 2013 vacancy rates for midwives was over 80%. The main reason for the high vacancy rates was also poor service conditions and work environment (MOHCC, 2013).

1.2.2 Antenatal Care and Prevention-of-Mother-to-Child Transmission in Zimbabwe

Despite the challenges in the health sector highlighted above, Zimbabwe continues to make efforts to improve maternal health and address HIV. All public health facilities provide ANC. In the 2010 DHS survey, 90% of women aged 15-49 years had received ANC from a skilled provider (MOHCC, 2012). However, this was a slight decrease from the percentage reported in the 2005/6 DHS survey (94%), and was attributed to higher user fees as well as personal socio-economic issues such as increased transport costs (MOHCC, 2012).

According to the MOHCC, all facilities in Zimbabwe are mandated to offer provider initiated

counselling and testing (PICT) services (MOHCC, 2012). Prevention-of-mother-to-child services are integrated into ANC services, with 95% of all public health facilities offering PMTCT services (MOHCC, 2012). This means in theory all women can be offered HIV counselling and testing (HCT). Should they refuse, they are still able to access voluntary counselling and testing (VCT) at subsequent visits (MOHCC, 2012). The MOHCC is advocating for PICT due to the low uptake of HCT (MOHCC, 2012). Rather than waiting for patients to request HCT as is the norm with VCT, with PICT the health service provider recommends and provides testing and counselling (Makhunga-Ramfolo, Chidarikire, Farirai, & Matji, 2011).

The MOHCC recommends that pregnant women visit the ANC/PMTCT clinic at 12 weeks gestation. During the first visit, the patient's demographics are recorded and they are issued with a personal booking card, for a fee. A physical examination is conducted as well as screening tests (MOHCC, 2012).

1.2.3 Study Context

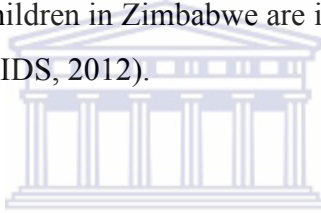
There are 36 suburbs in Harare, with 15 high density, eight medium density and 12 low density suburbs (Njaya, 2014). High density suburbs are characterised by low socio-economic status with illegal agricultural activities and street vending comprising the main methods of economic activity (Njaya, 2014). Harare has 12 polyclinics, two satellite clinics and two infectious disease hospitals. The polyclinics offer HIV testing, ART initiation and follow-up and provide PMTCT.

Harare was chosen as a study site because according to the literature, HIV prevalence rates are higher in urban areas compared to rural areas (Kang'ethe & Chikono, 2014). Prevalence rates for HIV in 2015 were 14.3% in urban areas and 13.5% in rural areas (ZIMSTAT & ICF, 2016). As with the rest of the country, HIV prevalence in Harare is higher among women compared to men. According to the 2015 DHS survey, 16.5% of women were HIV positive compared to 10.5% of men (ZIMSTAT & ICF, 2016). Married women are at greater risk of HIV transmission because they are unable to negotiate for safer sex (Kang'ethe & Chikono, 2014). In a personal conversation with Dr. Maguranyanga, a public health researcher, he indicated that high density suburbs may be overrepresented in terms of HIV prevalence. This also helped to inform the researcher's decision to locate the study in high density suburbs.

1.3 HIV Prevalence and Mode of Transmission

Zimbabwe has one of the highest HIV prevalence rates in sub-Saharan Africa. According to the 2010-2011 Demographic and Health Survey (DHS), HIV prevalence among adults aged 15-49 is 15%. HIV is feminised, with the prevalence rate highest among women, at 18% for adult women compared to 12% for adult men (ZIMSTAT & ICF, 2012). According to the DHS, women become infected by HIV at a younger age compared to men. For example, among the 20-24 age group, HIV prevalence among men was approximately five percent, compared to approximately 12% for women (ZIMSTAT & ICF, 2012).

HIV prevalence among pregnant women aged 15-49 was 16% in 2011, similar to the general population (ZIMSTAT & ICF, 2012). Mother-to-child transmission is the second leading cause of HIV transmission in Zimbabwe, after heterosexual sex (ZIMSTAT & ICF, 2012). It is estimated that every year, 14,600 children in Zimbabwe are infected with HIV, primarily through mother-to-child transmission (UNAIDS, 2012).



1.4 Anti-Retroviral Therapy Provision for Pregnant Women

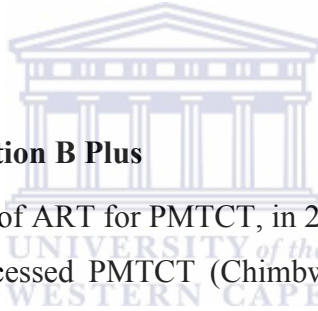
The WHO recognizes that provision of ART to pregnant women can reduce transmission rates from mother-to-child to less than five percent (WHO, 2010). As a result, the WHO has provided treatment and prophylaxis guidelines for the provision of ART for pregnant women and infants (WHO, 2012). These guidelines are shown in the table below (UNICEF, 2012).

Table 1.2

ART Treatment guidelines for pregnant women and infants, 2012

	Treatment (CD4 ≤ 350 cells/mm3)	Prophylaxis (CD4 count >350 cells/mm3)	Infant receives
Option A	Triple ARVs started soon after diagnosis, continued for life	Antepartum – AZT starting from 14 weeks gestation Intrapartum – single dose of nevirapine and first dose of AZT/3TC Post-partum – AZT/3TC daily for seven days post-partum	Daily nevirapine from birth until one week after stopping breastfeeding; if mother is not breastfeeding or is on treatment, then through 4-6 weeks
Option B	Triple ARVs started soon after diagnosis, continued for life	Triple ARVs started from 14 weeks gestation and continued intrapartum and childbirth if not breastfeeding or until one week after stopping breastfeeding	Daily nevirapine or zidovudine from birth until age 4-6 weeks regardless of infant feeding method

(Source: UNICEF, 2012)



1.5 Introduction of Option B Plus

Despite the acknowledged benefits of ART for PMTCT, in 2011 only 57% of pregnant women in mid-and low-income countries accessed PMTCT (Chimbwandira et al., 2013). An estimated 300,000 infants in sub-Saharan Africa were infected with HIV by their mothers in the same year (Chimbwandira et al., 2013). Countries such as Malawi subsequently introduced what is now referred to as ‘Option B Plus’, where HIV-positive pregnant women are initiated onto triple anti-retroviral drugs, regardless of CD4 count or WHO clinical staging (Chimbwandira et al., 2013). This is beneficial in resource-poor settings because they do not have to rely on CD4 testing to initiate therapy (UNICEF, 2012). In 2012, the WHO formally recognised and adopted these revised guidelines (Chimbwandira et al., 2013). The rationale for this third option includes aligning with the goal of eliminating paediatric HIV by 2015, while keeping their mothers alive (UNICEF, 2012). New evidence also suggests that providing ART to people with a higher CD4 cell count reduces the transmission risk among sero-discordant couples (WHO, 2012).

1.6 Option B Plus in Zimbabwe

Due to a high estimated number of pregnant women with HIV, Zimbabwe was one of 22 priority countries highlighted in the UNAIDS Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive, (EGPAF, 2014). This led to the upscaling of PMTCT provision countrywide.

Subsequently, Zimbabwe adopted Option B Plus in September 2013. In order to increase access and coverage, the MOHCC decentralized ART services to all maternal, neonatal, and child health (MNCH) facilities throughout the country (EGPAF, 2014). It is estimated that by September 2015, 1,495 out of 1,560 health facilities offering PMTCT were providing Option B Plus and 46,391 women were receiving ART on Option B Plus (Takarinda, Harries, & Mutasa-Apollo, 2016).

Adoption of Option B Plus meant that more women are eligible for ART within MNCH settings. There was need therefore to train and allow nurses and other health workers to initiate ART in the MNCH setting (EGPAF, 2014). Previously, only doctors initiated patients onto ART. Given that in 2010/11, 80% of ANC services were being provided by nurses, they play an important role in ART provision (ZIMSTAT & ICF, 2012). Also the critical shortage of doctors in the public sector as shown in Table 1.1 means upskilling nurses is a viable solution.

1.7 Option B Plus – Challenges

While the benefits of adopting Option B Plus have been discussed above, there remain some challenges. Ferguson and the WHO (2013) identified three challenges in relation to Option B Plus. Firstly, women are initiated on life-long ART and are initiated onto treatment earlier compared to previous regimens, so there is a greater chance for drop-outs. Attrition rates tend to be higher post-partum. Secondly, Option B Plus entails remaining in care for the rest of one's life. Acceptability of remaining in care may prove to be a challenge with Option B Plus and will impact on adherence. Lastly, good referral pathways will be required to ensure adherence, particularly when transitioning from PMTCT services to general HIV care.

The cost of providing ART to an increased number of women needs to be taken into account (Besada et al., 2012). After the introduction of Option B Plus in Malawi, the number of pregnant and breastfeeding women initiated on ART increased from 1,257 in 2011 to 10,663 in 2012. There are other associated costs such as training health staff (WHO, 2012).

Health systems in resource-poor settings are already strained. There is concern that the introduction of Option B Plus will place further strain on resources such as health personnel and medicines which may need to be diverted from the general population (who are HIV negative) to focus on a particular group (Coutsoudis, Gaga, Desmond, Barron & Black, 2013). Coutsooudis et al. (2013), have also discussed some ethical concerns with Option B Plus. They question the ethics of providing life-long ART treatment to women where the long-term effects of that treatment are not known.

1.8 Problem Analysis and Statement

Option B Plus is a relatively new regimen for PMTCT. Malawi first introduced the regimen in 2011 (Chimbwandira et al., 2013), and the WHO only recommended Option B Plus in 2012 (WHO, 2012). Zimbabwe subsequently implemented Option B Plus in September 2013. Therefore, there are challenges that need to be researched and addressed in the Zimbabwe context.

The previous section discussed the many challenges with Option B Plus. This study will focus on adherence as a particular challenge to Option B Plus. This is an important consideration because the success of ART largely depends on adherence to the treatment regimen, as well as retention in care (Thompson et al., 2012). Failure to adhere leads to an increased risk of opportunistic infections, HIV transmission and drug resistance (Mohammadpour, Yekta, & Nikbakht Nasrabadi, 2010; NMTPAC & MOHCC, 2013). The introduction of Option B Plus and resulting poor adherence will result not only in drug resistance but an increase in multi-class drug resistance in mothers and children, and possibly their partners which poses an even greater challenge to the health system (Leach-Lemens, 2012).

According to the WHO (2014), drug resistance leads to treatment failure and the need for second and third line treatment, which is costly particularly in resource-poor settings. Drug resistance also results in the spread of drug-resistant HIV to the general population (WHO, 2014). In a cross-sectional study of 2590 ART-naïve adults in six sub-Saharan countries (Kenya, Nigeria, South Africa, Uganda, Zambia, and Zimbabwe) to assess ART resistance prevalence, just under six percent of the sample was found to be ART resistant (Hamers et al., 2011). The same trend is observed in developed countries where the prevalence of drug-resistant HIV is also increasing. In 2003, drug resistant HIV prevalence was 14% for the United Kingdom and 15-26% in North America (Brindeiro et al., 2003).

1.9 Study Rationale

Qualitative research methods were used to explore the barriers to ART adherence for pre-and post-partum women initiated onto Option B Plus in Harare, Zimbabwe. Semi-structured, in depth interviews were conducted with twenty non-adherent pre-and post-partum women, as well as four key informants who are health workers at two health facilities (Edith Opperman and Kuwadzana Polyclinics).

The WHO recognises HIV-positive pregnant women as a priority population in terms of ART provision (WHO, 2016) but there is even less data on ART adherence during pregnancy and there is no published systematic review on pregnancy and ART adherence (Nachega et al., 2012). In Zimbabwe, three years after implementing Option B Plus, there is a general lack of data on adherence and retention in care on Option B Plus (Takarinda et al., 2016). It is hoped that this research will contribute to the body of knowledge regarding barriers to ART adherence, both during and after pregnancy. This knowledge can then be used to provide recommendations and strategies to improve ART adherence to ensure the continued success of ART in decreasing mortality and morbidity. The findings of this study have become even more important in light of the move towards ‘universal test and treat’ as barriers similar to those described by women initiated onto Option B Plus are likely to be experienced.

1.10 Aim

To explore pre-and post-partum barriers to anti-retroviral therapy (ART) adherence for IV-positive women initiated onto Option B Plus in Harare, Zimbabwe.

1.11 Objectives

- 1) To explore the barriers to adherence as perceived by pregnant and post-partum HIV-positive women who are currently on ART.
- 2) To explore barriers to adherence as identified by health workers.

1.12 Thesis Outline

Chapter One introduces the research and describes the problem analysis and statement as well as the rationale for conducting the study. The study aim and objectives are also outlined.

Chapter Two reviews the literature on ART adherence on Option B Plus, PMTCT regimens and ART in the general population.

Chapter Three describes the study design and method used to conduct the study, including rigour and ethics considerations.

Chapter Four presents the findings of the study.

Chapter Five discusses the findings of the study, with reference to the literature that was reviewed.

Chapter Six draws conclusions about the study and provides recommendations to improve ART adherence on Option B Plus.

1.13 Summary

This chapter introduced the study by describing the study setting, Option B Plus, the problem analysis and statement and the rationale for conducting the study. The next chapter will review the literature on barriers to ART adherence.



CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The introduction of anti-retroviral therapy (ART) has enabled HIV-positive women to pursue motherhood (Boehme et al., 2014). However, the success of ART in decreasing morbidity and mortality in mothers, as well reducing perinatal infections is dependent on adherence to treatment (Bardequez et al., 2008). Studies have shown that pregnant women will adhere to treatment while pregnant, but this declines during the postpartum period (Vaz et al., 2007). This is despite increased risk of morbidity and mortality during this period as a result of increased immunosuppression (Boehme et al., 2014).

Nachega et al. (2012), report that pre-and post-partum ART adherence levels for pregnant women in low-and mid-income countries is below those recommended to ensure the HI virus does not replicate. In a review of 51 studies involving more than 20,000 women from Zambia, Kenya, South Africa and the United States, 73.5% of pregnant women achieved adequate adherence pre-and post-partum. Adherence was set at 80% or greater (Nachega et al., 2012).

For the purposes of this research, adherence is defined as “*the ability to start, manage, and maintain a given medication regimen at the times, frequencies, and under specified conditions as prescribed by a health care provider.*” (Patel, Hirschhorn, Fullem, Ojikutu, & Oser, 2010: pp 2).

In reviewing the literature, this study first looked at barriers to ART adherence from studies specifically aimed at women initiated onto Option B Plus. Due to limited available literature on barriers to ART adherence on Option B Plus (in part due to the fact that Option B Plus was a relatively new regimen when the study was conducted) this study also reviewed barriers to adherence on prevention-of-mother-to-child transmission (PMTCT) regimens in general. Lastly, because Option B Plus proposes life-long treatment, barriers to adherence in general were reviewed, but with a special focus on how these barriers affected women, since Option B Plus is accessed by women.

2.2 Barriers to adherence

This literature review will discuss the barriers to ART adherence. These are divided into health facility factors, individual factors and societal factors (Ferguson & WHO, 2013).

2.2.1 Health facility factors

Health facility factors that were identified in the literature are distance and transport costs, staff shortages which had an impact on waiting times and quality and quantity of counselling, lack of physical space in health facilities, user fees and medicine shortages.

2.2.1.1 Distance and Transport costs

Distance and transport costs involved in getting to a health facility were identified in the literature as barriers to ART adherence for pregnant and post-partum women (Ferguson & WHO, 2013). A qualitative study conducted by Boehme et al. (2014) on post-partum adherence for HIV-positive women in Alabama, USA showed that 33% of respondents cited lack and/or cost of transport as reasons for not attending HIV care services. Women in this study cited competing priorities, with the cost of providing for their baby taking precedence over paying to get to the health facility to access treatment and other health services. Although this study was conducted in a developed country, the subject population is comparable to the developing world because it is characterized by economic hardship and high incidence of HIV (Boehme et al., 2014). However, this study only concentrated on adherence post-partum, with no information on adherence during pregnancy. Similar studies conducted in Malawi and Uganda also found that lack of transport money prevented women from accessing prevention-of-mother-to-child transmission (PMTCT) services at health facilities and therefore adhering to ART regimens (Bwirire et al., 2008; Lubega et al., 2013).

In a study on adherence to ART in the general population conducted in Malawi, the issue of transport costs acting as a barrier to ART adherence was found to be gendered (Nyirenda, Makwiza, Bongololo, & Theobald, 2006). In this study, women especially cited lack of transport as affecting ART adherence. In contrast, men did not cite transport costs as a major barrier to

adherence. The reason for this is because men generally have access to and control over money in the family and are able to save money for transport (Nyirenda et al., 2006).

2.2.1.2 User fees

User fees are defined as “official charges payable at the point of service for publicly provided health services” (Souteyrand, Collard, Moatti, Grubb, & Guerma, 2008). Health facility user fees were introduced in most developing countries in the late 1980s and 1990s based on recommendations from the World Bank. The goal of introducing user fees was to raise additional revenue for health facilities, improve quality of care and reduce unnecessary referrals and demand for services (James et al., 2006; Souteyrand et al., 2008). However, user fees have had the opposite effect, by preventing the use of health services including preventive services. Poor people are the most affected, and cannot afford paying even small user fees (Opwora et al., 2015). They may have to resort to borrowing or selling assets in order to access health facilities (Lagarde & Palmer, 2011; McIntyre, Thiede, Dahlgren, & Whitehead, 2006). This may push households into further poverty (McIntyre et al., 2006).

Although the provision of ART in many resource-poor settings is free, user fees have been identified in the literature as a barrier to adhering to ART and remaining in care (Meyer-Rath & Richter, 2007). According to Hardon et al. (2006) user fees ranging from as little as United States (US) one dollar fifty to US three dollars in Ugandan and Tanzanian health facilities were identified as barriers to adherence on ART treatment. In Zimbabwe, no specific literature was found that discussed the impact of user fees on ART adherence. However, Buzuzi et al. (2016) reported that user fees had a negative impact on people with chronic conditions including HIV. The Ministry of Health and Child Care (2012) also reported that an increase in user fees between 2005 and 2010 had led to a slight decrease in antenatal care (ANC).

2.2.1.3 Medicine shortages

Medicine shortages are often cited in the literature as affecting adherence, especially in poor-resource settings (Patel et al., 2010). Medicine shortages may be exacerbated by an increase in the number of people initiated on ART as in Option B Plus. In addition poor procurement and

supply systems in resource-limited countries further undermine ART provision (Patel et al., 2010). If the women are unable to access medicines this will lead to missed doses, especially if they are unable to afford medicines sold from private institutions such as pharmacies.

2.2.1.4 Health worker shortages

Where ART provision is scaled up as is the case with Option B Plus, health worker numbers are often not increased to cater for the increased workload (Hardon et al., 2006). Health workers are therefore overworked, fatigued and lack motivation (Nuwagaba-Biribonwoha, Mayon-White, Okong, & Carpenter, 2007). This in turn impacts the quality of care and has adverse consequences for adherence. This literature review will discuss how existing research suggests that health worker shortages lead to long waiting times and inadequate counselling, which in turn impair adherence.

2.2.1.4.1 Long waiting times

Health worker shortages as well as health workers opening health facilities late has been identified in the literature as leading to long waiting times (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Hardon et al., 2006). In their study on the barriers to general ART adherence in Botswana, Hardon et al. (2006) reported waiting times of up to four hours and this meant that people accessing treatment often had to take an entire day off/out in order to access treatment. This is undesirable, particularly for women, as they either have to be at work, perform household chores or look after their babies. Long waiting times also lead to poor relationships between staff and patients (Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2010). If patients end up spending the whole day at a health facility, they are often forced to buy food, leading to additional costs for the patient (Hardon et al., 2006). Given that women initiated onto Option B Plus are often asymptomatic, long waiting times may discourage them from accessing and adhering to treatment (Kagee et al., 2011).

2.2.1.4.2 Poor quality and quantity counselling

Poor quality counselling as a result of health worker shortages has a negative impact on adherence. Communication skills as well as the actual information given out during counselling all impact on adherence (Chopra, Doherty, Jackson, & Ashworth, 2005). In Malawi, women receiving PMTCT reported that they did not perceive long-term ART as part of PMTCT, suggesting health workers may not have expressed this point adequately during counselling (Ferguson & WHO, 2013).

The type of worker providing counselling is important in terms of quality of counselling. In resource poor settings lay counsellors are used to provide pre-and post-test HIV counselling in order to alleviate the burden for health workers (Kagee et al., 2011). However, lay counsellor training is often poor and they may end up only providing information, rather than recognizing and changing a patients behaviour such as non-adherence (Kagee et al., 2011).

The quantity of counselling is also important and refers to the number of sessions and duration of each session (Delva, Mutunga, Quaghebeur, & Temmerman, 2006). In a study on counselling in a PMTCT program in Mombasa Kenya, Delva et al. (2006) found that the average duration of counselling was much shorter compared to that offered in developed countries, and this had a negative impact on adherence. In a study conducted by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) on the acceptability of Option B Plus in Malawi, most women reported that they were unable to obtain adequate information about the program because health workers were rushed and the women could not ask questions (Keehn & Karfakis, 2014).

Lastly, the study by Delva et al. (2006) found that confidentiality and the counsellor's ability to empathise with the women's concerns about stigmatisation and partner response to the women's HIV diagnosis determined effectiveness of counselling. Although this is not necessarily related to health worker shortages, it is still an important factor to consider in terms of the impact of counselling on adherence.

2.2.1.5 Health worker attitude

Health worker attitude has been identified in the literature as a barrier to adherence (Patel et al., 2010). Issues of discrimination and uncaring attitudes were discussed in the literature (Anígilájé, Ageda, & Nweke, 2016; Reis et al., 2005). In Malawi, women reported feeling vulnerable when accessing services due to health workers being “harsh, threatening and lacking respect” (Ferguson & WHO, 2013). In Uganda, 33% of women accessing PMTCT services reported that health workers were rude and displayed generally unacceptable behaviour (Duff et al., 2010). Health workers have also been accused by the women of being discriminatory towards HIV-positive women. In a study on the barriers to accessing PMTCT conducted in Vietnam, some women were asked to stand during counselling or to first cover the chair with newspaper before sitting. In the same study post-partum women reported that they had often been isolated in their own rooms and the care they had received from health workers was noticeably different to that of HIV-negative women (Nguyen, Oosterhoff, Ngoc, Wright, & Hardon, 2008). Although these studies were looking at barriers to accessing PMTCT services and not just ART adherence, it would follow that the same health worker attitudes would negatively impact adherence pre-and post-partum.

Health worker attitude regarding confidentiality was also cited as a barrier to adherence in the literature (Ferguson & WHO, 2013). A 2003 study in Uganda found that HIV-positive women did not access services because they feared health workers would reveal their status (Nudelman, 2013). In Nigeria, 38% of health workers self-reported that they had divulged an HIV-positive patient’s information to someone else without the patient’s permission (Reis et al., 2005). A perceived lack of confidentiality will result in women not accessing services and non-adherence to ART.

Some studies have attempted to provide reasons for the negative health worker attitude. A multi-country study on maternal health worker’s attitude conducted in Africa, Asia, Latin America and the Middle East found that heavy workload, long working hours, inadequate supervision, poor salaries and lack of equipment were all self-reported by health workers as contributing to negative health worker attitude (Mannava, Durrant, Fisher, Chersich, & Luchters, 2015).

2.2.1.6 Lack of space

The physical layout of the health facilities affects confidentiality which in turn affects adherence. Health facilities may lack space to discuss personal issues with clients, or the spaces may be too small. A study on barriers to ART adherence in the general population conducted in rural Mozambique noted that clinics used to test and treat HIV-positive patients were small (Groh et al., 2011). In an effort to address this problem, the clinics used separate rooms for this service, inadvertently disclosing the patient's status (Groh et al., 2011). A study conducted on barriers to general ART adherence in Zambia found that HIV counsellors were sharing a room with the clinic's accountant due to a lack of space (Sanjobo, Frich, & Fretheim, 2008). This has the potential to compromise patient confidentiality. Where confidentiality cannot be guaranteed, patients will either withhold information or stop visiting the health facility, which affects adherence (Hardon et al., 2006).

2.2.2 Individual barriers

In writing this section on individual barriers, it is important to first discuss the gender roles assigned to women as this will provide context for the barriers, as well as how these barriers affect women in particular. While gender roles influence individual barriers as will be discussed in this section, it is important to note that gender roles in fact represent societal factors that affect adherence (Ferguson & WHO, 2013). Countries in sub-Saharan Africa such as Zimbabwe are patriarchal, where men largely dominate and rule. Historically as a result of colonisation, men were given the task of working and bringing in money, while women largely performed household tasks (Shoola, 2014). Zimbabwean men have also been given a lot of power in terms of decision-making, including sexual health matters (Pearson & Makadzange, 2008). Some women on the other hand do not have access to work that would alleviate poverty and they also lack legal and social protection from vulnerability while also enabling them to access to healthcare (UN Zimbabwe, 2013).

Several studies globally have shown that women are more likely to be non-adherent compared to men. This is because women are treated unequally due to socio-cultural and economic factors, as discussed above (Wasti, Simkhada, Randall, Freeman, & Van Teijlingen, 2012). Women's role

as homemakers and primary caregivers also often acts as practical barriers to adherence because women may be too busy to visit health facilities or take their medicine at the appointed time (Boehme et al., 2014; Ngarina, Popenoe, Kilewo, Biberfeld, & Ekstrom, 2013).

The individual factors that were identified in the literature as being barriers to ART adherence were being asymptomatic, immediacy of treatment initiation, side-effects, stigma, fear of disclosure, socio-economic status, literacy levels, lack of food, post-partum adherence, traditional and religious beliefs and forgetfulness.

It is also important to acknowledge that some of the barriers discussed in this section affect the individual but are a reflection of broader societal and/or structural barriers. For example, internalised stigma relates to how the individual views themselves as different to others, but this is a result of broader societal perceptions regarding people who are HIV-positive. The socio-economic status of the women is also a reflection of structural and societal issues such as women's lack of access to education and employment.



2.2.2.1 Initiating treatment in asymptomatic women

Option B Plus proposes life-long treatment regardless of CD4 count. This means that some women may be asymptomatic when initiated on ART. The literature suggests that being asymptomatic may act as a barrier to long-term adherence (Ngarina et al., 2013). In a qualitative study conducted with 23 women in Tanzania, seven of them reported stopping their medication because they felt well and some even reported gaining weight (Ngarina et al., 2013). Young women in Malawi and Uganda were concerned about being initiated onto ART for life at such a young age and with a high CD4 count (Webb & Cullel, 2013).

2.2.2.2 Immediacy of treatment initiation

Dealing with the 'triple burden' of diagnosis, immediate life-long treatment and pregnancy has been identified in the literature as a significant barrier to ART adherence on Option B Plus (Black et al., 2014). Initiation onto Option B Plus often leaves very little time for women to process their diagnosis. Coupled with the power imbalance inherent between health providers

and patients, women report feeling pressured to accept treatment without information on side effects, the commitment required for life-long treatment and without adequate support and referral pathways for adherence (Matheson et al., 2015). Women have experienced denial, depression and shock upon getting the diagnosis and treatment (Gourlay et al., 2013). Pregnant women in Malawi who were initiated onto Option B Plus reported feeling “scared” and “traumatised” about life-long therapy on ART and reported that they preferred receiving prophylactic treatment only while pregnant (Kieffer et al., 2014).

2.2.2.3 Side-effects

The occurrence of or fear of side-effects while on ART treatment has been identified in the literature as a significant barrier to adherence, especially where there is inadequate counselling and poor understanding of these side-effects (Merten et al., 2010). The most common reported side effects on ART include nausea, vomiting, dizziness and hallucinations. The women’s expectation is for the medicine to make them feel healthy, so the occurrence of side-effects in women who are generally asymptomatic has been identified in the literature as a barrier to adherence on Option B Plus (Kim et al., 2016). In addition, side-effects such as rash which may inadvertently identify one as being HIV-positive may act as a deterrent to adherence. Increased appetite, which is also a side effect of ART and may act as a barrier to adherence if food is not readily available (Merten et al., 2010).

In a study on attrition rates and adherence for women initiated onto Option B Plus in Malawi, 10% of the women reported non-adherence due to side-effects (Tweya et al., 2014). A multi-country meta-ethnographic study on the barriers to general ART adherence found that participants in South Africa associated side-effects with being poisoned, a finding which reflects a general distrust of the health system brought on by the country’s political history (Merten et al., 2010). Although side-effects tend to disappear with time, increased patient load and poor quality counselling may result in patients not receiving adequate information about side-effects, which impacts adherence (Merten et al., 2010).

2.2.2.4 Stigma

Stigma emerged in the literature as a reason for non-adherence (Ekama et al., 2012; Ferguson & WHO, 2013; Gourlay et al., 2013; Patel et al., 2010). Despite advances in HIV treatment which mean that HIV is no longer a fatal condition, stigma continues to be an issue which affects many HIV-positive people (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). It is believed that HIV-related stigma is a result of the association of HIV with sexual promiscuity and homosexuality (Sweeney & Venable, 2016). This is important in a conservative and religious society such as Zimbabwe. A study on stigma in Zimbabwe found that 65.5% of the respondents had experienced stigma (ZNNP+, 2014). In the same study, women had experienced stigma more often compared to men. For example, 22.7% of females reported being excluded from social gatherings, compared to 18.3% of men (ZNNP+, 2014). Interestingly, 7.5% of the respondents had been discriminated against by people who were also living with HIV (ZNNP+, 2014).

Stigma involves labelling someone as different and associating negative stereotypes with the person. This often leads to discrimination and affects their physical, social and psychological well-being (Sayles et al., 2009). Shona words such as *shuramatongo* (meaning HIV kills entire families) or *Jehovah ndoyako* (Lord I am coming home, meaning death is certain) are often used to refer to HIV and depict a disease which will end in death (Mawadza, 2004).

The literature talks of three types of HIV-related stigma, namely anticipated stigma, enacted stigma and internalized stigma (Sweeney & Venable, 2016). Anticipated stigma means that due to an HIV diagnosis, one expects to be discriminated against or prejudiced or stereotyped in some way. Enacted stigma means one has actually experienced discrimination, stereotyping or prejudice (Bond, Chase, & Aggleton, 2002; Sandelowski, Lambe, & Barroso, 2004). Internalised stigma means one internalizes and endorses “cultural norms that label him/her as a member of a deviant group, and assumes a spoiled identity” (Sayles et al., 2009).

Stigma affects a person who is HIV-positive in many different ways. If stigma is anticipated, HIV-positive people may avoid disclosure in order to be able to participate in societal norms such as marriage. If negative side effects such as skin rash, weight loss and lipid redistribution occur while on ART, people may stop taking their medicines in order to avoid inadvertently disclosing their status (Merten et al., 2010). Anticipated and enacted stigma also result in reluctance to visit PMTCT services and reluctance to take ART in public as this might prompt

questions about the use of the medication, therefore resulting again in inadvertent disclosure. This means women may miss doses if they are unable to take their medication discreetly (Boehme et al., 2014). Speaking about why they had missed doses, women in a study on the barriers to ART adherence on Option B conducted in Nigeria reported that when they were visited by family and they had to share a room they were reluctant to take their medicine as this would generate curiosity about the purpose of the medicine and lead to inadvertent disclosure. The women also reported that they would forget to carry their medicine when they visited relatives. The women were also concerned about causing distress to their family members once they disclosed their status (Anígilájé et al., 2016).

Anticipated or enacted stigma may cause people to access services away from where they live, resulting in additional transport costs and increased waiting times at these services which negatively impacts adherence (Kagee et al., 2011). Internalised stigma in particular has been associated with mental health issues such as depression, feeling worthless and lack of interest in activities and life in general. This in turn has a negative impact on adherence (Sweeney & Venable, 2016).

2.2.2.5 Fear of disclosure to intimate partners and family members

Disclosure to intimate partners has been identified in the literature as aiding adherence and has been identified by the World Health Organisation (WHO) as a prevention strategy (Medley, Garcia-Moreno, McGill, & Maman, 2004). There are many benefits associated with disclosing to sexual partners discussed in the literature but the most relevant benefits to this study are an increase in social support, reduced anxiety for the women and better access to HIV prevention and treatment programs (Medley et al., 2004). It can be argued that the same benefits would be derived from disclosing to family members.

The literature suggests that women generally tend to test early for HIV, for example during antenatal visits. Also, because of their role as primary caregivers, women are more likely to be motivated to remain healthy and are therefore more likely to test earlier for HIV (Ochieng-Ooko et al., 2010). Certainly with Option B Plus, women are more likely to test for HIV before their partners and will be the ones to disclose their status to either their partners or their families.

Despite the benefits of disclosure as discussed above, the fear of disclosure to partners and family members is a significant barrier to adherence for women accessing ART. This is because women fear being blamed for bringing the virus to their partners (Duffy, 2005; Medley et al., 2004). This phenomenon is not new, as women have been blamed for sexually transmitted infections (STIs) throughout history. In the African context, women have even been shunned by their in-laws and their own families following an HIV diagnosis. However, they are more than likely to have contracted the disease from their husbands (Duffy, 2005). In Zimbabwe, studies have shown that women in committed relationships are at greater risk of HIV infection from their male partners. The patriarchal nature of Zimbabwean society means women are not able to question their male partner's sexual behaviour or negotiate condom use (Gona & DeMarco, 2015). Condom use in particular has been identified as a male-controlled activity and women have little control over the use of condoms within relationships (Montgomery, Chidanyika, Chipato, & van der Straten, 2012; Motsi, Banda, & Mabvurira, 2012).

According to a study on Option B Plus in Uganda, there is a perception among the community that the person who is first diagnosed is responsible for infecting their partner and/or children (Webb & Cullel, 2013). Women in Uganda expressed fear regarding being sued by their partners or family members under the new criminalisation laws under debate in Uganda (Webb & Cullel, 2013). This may lead to women not disclosing to their partners or family members (Laher et al., 2012). Failure to disclose to partners means women lack a treatment partner, which has been shown to aid adherence (Skovdal, Campbell, Nyamukapa, & Gregson, 2011).

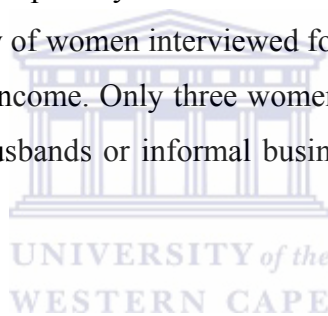
Given that women, especially in low and mid-income countries, tend to be economically dependent on their partners, disclosing their status may mean loss of financial support, divorce or being subjected to physical violence (Buessler, Kone, Robinson, Bakor, & Senturia, 2014). Therefore they will stop taking their medication or visiting HIV clinics in order to keep their status a secret.

2.2.2.6 Socio-economic status

The socio-economic status of women determines health, adherence (Gourlay et al., 2013; Ngarina et al., 2013), as well as many other aspects of daily life (Duffy, 2005). Given the high

unemployment rates in Zimbabwe as previously discussed, women have had to assume the role of providing for their families (Duffy, 2005). However, they are limited by access to higher education and the type of work they can perform (Duffy, 2005). This means that where financial resources are limited women will forego ART. If they have children, their needs such as clothes, fees and food take priority over the women's need for ART (Boehme et al., 2014; Duff et al., 2010). Women may not afford to pay for transport to health facilities or the cost of accessing PMTCT (if it is not free). In addition, the conditions associated with low socio-economic status such as poor housing, forced migration, violence and unemployment make it difficult to attend health facilities regularly and in turn adhere to medicine regimens (Kagee et al., 2011). Women may not have access to childcare which impacts their ability to attend health facilities and therefore adherence (Kagee et al., 2011).

In a qualitative study on PMTCT conducted with non-adherent women in Tanzania, 15 out of the 23 women interviewed reported that poverty hindered them from adhering to ART post-natally (Ngarina et al., 2013). The majority of women interviewed for this study had been educated up to primary level and had little or no income. Only three women were employed and the remaining twenty were dependent on their husbands or informal businesses for food, shelter and clothing (Ngarina et al., 2013).



2.2.2.7 Literacy Levels

Low literacy levels, which may be related to socio-economic status, can affect a woman's understanding of her diagnosis and treatment, which leads to non-adherence (Patel et al., 2010). In addition low education levels result in low income which means women become even more dependent on men (Ngarina et al., 2013).

A cross-sectional study on the factors of the prevalence and factors associated with non-adherence of PMTCT (single dose nevirapine) conducted in Bindura, Zimbabwe, showed that unemployed women with a secondary education had better adherence compared to unemployed mothers without secondary education (POR =0.11, 95% CI 0.01-0.87 ; POR= 3.36, 95% CI 1.43-7.91, respectively) (Kuonza, Tshuma, Shambira, & Tshimanga, 2010). Maternal education results in effective communication between health provider and patient, as well as better

retention of information on ART (Kuonza et al., 2010) Although the study looked at single dose ART, the same may be true for women initiated onto triple therapy on Option B Plus.

2.2.2.8 Poverty

Poverty has been linked to household food insecurity, which is a significant barrier to ART adherence (Anema, Vogenthaler, Frongillo, Kadiyala, & Weiser, 2009; Weiser et al., 2010). Food insecurity is defined as a lack of economic, social and physical access to safe food that is nutritious and in sufficient quantities to meet person's dietary requirements (Young, Wheeler, McCoy, & Weiser, 2014). In other words

Several qualitative studies have explored how food insecurity leads to non-adherence. Four mechanisms have been identified, such as increased hunger while taking ART (Weiser et al., 2010; Young et al., 2014). It has been suggested that ART users require food especially when commencing treatment due to increased appetite (Goudge & Ngoma, 2011; Young et al., 2014). A study conducted in Rwanda found that 76% of respondents on ART reported non-adherence due increased appetite and scarce food (Young et al., 2014). Secondly, ART users have reported either fearing or experiencing an increase in side-effects in the absence of adequate food (Goudge & Ngoma, 2011; Weiser et al., 2010; Young et al., 2014). Anti-retroviral therapy users in Malawi, Uganda and Kenya reported side-effects such as headache, dizziness, nausea, vomiting after taking ART without food (Young et al., 2014). The literature suggests that satisfying hunger or alleviating symptoms such as nausea and vomiting will take precedence over adherence to medicines (Goudge & Ngoma, 2011). In some cases, ART users have had to trade their medicines for food or other needs such as rent or school fees (Weiser et al., 2010). Lastly, where there are competing priorities, ART users have prioritized buying food in place of paying for transport to access health facilities, which leads to poor treatment and retention in care, and possibly poor adherence (Weiser et al., 2010; Young et al., 2014). Food insecurity may therefore result in patients taking their medicine only when they have access to food (Anema et al., 2009; Kagee et al., 2011).

Pregnant women as a special population are more likely to be negatively affected by food insecurity. This is because they require more food, may be physically unable to obtain and

prepare food and they may not be working or lack the ability to generate income. Cultural practices may also put restrictions on their movement or ability to access food (Young et al., 2014). Despite the negative impact of food insecurity on pregnant HIV women, there is little data on how this impacts adherence (Young et al., 2014).

2.2.2.9 Post-partum adherence

Post-partum adherence on Option B Plus is generally low, according to the literature. In a study on post-partum ART adherence conducted in Tanzania, most women reported a motivation to take their medication while pregnant and breastfeeding in order to protect their unborn child (Ekama et al., 2012; Ngarina et al., 2013). However, once the child is born, most women felt they could stop taking their medication, especially if they had experienced negative side-effects (Ngarina et al., 2013). Conversely, there are women who do not take ART even while pregnant for fear of harming the baby (Ferguson & WHO, 2013). In Uganda, young women initiated onto Option B Plus reported that they would likely stop treatment as soon as they gave birth (Webb & Culel, 2013).

In Malawi, breastfeeding mothers were two times more likely to miss their follow-up visits compared to pregnant women (Matheson et al., 2015). Therefore, they might have missed doses if they failed to collect their medicine. Loss to follow-up has generally been a challenge in many countries that have implemented Option B Plus (Matheson et al., 2015). Given the perceived coercive nature of initiation onto Option B Plus as discussed in the section on immediacy of treatment above, women in Malawi on Option B Plus were five times less likely to return for follow-up visits, compared to women who started on ART without being pregnant (Matheson et al., 2015). Attrition rates for these women were as high as 22% a year after starting ART. This further shows that once women have given birth, the ability to continue with treatment may be greatly reduced (Matheson et al., 2015).

2.2.2.10 Traditional and religious beliefs

The most common religion in Zimbabwe is Christianity. Among Christians, Roman Catholicism is the most common denomination, with Pentecostal and Apostolic Faith denominations becoming increasingly popular (Pearson & Makadzange, 2008). The increase in popularity is significant for adherence as will be discussed later. There is also a belief in ancestral spirits, who are believed to influence one's success and health. Witchcraft and other spirits are also believed to bring bad fortune (Pearson & Makadzange, 2008).

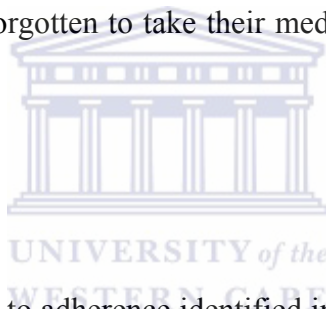
Traditional and religious beliefs play an important role in adherence, as they shape peoples decision-making and whether or not they accept western medicine (Maguranyanga & UNICEF, 2011; Wasti et al., 2012). Women may believe in traditional medicine more than western medicine. This is especially true when the belief is that witchcraft may be responsible for their condition (Leach-Lemens, 2012). The criticism of ART is that it is a western medicine which does not address the spiritual aspect of illness, such as witchcraft (Merten et al., 2010). In addition, ascribing HIV infection to a spiritual cause will also help to remove the blame and guilt from the individual to external forces, and may help in reducing stigma, allowing them to re-integrate into society (Merten et al., 2010).

In Zimbabwe, 33% of the adult population belongs to the Apostolic Faith sect and of these 64% are women of child-bearing age (Maguranyanga & UNICEF, 2011). The Apostolic Faith sect church is a "spirit-type church" that believes in both the holy- spirit and evil spirits. Evil spirits are responsible for illness while the holy-spirit provides good health and "quality of life", provided one follows the teachings and regulations of the church (Maguranyanga & UNICEF, 2011). As a result, the Apostolic Faith teaches faith healing and accessing western and traditional medicine is seen as a lack of faith. Sickness is also viewed as a sign of sin. Violating the churches regulations results in penalties (Maguranyanga & UNICEF, 2011). Therefore it is possible that being a member of the Apostolic Faith church may become a barrier to adherence if members of the church do not access health facilities and/or medicines, including ART. A qualitative study on ART adherence in general conducted in Tanzania found that religion was a barrier to adherence. Five of the respondents in the study reported that they had become non-adherent after being prayed for and encouraged to stop taking their medicine (Lyimo et al., 2012).

A mixed methods study on ART adherence in the general population conducted in Nepal found that religious beliefs were a significant barrier to adherence (Wasti et al., 2012). Patients who were on ART reported non-adherence while fasting during Ramadan, because they could not take water (Wasti et al., 2012). Although Zimbabwe is predominantly Christian, it may follow that abiding by any religious or traditional practices may also impact on adherence.

2.2.2.11 Forgetfulness

Forgetting when to take ART is cited in the literature as a barrier to adherence. Women's roles as homemakers and primary caregivers may act as a barrier to adherence (Ngarina et al., 2013; Nyirenda et al., 2006). A cross-sectional study conducted in Ethiopia to determine adherence levels on Option B Plus found that 34 (12.9%) of the respondents were non-adherent. The most common reason for non-adherence cited by the respondents was forgetfulness, with 92.3% of the respondents stating that they had forgotten to take their medicine (Ebuy, Yebyo, & Alemayehu, 2015)



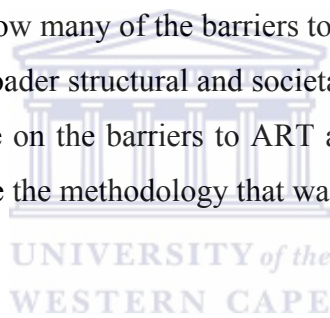
2.2.3 Societal barriers

The most important societal barrier to adherence identified in the literature is stigma (Duff et al., 2010; Gourlay et al., 2013; Leach-Lemens, 2012). Society's perceptions and stigma towards women with HIV in particular acts as a barrier to testing, seeking treatment and adherence to treatment for women (Nudelman, 2013). Reporting on a rapid assessment of gender related barriers to accessing PMTCT services (in Congo, Ethiopia, India, Nigeria and Uganda), Nudelman (2013) states that women are generally held responsible for spreading HIV and bringing it into the family. HIV-positive women are perceived to be of loose morals, who engaged in multiple sexual partnerships. In Zimbabwe, derogatory terms are used to describe HIV-positive women in particular, which place blame on the women for either infecting their male partners or for having been promiscuous. HIV-positive women are referred to as *mushonga wemakonzo* (rat kill, meaning that an HIV-positive woman will infect and kill their male partner). They are also called MaSibanda (meaning 'easy' woman) (Mawadza, 2004). Given society's control of female sexuality, this perception further stigmatises women and they

experience more negative attitudes compared to men (Nudelman, 2013). Also, HIV-positive women who fall pregnant are viewed as selfish for bringing an HIV-positive child into the world when they will possibly die from HIV (Nudelman, 2013). Women often internalise this stigma, leading to feelings of hopelessness and depression. This in turn results in women either not testing for HIV or following up on ART treatment (Nudelman, 2013).

2.2.4 Summary

This literature review identified health facility factors, individual factors and societal factors as barriers to ART adherence. The literature that was reviewed focused on barriers related to accessing Option B Plus, other PMTCT regimens and ART in general. There was a lack of information on barriers to adherence on Option B Plus partly due to the fact that it was a relatively new regimen at the time of conducting the study. The literature review (and the results as will be shown later) illustrates how many of the barriers to adherence are beyond the influence of the women and are related to broader structural and societal factors. It is hoped that this study will add to the body of knowledge on the barriers to ART adherence specifically for Option B Plus. The next chapter will describe the methodology that was used in this study.



CHAPTER 3 METHODOLOGY

3.1 Introduction

This chapter presents the methodology used in the study. A description of the study design is provided, as well as sampling procedures, data collection and analysis, and rigour. Ethical considerations are also discussed.

3.2 Methodology

This section will describe the study design that was chosen, sampling techniques used, data collection and analysis, as well as rigour and ethical considerations.

3.2.1 Study Design

Qualitative descriptive methods were used to provide a comprehensive summary of events in everyday language, as experienced by the individual or individuals (Sandelowski, 2000; Lambert & Lambert, 2012). Descriptive methods were chosen because although there is existing data on the barriers to ART adherence in general, there is very little information on adherence to ART on Option B Plus within this community in Zimbabwe. The study was seeking to describe the barriers to adherence as experienced by the women (Lambert & Lambert, 2012). In conducting the research, it was important for the researcher to ensure that the description of events and the meaning attached to these events was accurate (i.e. descriptive and interpretive reliability, respectively) (Sandelowski, 2000; Neergaard, Olesen, Andersen, & Sondergaard, 2009). Interpretive reliability was particularly important because the researcher wanted to understand the meaning women attached to non-adherence, without making too many assumptions. Understanding their interpretation will also influence how future measures to address non-adherence are structured.

Lastly, because there is very little information on Option B Plus in Zimbabwe, qualitative research was flexible enough to allow for the discovery of new findings that may not have been articulated in the research question (Baum, 1995).

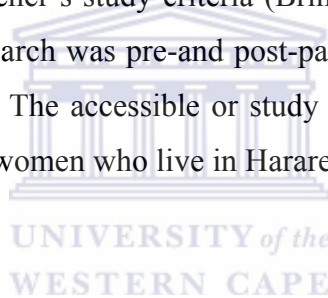
3.2.2 Sampling

This section will describe the study population and sample that was recruited for this study.

3.2.2.1 Study Population

3.2.2.1.1 Pregnant women and mothers

The literature describes the population as all the people or objects that are of interest to the researcher, that is, meet the researcher's study criteria (Brink, Van der Walt, & Van Rensburg, 2006). The population for this research was pre-and post-partum HIV-positive women who had been initiated onto Option B Plus. The accessible or study population (Brink et al., 2006) was HIV-positive pre-and post-partum women who live in Harare.



3.2.2.1.2 Key Informants

The population also includes key informants, who as a result of their skills and knowledge were able to provide deeper insight into the factors affecting adherence on Option B Plus from a service provider perspective (Marshall, 1996b). They were also chosen in order to corroborate research participant's accounts, improving the validity of the research findings (Shenton, 2004). For this research, health workers in Harare involved in direct service delivery on Option B Plus were interviewed as key informants.

3.2.2.2 Study sample

3.2.2.2.1 Pregnant women and mothers

This research was guided by literature on sample size which states that a suitable sample size is one that adequately addresses the research question. Single figures are used for detailed, simple studies, such as this one (Marshall, 1996a). In addition, the researcher was also guided by the fact that once new themes stopped emerging from the data, data saturation had been reached and the number of participants recruited was therefore sufficient (Marshall, 1996b). A total of 20 women were recruited for this study.

The first step in conducting this research was to identify health facilities in Harare which offer maternal, neonatal and child health services (MNCH), including prevention-of-mother-to-child (PMTCT). This was done in consultation with health workers (pharmacists, nurses, doctors) who work in the area of HIV and maternal and child health in Zimbabwe. The facilities had to service a large number of patients in order to facilitate recruitment of sufficient numbers of participants. The health facilities also had to have adopted Option B Plus. Based on these criteria and feedback from health workers two health facilities were chosen, namely, Edith Opperman Polyclinic and Kuwadzana Polyclinic (these are clinics run by the local councils of Mbare and Kuwadzana, respectively).

For this research, pre-and post-partum HIV-positive women initiated onto Option B Plus who were or had been non-adherent were conveniently sampled. (The reason convenience sampling was used is explained in the section on data collection). Convenience sampling is a technique used to recruit samples where they are easily accessed (Yu & Cooper, 1983). Convenience sampling is often used to recruit hard to reach populations who may be more difficult to reach because of stigma, for example. HIV-positive patients are an example of hard to reach populations. Techniques such as facility-based sampling are then used to recruit participants because it is easier to access participants at a place they are known to frequent (Magnani, Sabin, Saidel, & Heckathorn, 2005).

Although the age of sexual consent in Zimbabwe is 16, the participants chosen were aged 18 or over, due to the sensitive nature of the research and for ethical reasons. The participants had to reside in Harare or access health facilities situated in Harare as the researcher was not able to

travel outside Harare due to time and cost constraints. Participants had to speak either English or Shona because these are the common languages spoken in Harare, and the researcher is fluent in both languages.

3.2.2.2 Key Informants

The sample of key informants was health workers from the two selected health facilities who were involved in direct service delivery with regards to Option B Plus. At each site, one nurse and one counsellor were interviewed. The health facilities are primary health care clinics that employ nurses and counsellors. The clinics also employ a doctor each who is supposed to consult with patients once a week. However, during the four weeks of data collection, the doctors did not visit either of the clinics and could not be interviewed.

3.2.3 Data collection

Data collection occurred over a period of four weeks between December 2015 and January 2016. Data was collected at two health facilities, namely Edith Opperman Polyclinic and Kuwadzana Polyclinic. The researcher first went to the health facilities to introduce herself and the research, as well as to seek permission from facility managers to conduct research. The researcher also used this introductory visit to obtain feedback from facility managers as to the best method to recruit participants.

Initially, the researcher intended to purposively recruit participants (excluding key informants) through support groups due to the sensitive nature of the topic and ethical considerations. Health facilities would have been used to identify these support groups. However, once in the field it became apparent that although the health facilities knew of support groups they had very few links with them and were not able to assist the researcher in terms of recruitment. Also because data was collected over the December period, support groups in the two areas were not meeting because most of their members had travelled back to the rural areas for the holidays. The support groups were therefore unable to assist in participant recruitment.

Therefore, based on feedback from facility managers, participant recruitment occurred on-site at the health facilities. Recruitment occurred at the maternal and family health section of the clinics because this is where women access ART. As a result, the majority of women interviewed were post-partum, breastfeeding mothers. Initially, staff at the health facilities helped to recruit participants by recommending patients who had been non-adherent. However, during the pilot phase of the research, it became apparent that participants were hesitant to share their experiences for fear of repercussions from service providers. The researcher then decided to recruit participants without assistance from service providers by spending time talking to the women and building rapport as they waited in line to access health services. The researcher also made it clear to potential participants that the researcher was independent and not affiliated to any of the health facilities. Once women were identified as being or having being non-adherent in the past, they were asked if they were willing to participate in the study. A total of 20 participants were recruited in this way.

Semi-structured, in-depth interviews were conducted with each of the study participants in an office that had been allocated to the researcher at each of the health facilities. All participants were comfortable being interviewed at this location. In-depth interviewing is a technique that is used to allow researchers to gain deeper insight into non-adherence from the participant's perspective (Mack, Woodson, MacQueen, Guest, & Namey, 2005). It also provided an opportunity to learn as much as possible about adherence on Option B Plus (Mack et al., 2005), since very little is known about the subject. Semi-structured interviewing was used because it provides some structure to the interviewing process while being flexible enough to address the different aspects of non-adherence that may be important to the participants (Miles & Gilbert, 2005). (See Appendix 1 for interview guide for pregnant women and mothers)

In some instances, the participants requested to be interviewed in pairs because they felt they could draw from each other's experiences. Also because the participants would generally spend most of their day waiting in line at the health facility, they preferred to be interviewed in pairs so that they could get back home to eat as well as attend to their chores. In this case, the researcher asked each question to both participants to ensure that each participant had an opportunity to provide information.

The interviews were one hour long and were conducted in Shona, which was the preferred language for all participants. The interviews were audiotaped, with the researcher taking down additional notes. The interviews were later transcribed verbatim, in order to capture all the information provided by participants. The transcribed interviews were then translated into English by the researcher.

The researcher visited health facilities in order to identify key informants that would fit the inclusion criteria previously discussed. The researcher identified nurses and counsellors as the most suitable key informants to be interviewed. An interview date and time was then arranged, following which face-to-face, semi-structured, in-depth interviews were conducted. The interviews were conducted in Shona, as this was the preferred language for all of the key informants. The interviews were also audiotaped and later transcribed verbatim. The transcribed interviews were then translated into English. (See Appendix 2 for interview guide for key informants).

3.2.4 Rigour

Rigour is an important aspect of qualitative research methods which is used to ensure the quality of research findings in qualitative studies. Rigour allows the reader to assess the researcher's actions and influences in order to determine the trustworthiness of the findings (Koch, 2006). In this study, credibility, transferability, dependability and confirmability were used as criteria for rigour.

3.2.4.1 Credibility

Credibility is the ability to ensure that the study measures what it intended to measure (Shenton, 2004; Whittemore, Chase, & Mandle, 2001). A number of strategies were employed to ensure credibility.

A review of the literature on studies that sought to describe the barriers to ART adherence and in particular in pre-and post-partum women was conducted prior to data collection. This was then

used to determine whether the barriers to adherence described by study participants were similar to previous research (Shenton, 2004).

Interviewing pre-and post-partum HIV-positive women as well as key informants was used as a way of triangulating data sources. Triangulation of data sources was used to verify participant's experiences against information provided by key informants, thereby providing a detailed and accurate description of the barriers to adherence (Barbour, 2001; Mays & Pope, 1995).

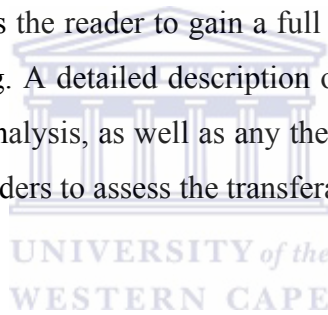
Shenton (2004) states that one of the ways of ensuring credibility is to obtain an honest account of events from participants. Several strategies were employed by the researcher to ensure that the accounts provided by participants were true. The process of obtaining voluntary and informed consent as described in the section below on ethics was used as a means of ensuring credibility. Obtaining informed consent ensured that data was collected from participants (both pregnant women and mothers, and key informants) who were sincerely willing to participate in the research and were likely to give an honest account of their experiences with non-adherence. Further, in order to ensure honesty from pregnant women and mothers, the researcher spent time waiting in line with the women, conversing and basically building rapport which allowed for open and honest dialogue. The researcher also made it clear that she was not affiliated to any of the health facilities and that the information discussed would be confidential and would not affect the way in which women access services. This seemed to enable open and honest discussion on the barriers to adherence.

A reflective journal was kept which documented all the events that occurred in the field during data collection as well as the researcher's response to findings. The researcher's response was used to assess the researcher's influence on the research process and results (Lincoln & Guba, 1986; Seale, 1999; Shenton, 2004). Being a pharmacist, the researcher had some preconceived ideas about the causes of non-adherence, largely based on a bio-medical approach. Reflexivity allowed the researcher to examine and be aware of these biases so as not to allow them to influence the research (Long & Johnson, 2000). Early on during data collection, the reflective journal allowed the researcher to see that using service providers as recruiters was introducing social desirability bias. Therefore, the recruitment technique was changed.

The researcher also held frequent debriefing sessions with mini-thesis supervisors during data collection in order to highlight any issues in the research as well as provide guidance based on their experiences and perceptions (Shenton, 2004).

3.2.4.2 Transferability

Qualitative research methods are generally not concerned with generalizability of results as the sample size is often too small to allow the results to be generalised to the population (Lincoln & Guba, 1986). However, by providing adequate contextual information about the area where research is undertaken, the researcher is able to assist the reader in determining if they can transfer the study to their own setting (Lincoln & Guba, 1986). The introduction and literature review section of this study provide detailed contextual information about the research site. The literature review was also used to provide a detailed description of the barriers to adherence, which Shenton (2004) states allows the reader to gain a full understanding of the research issue, and compare it to their own setting. A detailed description of the study methodology, including study design, data collection and analysis, as well as any theory informing the methodology was included in this report to enable readers to assess the transferability of the study (Anney, 2014).



3.2.4.3 Dependability

The goal of dependability in qualitative research is to allow future researchers to repeat the same work, as well as to assess whether appropriate research methodology has been followed (Lincoln & Guba, 1986; Mays & Pope, 1995). To achieve this, a detailed description of the research methodology was included in this report. As discussed by Shenton (2004), the methodology section included a step by step description of what was planned and implemented prior to data collection, how data was collected and analysed in order to obtain research results.

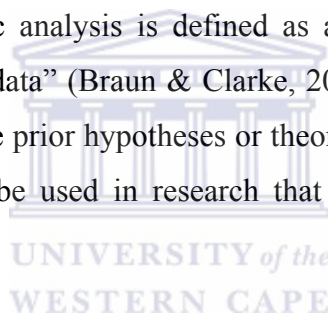
3.2.4.4 Confirmability

Confirmability refers to the extent to which other researchers can agree that the findings of the research are a true reflection of the participant's experiences as opposed to a reflection of the

researcher's ideas (Anney, 2014; Sandelowski, 1986). The researcher kept a record of the raw data, field notes, reflexive journal, data analysis and questionnaires. This is known as the audit trail and was used to assess the research process to ensure the accuracy of the research findings (Cutcliffe & Mckenna, 2004). Triangulation of data sources as previously discussed was also used to reduce researcher bias (Shenton, 2004). In addition, the reflective journal was used to ensure that the research findings were not influenced by the researcher's background as a pharmacist and her perceptions of non-adherence (Anney, 2014). This was done by documenting the data collection process and the researcher's response to the findings.

3.2.5 Data analysis

In this research, an essentialist thematic analysis approach was used to describe the research participants' experiences with non-adherence and the meanings they attach to these experiences (Braun & Clarke, 2006). Thematic analysis is defined as a method that is used to "identify, analyse and report themes within data" (Braun & Clarke, 2006). Thematic analysis was chosen because the researcher did not have prior hypotheses or theories regarding the subject. Due to its flexibility, thematic analysis can be used in research that is independent of theory (Joffe & Yardley, 2004).



3.2.5.1 Data analysis steps

An inductive approach was taken where codes and themes were derived from the data and the research question (Joffe & Yardley, 2004; Robson, 2011). Although the research was topic was specific in terms of describing the barriers to adherence on Option B Plus, the researcher was interested in providing a rich description of all the data (Braun & Clarke, 2006). The researcher also wanted to allow for the emergence of findings regarding Option B Plus in general that may not have been articulated in the research question.

3.2.5.1.1 Familiarisation

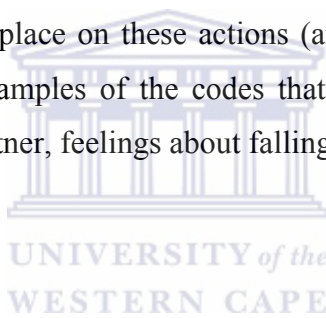
The researcher conducted and transcribed all the interviews and in that way became familiar with the data (Boyatzis, 1998). The transcripts were then repeatedly read also as a way of familiarising with the data (Vaismoradi, Turunen, & Bondas, 2013). Translation of the transcripts also helped with familiarisation of the data. During this initial phase, the researcher had already begun to develop initial ideas about codes and themes (Robson, 2011). These were kept in the reflective diary.

3.2.5.1.2 Coding

Data was coded manually by writing the codes in the margins of the transcripts (Robson 2011). Coding was both descriptive and analytical (Boyatzis, 1998). Examples of what was coded included the reasons for non-adherence as experienced by the women (descriptive) as well as the meanings and interpretations they place on these actions (analytical) (Robson, 2011). Words or sentences were used as codes. Examples of the codes that were derived at this stage include household chores, disclosing to partner, feelings about falling pregnant.

3.2.5.1.3 Identifying themes

The codes were collated and similar codes were grouped into themes and sub-themes. All data relevant to the codes within that theme or sub-theme was then cut and pasted onto one sheet (Aronson, 1995; Vaismoradi et al., 2013). The next phase involved refining these themes and sub-themes to ensure that they truly described and/or interpreted the barriers to ART adherence on Option B Plus (Boyatzis, 1998). It was also important to ensure that the themes were an accurate reflection of the data (Vaismoradi et al., 2013). Finally each theme was named in order to accurately reflect the data relating to that particular theme.



3.2.6 Ethics Considerations

Permission to conduct research was first sought and obtained from the University of the Western Cape Senate Research Committee. Following this, permission was then obtained from the Medicines Research Council of Zimbabwe as well as the ethics committees of each of the research sites discussed above.

Participation in the study was voluntary. All research participants were given a participant information sheet which contained all relevant information regarding the study and assured them of confidentiality. All participants were literate and read the information sheet for themselves. Consent was then obtained by signing a consent form. The research participants were adult women and health workers who were deemed legally competent to give consent. (See Appendices 3 and 4)

Due to the nature of the study there was a risk that participants may have experienced negative feelings regarding their HIV status or about being non-adherent. Where necessary, and depending on the nature of the issue provision was made to refer participants to either a psychiatrist or more general counselling services. (See Appendix 5). However, none of the participants requested these services. The researcher also ensured that the participants did not feel judged for being non-adherent, by asking non-judgmental questions as well as providing non-judgmental responses to their answers. Also, it was stressed that research participants would not be penalised by health workers for failing to adhere. This may have been of concern to research participants as they may have feared that this service will be withdrawn.

Confidentiality was an important consideration for this study because the participants are regarded as an at risk group due to their HIV status and pregnancy. Participants were not identified in any way, and any information they provided had personal identifiers removed through the use of codes. Identifying information was only accessible to the researcher, who kept this information confidential.

3.3 Summary

This chapter provided a detailed description of the methodology used in this study. A description of the sample and how the sample was selected was provided. Data was collected using semi-structured interviews and analysed using an inductive thematic analysis approach. Rigour and ethical considerations were maintained throughout the study. The next chapter will discuss the results of the study.



CHAPTER 4 RESULTS

4.1 Introduction

This chapter presents the findings of the research project. As previously discussed in the methodology chapter, a thematic analysis approach was used to analyse the results. Based on the coding process, first main themes were identified. Once the main themes were identified, interrelated topics were grouped into sub-themes, relevant to the main theme. Finally, the themes and sub-themes were divided into health facility factors and individual factors. The results of the thematic analysis are presented in the table below:

Table 4.1 Results of thematic analysis of study data

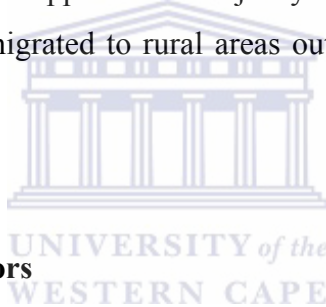
	Theme	Sub-themes
Health facility factors	Workload and staff shortages	Waiting times and hunger Negative staff attitude
	Cost of accessing health services	Distance and transport costs Medicine shortages and expired medicines
	Health facility policies	
Individual factors	The early days after diagnosis and treatment initiation	Difficulty in accepting diagnosis Difficulty in accepting treatment Side-effects
	Stigma	Non-disclosure to i) family ii) friends/community iii) partners family
	Intimate partner dynamics	Non-disclosure to intimate partners Lack of partner support Domestic violence Safer sex practices Stress
	Religion	

It is also important to note that although the study sought to explore the barriers to adherence to anti-retroviral therapy (ART) on Option B Plus, there were some findings that do not necessarily relate to taking medicines but have an impact on the overall well-being of mothers, their children and their intimate partners. These were therefore included in the findings.

Throughout this chapter, some of the women's experiences have been described in brief detail in order to illustrate a point or theme. In keeping with ethical requirements regarding confidentiality and anonymity, pseudonyms have been used.

4.2 Demographic characteristics of the sample population

The women ranged in age from 18 to 35 years. Of the 20 women interviewed, only two were employed. One was an informal trader and the other worked in a clothing shop. The rest of the women relied on their partners for support. The majority of the women lived permanently in Harare, while a few women had migrated to rural areas outside Harare but still collected their medicine from clinics in Harare.



4.3 Health facility factors

4.3.1 Workload and Staff Shortages

The health facilities where the interviews were conducted had a heavy patient load. One health facility reported that 5000 patients accessed the facility every month, which he indicated was a high number of patients. While they may not all have been accessing ART on Option B Plus, this figure highlights the volume of patients that health workers have to attend to. Key informants reported that the introduction of Option B Plus significantly increased the workload, because ART provision has been decentralised to local clinics. Prior to the introduction of Option B Plus, clinics used to refer to either tertiary or infectious disease hospitals.

Personal challenges I could say one is the workload. It [Option B Plus] increased the workload because back then we used to refer like if we test someone we would refer someone to our two [infectious diseases] clinics either Beatrice or Wilkins. They used to

deal with ART but when it was decentralised [and] the workload increased so that's another challenge. (Key informant, nurse #1)

In addition to the heavy workload, all key informants interviewed for the study reported that the facilities were experiencing staff shortages. At one health facility, the nurse interviewed for this study reported that in order to function optimally, the facility required a minimum of eight nurses but only six were employed. Furthermore, the nurse reported that at any given time only five would be at work as someone might be on leave or sick. In addition to providing ART on Option B Plus, these five nurses had to distribute the workload for a number of services among themselves, including immunisations, weighing babies and conducting home visits. The nurses reported that managing this heavy workload was a challenge.

Heavy workload affected the women's ability to access services which in turn affected adherence. Key informants reported that they had resorted to a booking system which meant that some patients were turned away or told to come back at a later time. However, not all patients returned.

...so most of the time she (the nurse) tells them to come back at 2pm that is when she will be dispensing the medication for those that would have come for review...they could have arrived in the morning and they are told to come at 2pm sometimes it might frustrate them... (Key informant, counsellor #1)

Due to the heavy workload and limited time, key informants reported that the counselling sessions focused on the need to maintain the mother's health, prevent vertical transmission to the child, as well as how to manage side-effects. They reported that they did not have adequate time to discuss adherence. In addition key informants reported that the women only received one counselling session before starting ART, whereas with previous ART regimens, both for prevention-of-mother-to-child transmission (PMTCT) and for the general population, at least three counselling sessions were provided prior to initiating treatment. Key informants reported that providing only one counselling session before starting treatment made it difficult to assess whether the women would be adherent.

...counselling will be affected it will be less for every client you will have to reduce the time maybe the client has different problems but when you look at the queue you might

not be able to speak about a lot because a client may need more time... (Key informant, counsellor #2)

The impact of heavy workload and staff shortages was highlighted by Marys' experience. Mary was initiated on ART when she was four months pregnant. Mary was very reluctant to go on life-long treatment. Mary says she had heard from her friends that she only needed to take one pill during labour, as per previous PMTCT guidelines. Therefore, she decided not to take the medicine she had been given, believing it was not necessary. She continued to access antenatal care (ANC) services during this time. It was only in her eighth month of pregnancy that one nurse noticed that she had not collected her medication for four months and finally gave her medicine. At the same time a local non-governmental organisation (NGO) came to the health facility and provided education on the new PMTCT regimen on Option B Plus, which Mary reports helped her better understand the new PMTCT regimen. It was only then that she accepted the fact that she would be on life-long treatment.

Mary's experience highlights two issues. Firstly, heavy workload and possibly staff shortages might have enabled Mary's non-adherence to go unnoticed by health workers even though she continued to access ANC services. Secondly, Mary might not have clearly understood how to take the new PMTCT regimen, possibly due to inadequate counselling during treatment initiation.

4.3.1.1 Hunger and waiting times

At both facilities, women reported that they spent the entire day at the clinic, usually arriving at seven in the morning and leaving at four in the afternoon. The women reported that they and their children would go hungry while waiting at the health facilities and they often did not have money to purchase food. Breastfeeding mothers reported being particularly concerned about not being able to produce breast milk due to hunger.

You will have travelled from far and you want to hurry to get to the service so you can leave early but you still get home at four in the afternoon and you still need to breastfeed but for the milk to come out you need to have eaten. (Post-partum female #16)

Besides hunger, key informants and the women reported how long waiting times were a barrier to keeping appointments at the health facilities given that they were asymptomatic. Some women had defaulted when they had to choose between spending a long time at the clinic or attend to other things such as household chores or attend funerals. The women reported that because they did not feel 'sick', they would sometimes delay going to health facilities if there were competing priorities.

4.3.1.2 Health worker attitude

It was interesting to note that most of the women who complained about waiting times attributed it to negative health worker attitude such as discrimination rather than on the workload or staff shortages.

They do whatever they want because you are the one who is sick and you want to see the doctor. Even if you have plans you are forced to wait. They do what they want if they decide to go for tea and they decide to come back late that's it. (Post-partum female #12)

The women also talked about how the health workers were generally uncaring and lacked respect in their treatment of the women. They attributed this to discrimination because of their HIV status.

...they were serving us in a hurry such that if you remained seated they would say 'you are just sitting there, can't you get up?' As a grown woman you are made to feel as if you are a child. I don't know how they operate... (Post-partum female #6)

Many women reported negative experiences with health facility workers when they had defaulted or missed appointments. They reported that they were shouted at, would be the last ones to be served or refused further supply of medicines. According to the women, health workers were also not willing to accept their reasons for missing appointments or not having medicines. The women reported that this made it difficult for them to approach health workers for assistance when they were non-adherent.

If a person fails to come it means they would have faced a certain difficulty. We simply will not come and collect it means you would have faced a certain difficulty so they

should accept that. It's the same as someone whose bag is stolen and they have the pills in there, if you go there (to the clinic) they will accuse you of selling the pills. They will tell you to go and buy at the pharmacy. (Post-partum female #2)

The women also reported that health facility workers were generally unhelpful with other matters not necessarily related to Option B Plus. One woman narrated an incident where she and her husband contracted a sexually transmitted infection (STI) and the staff at the clinic where she accessed ART and was closest to her, were unhelpful. She only managed to access treatment for the STI from another health facility.

I came here and told them that my husband had an STI and then he developed warts then we came here and explained to them and they asked if we had been treated before and we said yes but we have both developed sores and they said why are you afraid of the warts and they told us to go home and said it will go away...we then went to Mbare [Clinic] and they gave us an injection which they told us to buy...so it's something that affects me that they treat us in a rough manner every time and we live close by, you can actually die yet you live close by. (Post-partum female #7)

Another woman narrated an incident which highlights the negative attitude experienced by these women. She had missed an appointment due to not having money for transport. As per clinic policy, she was told to attend counselling sessions and she could only get pills for one day at a time. She however, could not afford to come every day. She was made to sit all day before anyone could assist her. She described how this was a painful experience for her, particularly because she had her child with her and in addition she was still recovering from a caesarean section.

While discussing her motivation for taking medicines, one woman inadvertently disclosed that health facility workers had discussed other patients with a group she was part of.

...I have seen so many graves due to HIV also I have seen graves of people who would default. There is a person whom we saw who was sick here, and we were told (by the nurses) that her problem was she was defaulting. (Post-partum female #16)

In this particular incident, staff had disclosed that a sick patient had been non-adherent.

4.3.2 Cost of accessing health facilities

Although the provision of ART on Option B Plus is free in government institutions in Zimbabwe, there are associated costs that emerged as barriers to adherence. Health facilities in Zimbabwe require people to pay United States (US) one dollar (R15) per visit, which is an administration fee. In addition, anyone accessing the health facilities is expected to buy a clinic card or book, also for US one dollar. Failure to pay this fee means they cannot access any health services. Most of the women interviewed for this study reported that they had failed to access health services at some point because they did not always have the one US dollar. In some instances they reported that they had resorted to borrowing money in order to access their medicine. Where money was scarce, the women prioritised paying the user fee for their child(ren) to access services. In some instances, some women reported that they had defaulted for months after using their money to pay for the user fee for their child(ren).

...the day I came I had one (US) dollar only and they said I needed a card and I prioritised my child's health card. Then it was stamped and I was given the medication then I thought when I get another (US) dollar I will come and get mine. (Post-partum female #9)

Early antenatal visits are promoted as part of PMTCT to ensure that pregnant women are tested and initiated onto treatment as early as possible. In this study, most of the women only accessed antenatal services from the sixth month of pregnancy, with others presenting to facilities for the first time during labour. The reason given was that at \$25 (R375), the cost of ANC was prohibitive for many. Some women reported that they had faced competing priorities and had used the money for other things such as attending funerals.

I first came when I was in my fifth month and I was given a date that I should come when that date arrived, my mother's older sister died and I used the money (for the funeral) and it proved difficult to get the money back so I finally got it when I was in the seventh month. (Post-partum female #8)

4.3.2.1 Distance and Transport Costs

A few of the women interviewed for this study no longer lived in Harare but still chose to collect their medicine at clinics in Harare. The most common reason provided by the women for living outside Harare was that their partners had become unsupportive following their HIV diagnosis, and had stopped buying food or giving them money. The women reported that they had resorted to living in the village, either with their in-laws or with their own parents. Key informants reported that the women continued to take their medicines in Harare because they would not have disclosed their status to their in-laws or parents and this made accessing health facilities in the village difficult. Due to the long distances travelled, the women reported that transport costs were higher and as a result they had sometimes failed to come and collect their medicines. The women also experienced negative attitudes from clinic staff, who did not accept that lack of transport money was an acceptable reason for missing appointments.

I did not have money for the commuter omnibus to come here. They then told me that they are closing my file and I was supposed to come for the next four days, then I went to the clerk and told him/her that I fully understood what the sister was saying to me but the problem is I did not have money for the commuter to come here but they did not accept that. (Post-partum female #5)

A number of women interviewed for this study reported that their partners had disappeared following the women's diagnosis, and they were unsure where their partners were. Some women reported that they suspected that they had left for either South Africa or Botswana. Therefore, even those women who needed to travel short distances still struggled to find transport money in their partner's absence and had failed to collect their medicines at the appointed time.

He just left...he left in the morning saying he wanted to get into town and he bid me farewell asking me for money and I said I only have this dollar (R15) to buy soap. So I'm not sure if I will get to the 20th and if he will be back and I would have sourced money or not (to come back to the clinic). (Post-partum female #20)

The issue of partner disappearance is symptomatic of a broader issue impacting adherence, that of lack of partner support. This point on partner support will be elaborated on later in this chapter.

4.3.2.2 **Medicine Shortages and Expired Medicines**

As part of PMTCT policy, children born to HIV-positive mothers are given cotrimoxazole prophylaxis. During the course of the study most of the women in both facilities reported that cotrimoxazole was in short supply and they had to buy from the pharmacy. At three or four US dollars a bottle (R45-R60) for a month's supply, most women reported that they could not afford to buy the medicine. The women need to buy three months' supply as they collect medicine every three months. Some women resorted to giving half the recommended dose in order to ensure the medicine lasts the three months before their next appointment. In addition to medicine shortages, some of the women reported that they had been given expired medicine for their children. This was reported at both sites and had been happening over a period of time. The women were therefore hesitant to give their children this expired medicine, leading to non-adherence. Most women indicated that ensuring their children's health was top priority for them and not being able to give them medicine caused stress.

4.3.3 **Health facility policies**

The two health facilities where this study was conducted had adopted certain policies that were meant to ensure adherence or ease waiting times. However, these policies had the opposite effect and resulted in non-adherence. For example, if women missed their appointment, they were supposed to go for counselling for at least three days and could only get a day's supply of medicine until the counselling sessions were completed. This was done to reinforce the importance of adherence through counselling and to monitor adherence during that time.

...the formula we use is if they default and they have their counselling sessions we will not give them their supply for three months so let's say they come today we will give them a pill for today so that they come for counselling when they finish counselling then we will give them their three month supply. (Key informant, counsellor #1)

However, most women viewed this policy as punitive, with some reporting that during those three days they were not given any medication. In addition, they were not always able to present at the facility everyday due to other commitments such as attending funerals or transport costs associated with travelling to the health facility every day.

Plus they have a certain punishment where you come for three days (if you have defaulted) to just mark the register of which in those three days you will not have pills at home and they won't give them to you here. What will they be thinking you are drinking and how you are surviving? They should at least give you one to drink on that day so that you don't have to come the next day but they won't give you. (Post-partum female #7)

In an effort to reduce waiting times, especially for pregnant women collecting ART, the facilities either made them queue separately or get their medicines from a separate room. However, most women felt this strategy made it easier for people in their communities to recognise that they are HIV-positive and receiving ART.

...when they changed us taking us to that room...everyone would see you going into that room to get your pills...everyone you did not want to know would know that Mrs so and so was at the clinic getting pills. (Pre-partum female #1)

In addition, women on Option B Plus were issued with large green books (A5 size) which were easily identifiable. The women reported that people in the community had come to recognise that the green books were given to women on ART, but the size of the books made it difficult for the women to conceal them in their handbags. Key informants corroborated this, stating that even when the women were not made to queue separately, people in the community were still able to identify women accessing ART because of the green books they issued.

Even the green book was an issue because they all used to sit in a queue like any other person who is sick but because of the green book there was some stigma, if I was holding it then the person next to me knew that I was on treatment (Key informant, nurse #2)

In concluding this section on health facility barriers to adherence, I have included a case on Shupi, a 19 year old mother who is HIV-positive and so is her one year old son. She struggled to accept her and her son's diagnosis when she was first told they were both HIV-positive. Shupi also reports that on the day she was tested she did not receive any counselling as the clinic was busy. It took her one week to start taking her medicine. She missed her next clinic appointment because she had travelled to the village and did not have transport money to travel back to Harare. When she finally returned to her home in Harare, she was told she would need to first need to undergo counselling, as per health facility policy, before being given her medicine. She

was reluctant to do this because she lived next door to the clinic with only a fence separating them. Counselling was conducted outside under a tree where the people she shared her house with could see and hear everything. As a result she did not go for counselling and did not receive medicine for her and her son. She decided to access her medicines from a different clinic far from where she stayed. As part of their policy the new clinic required a transfer letter from the previous clinic before they could assist her or her son. Her previous clinic continued to insist that she undergo counselling in order to obtain the transfer letter. Given her reluctance to undergo counselling at her previous clinic in full view of everyone and feeling generally frustrated with her treatment at both clinics, Shupi again stopped going to any health facility. During this time she was also forced to go back to the village because her husband had stopped buying food and she and her son were hungry. She and her son therefore defaulted for six months.

Shupi's experience highlights a number of health facility related barriers that resulted in her and her son being non-adherent. She did not receive counselling on the day she was initiated on therapy. The health facility's policy of providing counselling for non-adherent women was presented a barrier for Shupi. In addition, the health facility provided counselling in full view of everyone, leading to inadvertent disclosure which ultimately led to her defaulting. In addition, Shupi also faced other non-health facility barriers such as lack of partner support, hunger and difficulty in accepting her and her son's diagnosis. Some of these barriers are discussed in the next section on individual barriers to adherence.

4.4 Individual barriers

4.4.1 Navigating the early days after diagnosis and treatment initiation

This study found that the early days of treatment presented a challenge in terms of ART adherence. Many women reported that when they were first initiated on ART they would often forget to take their medicine because they simply were not used to taking medicines every day. Those women who were initiated while pregnant reported being even more forgetful because they would sleep early and more often and would forget to take their medicine. In addition, most of the women interviewed for this study reported that they struggled with accepting their

diagnosis and being initiated onto treatment as well as the side-effects, which negatively affected adherence. These challenges will be discussed below.

4.4.1.1 Difficulty in accepting HIV status

Many of the women found it difficult to accept their HIV status in the beginning. This is because most of the women were tested as part of ANC and did not necessarily expect to be HIV-positive. Some women reported that they had been routinely tested and found to be HIV-negative throughout the years, therefore a positive result was shocking. However, even for those women who suspected that they might have been HIV-positive, accepting the diagnosis was still difficult. The most common reaction to the diagnosis described by the women was denial. Some women were convinced the HIV tests were faulty. Some women reacted by blaming their partners for their diagnosis.

When I was tested it was not my first time to get tested I used to get tested from way back from 2009 when I had my first child I would test negative I just thought my results would remain the same and from the group of people that I was tested with most of them tested negative and from the eight, two of us tested positive. That affected me, to this day it affects me. (Post-partum female #9)

As a result of not accepting their diagnosis, many women reported that they often skipped taking their medicine, particularly in the beginning. Most women felt overwhelmed with the diagnosis itself, having to start treatment immediately and worrying about the outcome of their condition for them and their unborn children.

When I was tested I was found to be positive I found it difficult to accept I had no idea that would be the outcome then I found when I started drinking the medication and I would drink sometimes and stop at times maybe skip a day or two days then drink them at a later period...ahh it's just hard to accept something you were not expecting... (Post-partum female #10)

An interesting observation though was that all the key informants seemed to think that most of the women did not have a problem accepting their diagnosis. They attributed this to the women

already suspecting they were positive due to their partners being unfaithful or the women being better informed about HIV.

Some simply accept the result because some tell you that they knew already because of their husbands' behaviour...it's rare to find ones that won't accept the result... (Key informant, counsellor #2)

However, what they may have perceived as acceptance may actually have been resignation, because during the course of the study many women appeared resigned to their fate, stating that there was very little they could do to change the situation. This resignation came much later on after the diagnosis.

It's difficult to accept. But I just saw that there is nothing I can do about it. The issue is this is my whole life this is not something that I can get rid of. (Post-partum female #11)

4.4.1.2 Acceptability of treatment

Besides experiencing difficulty in accepting the diagnosis, most of the women had difficulty accepting treatment. So even after they had accepted their status, they were not necessarily ready to start treatment. Both key informants and the women reported that the fact that they were generally well when initiated on ART made it difficult for them to take their medicine. In addition, being diagnosed and initiated on treatment on the same day was overwhelming for the women.

The challenge as I have alluded earlier on like the person is fit and all those things and they have just come to book and they are told that they are positive sometimes it's very difficult some people find it hard to understand or accept that this is the situation. As a result this may affect how they take the medication. (Key informant, nurse #2)

The idea of life-long treatment was also a challenge for the women. They found it difficult to accept that they would need to take tablets every day for the rest of their lives. Some women shared that they believed that with or without the medicine they were still going to die, so they would rather stop taking the medicine. They also disliked the fact that taking medicine everyday would interfere with their daily lives, for instance, if they needed to travel.

To be honest it stresses me out and I think what is going to happen but sometimes I think how long am I going to take these pills for? To what end? Should I stop? (Post-partum female #5)

Key informants also stated that the women found the idea of life-long treatment challenging, especially if they were young.

Yes with most people if you tell them it's life-long medication they show some concern. So I will have to be on medication for the rest of my life someone as young as 17 or less than that so they will be worried a lot. (Key informant, counsellor #1)

Part of the difficulty in accepting life-long treatment seemed to stem from confusion regarding the PMTCT regimens. Some women reported that they had defaulted because they thought that they only needed to take one pill during labour. They were referring to previous PMTCT guidelines where women were given single dose nevirapine during labour. The women reported that they preferred this regimen compared to life-long treatment.

The women reported that the size of the pill put them off taking their medicine when they were initiated on ART. As a result, they would often skip taking their medicine for a few days.

When I started I would skip at least two days. Ah the pill is big plus also just not accepting it in my head makes me skip and I will be thinking let me just skip I don't want this, my life is better off the way it is this pill is big let me just leave it. (Post-partum female #5)

Some women reported that when they were initiated on treatment they had to first seek permission from their partners in order to take their medicine. Some women reported that even when they disclosed to their own families, they were told to first seek permission from their partners and their partner's families before taking the medicine. Key informants confirmed that this was a common occurrence, resulting in delays in starting treatment, and in some cases the women never returned to the health facilities.

Yes there are some who can tell you that they are not yet ready to take the medication and they might come back maybe after they have consultations with their husband. (Key informant, nurse #1)

It's a same day thing which is a challenge because a person will leave their house with the intention to book for their delivery and they are told that they are HIV-positive and they should drink ARV's on that day without even consulting with the husband. (Key informant, counsellor #1)

4.4.1.3 Side-effects

Side-effects were a significant barrier to adherence. All of the women interviewed mentioned how side-effects had affected them, especially when they were first initiated onto ART. The common side-effects that were experienced by the women were dizziness, drowsiness, nightmares, nausea and vomiting. Key informants reported that they focused on side-effects in their counselling sessions. They informed the women about the type of side-effects they may experience and how to manage them. For example, they counselled the women to take their medicine at night, an hour before they sleep so that they do not experience the worst of the side-effects. However, despite extensive counselling, side-effects remained one of the major barriers to adherence.

Right when it comes to side-effects we tell them they may experience nightmares or severe ones like jaundice or they have severe diarrhoea or they get a rash then we encourage them to come back to the clinic if the symptoms persist. (Key informant, counsellor #1)

The fact that the medicine affected sleep by either causing nightmares or making the women feel extremely drowsy was a major reason why they stopped taking their medicine. Some women were concerned that because their sleep was affected they became moody and this affected how they related with their children and partners. They would then stop taking their medicine for a few days in order to feel normal.

What's hard for me when it comes to these pills are the side-effects. I don't want to lie these pills have side-effects that sometimes I get agitated when I fail to sleep after taking them. If someone does something to me I get so angry because I will want to sleep and I

will not want to speak to anyone. So sometimes I think it's better not to take them and I feel free... (Post-partum female #9)

In addition the women reported that if they had visitors it made it difficult to take their medicine because they would need to go and sleep immediately. They did not want to have to explain why they were going to sleep or what medication they were taking as this would lead to inadvertent disclosure of their status.

I stop from time to time because I will have visitors. The time I take my pills I have a problem where I cannot look at the light because I will be feeling dizzy and I feel like collapsing so if they are people around it's difficult for me to drink the pills and still stay up... (Post-partum female #3)

Some women experienced nausea and vomiting when they first started taking their medicine. Being pregnant made the nausea and vomiting worse and so they would stop taking their medicine in the first few months of initiating therapy.

But I would wake up and vomit and I was also pregnant so I would skip and say to myself today I am not drinking... (Post-partum female #1)

There seemed to be a strong belief among the women that the medicines caused psychiatric effects which they referred to as madness. Key informants reported that this may be because the medicine can sometimes cause hallucinations. Fear of experiencing this side-effect caused some women to refuse to be initiated onto Option B Plus. Some women agreed to start but as soon as they experienced hallucinations they stopped taking their medicine.

The fact that someone may react to the pills just like my friend (who experienced hallucinations while on ART) I try and encourage her but she gets rough with me...I can say right now she has gone quite some time without taking she stopped two years ago around October...she thinks they (the pills) are making her go mad... (Post-partum female #15)

4.4.2 Stigma

Stigma emerged as a significant barrier to adherence in this study. The women reported that stigma surrounding HIV was due to the fact that it is a sexually transmitted infection and that people tend to assume that they were promiscuous. One woman stated that this was her belief before she herself tested HIV-positive.

Most people say that the disease is contracted through sex so they won't know that I got it from my husband or how I contracted it. But some people will start looking at you like you are a prostitute, why did you get the disease...you were not settled ...you won't live long, you will die soon... (Post-partum female #18)

There appeared to be concerns about stigma regarding the diagnosis itself but also stigma about being on treatment. This seemed to stem from the belief that treatment on Option B Plus causes 'madness.' So the women were even less willing for people to find out that they were on ART.

People will label you as a sickly person and if you say anything they will start saying 'isn't it they say these pills make you go crazy' so they will be saying 'don't you know that the pills are making her go crazy.' No one will listen to you because they will be saying that you are sick so it's better to just keep quiet (and not disclose your status). (Post-partum female #19)

Also quite interesting was the terminology used by the women to describe people who are HIV-positive. Discussing how they identify people who are HIV-positive one woman said they look for swollen lymph glands, which they referred to as 'goodbyes', implying that the person is about to die. Some women called these swollen lymph glands 'Jehovah I am coming', another reference to dying.

Although the women spoke at length about stigma, some key informants believed that this issue had been adequately addressed in Zimbabwe and was no longer a barrier to adherence.

Stigma nowadays has gone done because here a person can address him/herself in front of patients so stigma has been addressed here in Zimbabwe. It's a few people who still worry about such... (Key informant, counsellor #2)

The fear of anticipated stigma led to certain behaviours or decisions by the women which ultimately resulted in non-adherence. Although most of the women had not personally experienced stigma, they were almost certain that they would be discriminated against should they reveal their status. This in turn led to some of the women not disclosing their status to family or friends/community despite having been advised to do so during counselling. The women were particularly hesitant to disclose to their partner's families, as they feared the family would blame them for infecting their partner.

The sections below will discuss non-disclosure to friends and family (both their own and their partner's family), travelling and hiding medicines in general.

4.4.2.1 Non-disclosure to partner's family

The women were especially reluctant to disclose their status to their partner's family. The main reason given for this was that the women feared that they would be blamed for infecting their partners. They also feared that they would be discriminated against and ridiculed for being HIV-positive.

...plus what also made him scared to tell his parents was the fact that they used to tell him that his wife was a whore so he was afraid that they would say you see what your whore did. That's what he was afraid of. (Post-partum female #10)

Those women who had disclosed to their partner's family had been blamed for infecting their partners. In addition, their status had been disclosed to other people they did not necessarily want to find out.

Aah they did not accept it they thought that I had brought it on their child... (they said) but you must know that you brought this our child was okay all this time, how did it come about now that you are together (he is HIV-positive)....it was the sister, she seemed a bit free (open-minded) I was shocked that this free person went and told the mother and they turned on me in a short time. (Post-partum female #11)

Key informants also agreed that it would be difficult for the women to disclose their status to their in-laws because they would be blamed for infecting their partners.

Then cultural , the issue of disclosure for them to tell their father or mother in law that they are now on medication , they will be afraid of getting scolded that they gave the (virus) to their child. (Key informant, counsellor #1)

4.4.2.2 Non-disclosure to own family

The women's reasons for not disclosing to their own family were different compared to their reason for not disclosing to their partners family. Most of the women reported that they feared disappointing their families by revealing their HIV status. Even more common, the women were concerned that disclosing to their parents especially would cause stress and even physical illness to their parents.

....telling my mother or my brother would have stressed them. I wasn't sure about how my mother would respond to the news especially since she is hypertensive...you will cause her blood pressure to go up because she will be thinking my child has that disease. (Post-partum female #18)

Interestingly, some of the women who did disclose to their family members did not do so voluntarily. Rather they were forced by circumstances such as falling sick or lack of material support from partners which meant the women had to disclose to their family in order to receive help.

...when my husband went to Botswana and he just went quiet when he was there and I was told to go to the rural areas so I thought about how hard it would be for me in the rural areas in terms of getting medication for my child what would I do. Then I told my niece and my sister (about my status). (Post-partum female #13)

Even when the women were forced to disclose their status to their family members, they chose a third party, usually a health worker to break the news.

My mother came and we went for the classes at Gomo (Harare Hospital). In fact I did not tell her straight that this is my condition, she escorted me and I said lets go where I am going. She heard people lecture and give testimony that they have been doing this (taking ART) for 15 years. (Post-partum female #16)

Non-disclosure to family members meant the women had to take their medicine discreetly which often led to missed doses. This point will be elaborated on in subsequent sections.

4.4.2.3 Non-disclosure to friends/community

Many women talked about their fears should they disclose to their friends or community members. These included being ridiculed or laughed at, or being shunned. The women were concerned that people would refuse to share food or utensils with them.

What I have seen when people detest you they will not even get into your house thinking that your belongings have (HIV) ... they will not even drink water from your house that's why I don't come out in the open. (Post-partum female #4)

Although most of the women had not personally experienced stigma, they had witnessed this happen to other people. One woman spoke of her landlord who is a HIV lay counsellor but would often make disparaging remarks about HIV-positive people. She therefore did not disclose her status to her landlord.

...because when you hear that so and so is taking these pills, they start to gossip so you realise it's better to keep quiet. They will not want to play with your child. They don't want because they say my child will infect their children. (Post-partum female #11)

4.4.2.4 Effects of non-disclosure

There were several outcomes that impacted on adherence that resulted from non-disclosure to family and friends/community. Non-disclosure to family meant that the women were not able to take their medicine when they travelled. The women were not at liberty to carry their medicine or take it in the company of people they had not disclosed to. This was especially so with their in-laws. Non-disclosure to family/friends resulted in the women accessing health services far from where they lived. These outcomes will be discussed below.

The most common reason given by the women for travelling was to attend funerals. It is common practice in Zimbabwe for people to attend funerals for up to three days, without

returning home. Typically funerals are held in the villages which are a considerable distance from Harare. The women reported that they either did not carry their medicine or they counted out tablets and put them in a container for other medicines such as headache tablets. However, they had often missed doses because they had sometimes counted out fewer tablets than the number of days they attended the funeral. Other times they had failed to come back when they had expected to and had run out of tablets. The women were reluctant to carry the entire bottle of tablets because they are easily identifiable and could result in inadvertent disclosure. Even when they did have adequate tablets, sometimes they were unable to take their medicine as they could not find a discreet place to do so. The women seemed to find it harder to take their medicines when attending funerals at their partner's families' homes.

...then there was a day I went for a funeral at my husbands' rural home in Chihota I skipped because I had not carried them plus people from my husbands' rural home do not know but they suspect that we are on medication but no-one really knows. (Post-partum female #20)

In addition to attending funerals, the women travelled to visit their in-laws. According to key informants, there is an expectation that daughters in-law must regularly visit their in-laws. Especially from planting to harvesting season (December to April), some women are expected to stay with their in-laws and help with tilling the land. This can make it difficult to take their medicine or return for scheduled appointments at health facilities should they run out of medicine, especially when they have not disclosed their status to their in-laws.

Then migration like right now (December) women are going to the rural areas to till the land when they go to the rural areas maybe the clinic is far away...she did not disclose and she did not tell the mother in law that she is on medication. So for her to go to the clinic (in the village is difficult)... (Key informant, counsellor #1)

As a result, many women reported that they had defaulted while visiting their in-laws. Most women reported that when they visit their in-laws they would not carry their medicine to avoid inadvertently disclosing their status. Those women that did carry their medicine had to hide their medicine and as a result either completely missed doses or did not take their medicine on time.

...I was in the rural areas, I did not find the opportunity to drink the pills because people there don't know. I am afraid that they will find the pills in my bag so I usually go without them. Even now no one is supposed to know where I have gone or that I have come to collect my pills no one should know. (Post-partum female #9)

Key informants also reported that women who are pregnant for the first time are expected to stay with their in-laws for an extended period of time. If they have not disclosed their status this could make it difficult for them to attend health facility appointments or to take their medicine. This becomes particularly difficult in the first few weeks of treatment initiation, when the women are given only two weeks' supply of medicine at a time. Key informants reported that some women do not return after two weeks, thereby defaulting.

...for most people it will be their first pregnancy or whatever, there is a culture that the woman must go back to the rural areas and in some cases they would have not disclosed.... So they (the in-laws) might hold that person there when they go and we are saying you need to come back for review after two weeks there is no way that person will say I am going back to take medication without disclosing, you understand? (Key informant, nurse #2)

The women reported that their children had also been non-adherent due to non-disclosure. If the women travelled or the children themselves travelled, it was difficult to administer their medicine because the women were afraid their care-givers would enquire about the purpose of the medicine. Key informants reported that even working mothers were reluctant for their nannies to administer medicines to their children for the same reason.

Due to non-disclosure to friends/community members, some of the women reported that they had resorted to accessing their medicine from health facilities far from where they lived in order to avoid being seen by people from their community.

...it's a problem especially where I live in the flats, you fail to find people you can get along with because all they will be saying is that person is sick... you feel like you are not a person amongst people...as for me no-one knows because all the people from here (Mbare) take (their medicine) here or at Nazareth so I just go to Chitungwiza and get my medication and I just live like that. (Post-partum female #13)

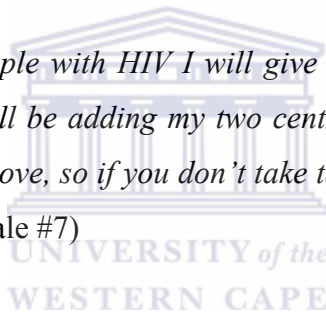
Key informants also reported that they saw a large number of women accessing services who do not live in the vicinity of the clinic. They also attributed this to a reluctance to disclose their status in their communities.

...three-quarters of the people who default are from Epworth usually because they seek treatment here... (Key informant, nurse #1)

This presents a problem however where the women do not have money to travel to health facilities far from where they live. Key informants also reported that it also increased their workload if more people from different areas came to access ART from their facility.

Interestingly, the women had adopted different coping mechanisms to avoid suspicion about their status from friends or community members. Many women reported that they often joined in when people with HIV were being mocked. In this way they avoided raising suspicion about their own status.

...even when they shun people with HIV I will give my opinion (laughter). That people are juicing these days, I will be adding my two cents (laughter). It's just like a car if it doesn't have fuel it won't move, so if you don't take tablets that is as good as you are not a person. (Post-partum female #7)



4.4.3 Intimate partner dynamics

This section has been titled intimate partner dynamics because there were certain issues relating to intimate partner relationships that were barriers to adherence. These include disclosing to male partners, male partner support, domestic violence, stress and negotiating safer sex practices with male partners.

4.4.3.1 Disclosing to partners

Many women reported that they were hesitant to disclose to their partners once they found out they were HIV-positive. They feared that their partners would blame them for infecting them with HIV and would end their relationship. Some of the women did not disclose their status to their partners for years.

I did not tell him for two years, I thought he will go (and get tested) and he will tell me first. I was afraid to tell him because I thought he would say I gave him the disease.
(Post-partum female #20)

Due to the fact that the women had not disclosed their status to their partners, they were unable to take their medicine in their presence. They either took their medicine before their partners returned home from work or took the pills in another part of the house.

In those days he was going to work until about nine so I chose to drink the pills at nine in the evening so he won't be there. If he entered the house I would wait a while and go and take them, I'd act like I am going to get water and I would have thrown the pill in my mouth already. (Post-partum female #4)

...for me to open that medicine bottle while he is there? I don't do that and he has never seen me (take my medicine)... (Post-partum female #12)

Even key informants acknowledged that the fear of disclosure was a major barrier to adherence because the women were tested on their own during ANC visits and found it difficult to disclose to their partners. As a result they were unable to take their medicine or attend scheduled appointments at health facilities.

Right like when a person discloses their status at home and they say I'm positive men without getting tested would say you know where you got HIV and that will disturb their marriage and they are divorcing and all those things. (Key informant, counsellor #2)

To overcome this, most health facilities had devised a strategy where after testing the women, they encouraged them to come with their partners and they would test them together and reveal the results as though they had both been tested for the first time.

4.4.3.2 Lack of partner support

Some of the women who had disclosed their status to their partners reported that their partners had a difficult time accepting the diagnosis. Most of their partners refused to get tested or were not on treatment. This worried the women as they were concerned about re-infection and possible infection for their unborn children.

He just said if they found you to be positive then you are the one who is positive. I will be found positive when I'm found positive. What can you do? But you will be thinking what about this child I am carrying? What usually happens when you are tested and your husband has not been tested, the man's virus can be much stronger than yours... (Post-partum female #17)

Since the women's partners had a difficult time accepting their diagnosis, they withheld financial and emotional support. The women reported that their partners sometimes would not give them money for transport to travel to health facilities. This then affected adherence. Some women reported that their partners had stopped coming home, especially if they worked outside Zimbabwe. In other instances their partners had left the country without informing them. The women reported that their partners had stopped buying food and this had forced some women to live in the rural areas and because they did not always have money for transport, they were sometimes unable to come back to Harare to collect their medicine. Some women resorted to living in the rural areas with their in-laws which also presented challenges in taking medicine in their presence as discussed previously.

As for me I'm hurt and it's made me think a lot because since I was found to be positive I have been fighting with my husband. My husband drives trucks we fought so much that I could not live at (our) home. I am at his rural home (in) Mount Darwin so for me to come and get my medication and the child's. I came once and I was told there was no (medicine for mu child) and he is not coming to the rural areas. So I will be thinking okay the money to go (to the rural areas) and then (come) back. (Post-partum female #4)

4.4.3.3 Domestic violence

Some of the women reported that they had been victims of domestic violence. This seemed to be a pattern in their relationship even before being diagnosed as HIV-positive. They reported that they would physically fight with their partners and would need to seek refuge elsewhere for a few days. They had therefore missed doses during that time.

We fight so when we fight I run away to my parent's house so that we don't continue fighting. We can fight to the extent that we hurt each other so I will be running away because at that point we would have hurt each other so it's better for me to run away and go to my parent's house...yes there was a time we fought and I forgot to take my medication I left it at home then I realised it the next day... (Post-partum female #14)

4.4.3.4 Safer sex practices

Although safer sex practices are strictly not about adherence to ART, they still form an integral part of the broader message on HIV prevention. Condom use, though encouraged by health workers, was the one area where almost all the women reported that their partners refused to comply.

... if you only tell the wife most of them would just say my husband said it does not matter so let's not use protection we are already HIV-positive. (Key informant, counsellor #2)

Even with sero-discordant couples, the male partners still refused to use condoms. The women felt powerless to negotiate condom use, often stating that they gave in to their partner's demands in order to protect their marriage.

...that's why they encourage you to use Protectors® (a brand of condoms) but the men won't agree to that.

How do you react to him not using condoms?

Nothing you just listen to what he wants, he is the father of the house. (Post-partum female #15)

Some of the women were accused of being promiscuous when they insisted on using condoms.

They said we should use Protectors®. But you know men are a problem. I took them (condoms). Then they say you are being promiscuous so it's a problem... (Pre-partum female #1)

4.4.3.5 Stress

Stress was often reported as a barrier to adherence. Many women reported that they had been stressed to a point where they had either become physically ill and their CD4 count had dropped.

Overthinking that's what causes my CD4 count to be low. Like today they were telling me that I am over-thinking that's why my CD4 count is low. (Post-partum female #17)

Strife between intimate partners was the most common reason for the women feeling stressed. Most women reported that their partners withholding financial and emotional support resulted in arguments. Some women reported that they resented their partners because they believed they were the ones who had infected them. Sometimes life's challenges such as financial difficulties or even dealing with difficult teenagers left the women feeling stressed.

...you can become stressed maybe life is hard and you do not have money and you do not have anything to eat, you think about a lot and you can forget to take your medication and think about it later that you forgot to drink your medication. (Pre-partum female #1)

The women would cope by sleeping and would forget to take their medicine.

4.4.4 Religion

Religion played an important role in the women's lives. Many women reported that their religion had helped them eventually deal with their diagnosis. Some had received material and spiritual support from church. Key informants reported that because religion is such an important factor, some women had defaulted if they had been told not to take medicines or if they were told they

had been miraculously healed. Key informants reported that they have had to address this during counselling and emphasise the importance of adherence as opposed to relying on faith healing.

Mmm the problems are religious like the Apostolic Sect, the churches they attend they go and they are told they are negative and they are told not to drink their pills and they actually stop then we see them getting sick after some time and they come back ... (Key informant, nurse #2)

Proving the influence of the church, one of the women who is a member of the Apostolic Sect indicated that the only reason she was taking her medicine is because the Holy Spirit had allowed her to do so.

Yes the Holy Spirit told us to take pills because they have not found holy water that can cure the disease. They tell us to take pills. (Post-partum female #20)

In concluding this section on individual barriers, I have included a case on Karen, a 20 year old HIV-positive mother. She was diagnosed when she was pregnant with her first child and was immediately initiated on ART. While she was pregnant her husband left her and she did not know his whereabouts for a couple of months. He later contacted Karen and informed her that he was living and working in South Africa. After giving birth, Karen was told that she had to go and live with her mother-in-law as part of the traditional practice in their family. Her mother-in-law belongs to the Apostolic Sect and once she arrived there she was forbidden by her mother-in-law to go to the clinic to get medicine for herself and her son. Her mother-in-law tore her clinic cards and threw away her medicine. She would lock the gate so that Karen could not leave. Karen defaulted for six months, only leaving her mother-in-law's house with the assistance of her family.

Karen's experience highlights a number of individual barriers that have been described in this section. First, Karen's partner was not supportive and left her soon after she discovered she was HIV-positive. Observance of traditional practices meant that she had to go and live with her mother-in-law after giving birth, which made it difficult to access health facilities in Harare. Most importantly, Karen's mother-in-law's religious beliefs proved to be the most significant barrier to adherence as she was forbidden from accessing health facilities or taking medicines.

4.5 Summary

In summary, this chapter described the barriers to adherence as perceived and experienced by the women. It also included health workers' perception of the barriers to adherence. Heavy workload and staff shortages at the facility resulted in hunger and long waiting times. Negative staff attitude was also discussed as a barrier to adherence. Despite providing free ART, there remained out-of-pocket expenses which were prohibitive for most women. These included user fees and transport costs. Drug shortages, especially cotrimoxazole also meant that the women had to buy medicines for their children, which they could not always afford. Health facility policies which were meant to promote and monitor adherence as well as ease waiting times had the unintended consequences of discouraging the women from accessing health facilities. These include additional counselling sessions and separate queues for women accessing ART.

The early days of diagnosis and treatment initiation appeared to be challenging for the women who struggled with accepting diagnosis, treatment and managing side-effects. The fear of anticipated stigma led to non-disclosure to family and friends/community. This in turn led to missed doses when the women travelled because they would either hide their medicines or not carry them at all to avoid inadvertent disclosure. Non-disclosure was the main reason why the women accessed ART from health facilities far from where they lived which increased workload for health facilities and increased transport costs for the women. Some of the women had not disclosed their status to their partners for fear of abandonment or withholding of financial and emotional support. Therefore the women had to hide their medicine from their partners. Those women who had disclosed had experienced a lack of material and emotional support which had contributed to non-adherence. Domestic violence and stress within intimate partner relationships was also a barrier to adherence. Religion played an important part in determining adherence, with women either taking or not taking their medicines based on instructions they had received from religious leaders. Religion was so important that health workers had to address this issue during counselling and initiation of ART.

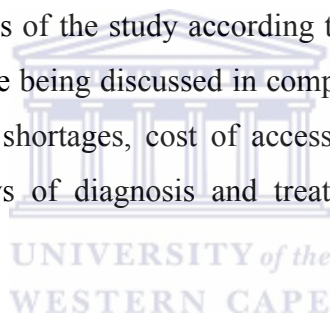
To conclude, most of the individual barriers discussed by the women were a product of societal norms regarding gender roles. The role of gender will be highlighted throughout the next chapter which will discuss the results.

CHAPTER 5 DISCUSSION

5.1 Introduction

This chapter will discuss the results of the study. The study sought to describe the barriers to anti-retroviral therapy (ART) adherence on Option B Plus as experienced by pre-and post-partum women in Harare, Zimbabwe. The adoption of Option B Plus means more women will be initiated onto ART. Therefore, if they do not adhere, there will potentially be an increased number of women with multi-drug resistant HIV, and so will their partners and children (Leach-Lemans, 2012). An increase in multi-drug resistant HIV, coupled with a general increase in the number of women accessing ART will cause additional strain on an already burdened health system (Coutsoudis, A., Gaga, A., Desmond C., Barron, P. & Black, 2013).

This chapter will discuss the results of the study according to the main themes and sub-themes, with key findings under each theme being discussed in comparison to the literature. The chapter will focus on workload and staff shortages, cost of accessing health facilities, health facility policies, navigating the early days of diagnosis and treatment, stigma, partner support and religion.



5.2 Workload and staff shortages

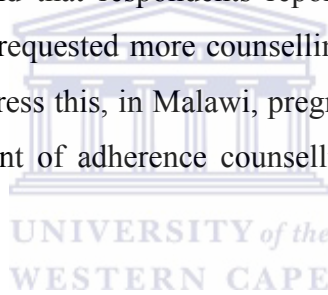
In this study, staff shortages and increased workload were cited as barriers to adherence. The adoption of Option B Plus, coupled with the decentralisation of ART provision has increased workload. Previously, ART was provided through two infectious disease hospitals and two tertiary hospitals in Harare. Clinics, such as the two where this study was conducted would refer HIV-positive patients requiring treatment to these hospitals, thus minimising their workload. Staff shortages are common in most health facilities in Zimbabwe. It is estimated that in public health facilities such as the ones where this study was conducted, there is a 44% vacancy for nursing posts (Munyuki & Jasi, 2009). The downturn in Zimbabwe's economy, as well as unfavourable working conditions is largely responsible for health workers including nurses leaving the country in search of greener pastures (MOHCC, 2013; Munyuki & Jasi, 2009).

Long waiting times were identified as a barrier to adherence at both facilities, by both key informants and the women. Hardon et al. (2006) and Gourlay et al. (2013) also reported that long waiting times were a barrier to adherence. In this study, however, key informants and the women differed as to their perceptions of the cause of the waiting times. Key informants attributed it to increased workload and staff shortages. The women attributed it to negative health worker attitude. In the study conducted by Hardon et al. (2006), long waiting times interfered with the women's ability to perform household chores or look after their babies. While the women in this study also reported that long waiting times affected their ability to perform household chores, their primary concern seemed to be hunger. The women reported that they and their children would go hungry while waiting at the health facilities but they were unable to afford to buy food. Breastfeeding mothers were concerned about the effect hunger would have on their ability to produce milk. During counselling sessions, health workers emphasised the need for the women to exclusively breastfeed in order to reduce the risk of HIV transmission to their children, but the women felt that the same health workers would then delay in serving them and in turn they would go hungry, affecting the amount of breast milk they could produce. Given that the need to protect their children is a strong motivator for the women (Ngarina et al., 2013), if the women perceive long waiting times as potentially affecting their ability to exclusively breastfeed and therefore protect their children, this may cause anxiety for the women and may discourage access to the health facilities.

The amount of time spent counselling the women was limited due to increased numbers of patients and staff shortages. The literature suggests that workers may rush through the counselling process (Keehn & Karfakis, 2014) and this was corroborated by key informants who reported that they did not have enough time to counsel the women adequately. Although the women did not necessarily articulate that they had received inadequate counselling, they did exhibit some misinformation regarding HIV and their treatment, which may be attributed to the limited time available for counselling. For example, some of the women reported that they had been confused about the prevention-of-mother-to-child transmission (PMTCT) regimen when first initiated on treatment, believing that they were only supposed to take their medicine during labour. An assessment of Option B Plus in Malawi also showed that inadequate counselling had

led to the women having limited information about their treatment because they had not been given an opportunity to ask questions (Keehn & Karfakis, 2014). The same study also found that some women were unaware of the fact that treatment was life-long on Option B Plus (Keehn & Karfakis, 2014).

Adding to the complexity of staff shortages according to key informants is the fact that initiation of treatment with Option B Plus is immediate, which means that in Zimbabwe the women have only one counselling session regarding treatment prior to initiation. The women are provided with follow-up counselling sessions every two weeks, but this is after they have already begun treatment. According to key informants, previous ART initiation regimens allowed for at least three counselling sessions before commencing treatment. This provided adequate time to help the women process and begin to accept treatment. Therefore, a shorter contact time prior to treatment initiation has the potential to lead to non-adherence. Similar studies on barriers to adherence on Option B Plus found that respondents reported that the counselling time they received was inadequate and they requested more counselling and follow-up support in general (Keehn & Karfakis, 2014). To address this, in Malawi, pregnant women initiated onto Option B Plus were offered the same amount of adherence counselling that was offered to other ART patients (UNICEF, 2012).



5.3 Health worker attitude

In this study, negative health worker attitude was perceived by the respondents to impact on adherence. The fact that the women were comfortable discussing their negative experiences with health workers despite being interviewed at health facilities shows that this was a significant potential barrier. Women in this study reported that health workers were rude and uncaring. The women perceived health workers to be discriminatory towards them because of their HIV status and the women felt that this was the reason health workers treated them poorly, including taking extended tea and lunch breaks which resulted in long waiting times. These same negative attitudes were reported in studies conducted in Malawi, Uganda and Vietnam (Nguyen et al., 2008; Nudelman, 2013; WHO, 2012). In Vietnam, women accessing PMTCT were asked to cover chairs with newspapers before sitting (Nguyen et al., 2008). While discussing her

motivation for taking medicines, one woman inadvertently disclosed that health facility workers had discussed other patients who were also accessing ART at the same health facility with a group she was part of. Although this participant did not report this as a barrier to adherence, it is important to note that several studies have found that health workers breaching confidentiality by divulging HIV results to friends and family, for example, may deter people from accessing health facilities (Gourlay et al., 2013; Nguyen et al., 2008). Given that some of the women access health facilities in their communities, any perceived breach in confidentiality may discourage the women from going to these facilities, leading to non-adherence.

The power imbalance that is inherent between a patient and a health worker (Matheson et al., 2015) may make it difficult for women to address negative health worker attitudes and they may resort to not accessing these health facilities for prevention and treatment services. The women may also be reluctant to approach health workers should they experience any challenges with adhering to their treatment. Of particular concern is that discriminatory behaviour and stigmatisation from health workers may legitimise discrimination towards HIV-positive women by the general community (Reis et al., 2005).

It is also important to note that heavy workload, staff shortages and generally poor working conditions have been identified in the literature as possibly contributing to negative health worker attitude (Mannava et al., 2015). Therefore, it will be important to address these issues to ensure that the women's interaction with health workers is positive as this will potentially help to improve adherence.

5.4 Cost of accessing health services

Despite the provision of ART being free, costs associated with accessing ART are a significant barrier to adherence. In this study, there was an administration fee of one United States (US) dollar (R15) that was charged at every visit for pre-and post-partum women. For pregnant women, the cost of antenatal care (ANC) services, including delivery was \$25 (R375). Similar studies conducted by Hardon et al. (2006) also showed that user fees as small as US one dollar

fifty (R22.50) were a barrier to ART adherence. In addition, there were transport costs associated with travel to the health facilities.

In this study, many women reported delaying their antenatal care (ANC) visits because they did not have the money to pay for the services. According to the literature, mother-to-child transmission (MTCT) is the second leading cause of HIV transmission in Zimbabwe (ZIMSTAT & ICF, 2012). Early ANC visits as advocated by the Ministry of Health and Child Care (MOHCC) help to ensure early testing and treatment for HIV, thereby potentially reducing the risk of MTCT (MOHCC, 2012). Therefore, delays in accessing ANC services women may have an adverse impact on preventing vertical transmission from mother to child.

The costs associated with accessing health facilities were prohibitive for two reasons. First, Zimbabwe has experienced economic decline, with negative gross domestic product (GDP) growth between 2001-2006 (UN Zimbabwe, 2016). According to the United Nations (UN), in 2011 72.3% of Zimbabweans were poor (UN Zimbabwe, 2016). This means that 72.3% of Zimbabweans were unable to pay for basic food, clothing, health services, transport and education (World Bank, 1995). Therefore, even small user fee charges may be unaffordable for these women. Secondly, the inability to afford the costs was related to the fact that the women had little control and say over how the household income was to be spent. Many women spoke of having to consult or ask for money from their male partners in order to access health facilities. For some women they had to ask for money from their partner's family. These findings concurred with Nyirenda et al. (2006) in a study on the barriers to ART adherence in Malawi where they found that women had little access and control over household income and were disproportionately affected by lack of money compared to men.

5.5 Health Facility Policies

Many of the policies adopted by health facilities were meant to increase access, reduce waiting times or reinforce adherence. However, they had the opposite effect, discouraging women from visiting health facilities. In this study, women accessing ART on Option B Plus were made to access ART from separate rooms, or they accessed from the same room but were made to wait in

a separate queue. This was implemented by the health facilities to ease waiting times. However, separate rooms or queues for accessing ART have been identified in the literature as either resulting in patients withholding information or not visiting health facilities (Groh et al., 2011). The issuing of patient records (in the form of green books (A5) size which made them difficult to conceal because they do not fit into the women's handbags) also made it easy for women to be easily identified as accessing ART. For those women in this study who access ART from health facilities in the communities they live in, any health facility policy that may result in inadvertent disclosure will become a barrier to adherence.

Several studies have focused on the effects of poor quality and insufficient quantity of counselling on ART adherence (Chopra et al., 2005; Delva et al., 2006; Kagee et al., 2011; WHO, 2012). However, this study found that the reasons for providing counselling are just as important in determining adherence. Counselling appeared to be beneficial when the women were first diagnosed and initiated onto treatment. The fact that additional counselling was provided after the women had defaulted had the opposite effect because it was perceived to be punitive. This perception arose from the fact that counselling was mandatory, without taking into consideration the reasons that had led to the women defaulting. The women in this study had to attend sessions every day, which meant additional costs for transport and food. Given that transport costs and hunger have already been identified as barriers to adherence in this study and in the literature, expecting the women to travel to health facilities every day, even for a few days, may influence non-adherence.

In an effort to alleviate heavy workload, health facility staff in this study resorted to working on a numbering system where on the day of their scheduled appointment, the women were given numbers on a first come first served basis. The health workers would serve a certain number of women based on this numbering system and as a result those women who were unable to get a number would be turned away. Given that the women in this study already generally struggle to afford transport costs, they may struggle to return for a new appointment. Also, because the women are generally asymptomatic, there is less motivation to return.

5.6 Navigating the early days after diagnosis and treatment initiation

One of the biggest concerns with Option B Plus is the ‘triple-barrier’ of diagnosing and initiating treatment in pregnant women on the same day (Black et al., 2014; Nachega et al., 2012). Women in this study had difficulty accepting their diagnosis because it was unexpected and they were asymptomatic. However, they seemed to experience even more difficulty accepting treatment. Similar difficulties in accepting treatment initiation compared to HIV diagnosis were reported by pregnant women in a study on rapid initiation on ART in Cape Town, South Africa (Black et al., 2014). Young women in this study seemed to struggle with accepting their diagnosis and treatment, similar to studies conducted in Uganda and Malawi (Webb & Culler, 2013). The difficulty in accepting treatment initiation may be because ART may be perceived as being initiated only in people who are obviously unwell (Fox et al., 2010). This may be because previous World Health Organisation (WHO) guidelines recommended ART initiation when CD4 count had reduced significantly and was sometimes accompanied by clinical symptoms (UNICEF, 2012).

Side-effects, which are generally experienced early in treatment, emerged as an important perceived barrier to adherence by the respondents in this study. Several studies on barriers to adherence have also found that the fear of or experiencing side-effects causes non-adherence (Hardon et al., 2006; Merten et al., 2010; Tweya et al., 2014). The literature states that poor counselling and poor understanding of the side-effects may lead to non-adherence (Merten et al., 2010). In this study however, the counselling sessions focused on side-effects (as well as maintaining the health of the mother and transmission prevention to the unborn child) so the women appeared to possess a fairly good understanding of side-effects. However, the counselling took a bio-medical approach by explaining what the side-effects were and how to manage them, but did not take into account the psycho-social impact of these side-effects. The women were mostly concerned with how certain side-effects such as drowsiness or dizziness interfered with their ability to interact with their children and partners. The women were also concerned that side-effects such as dizziness or drowsiness would result in enquiries about the medicine they were taking and therefore lead to inadvertent disclosure. Therefore, while they understood and expected the side-effects to occur, they were not necessarily equipped to manage them from a psycho-social perspective and this could possibly lead to non-adherence. A study

conducted in Malawi on the barriers to adherence on Option B Plus also found that counselling as a whole focused largely on bio-medical aspects while paying less attention to the psycho-social aspects (Keehn & Karfakis, 2014). It is also important to note that these side-effects occur in women who are otherwise well, therefore there may be less motivation to take medicine that will make them feel 'sick.'

The significance of these findings is that the women in this study reported being non-adherent more often when they were pregnant compared to post-partum when they appeared to have accepted both diagnosis and treatment. This is in contrast to literature which states that adherence levels are lower post-partum (Ekama et al., 2012; Leach-Lemens, 2012; Matheson et al., 2015; Ngarina et al., 2013; Webb & Culler, 2013).

5.7 Stigma

In this study, stigma remained a challenge with regards to HIV in general and had a potentially negative impact on ART adherence. Stigma has been identified in the literature as one of the major causes for the reluctance to access health facilities or take ART, and stigma imposes an even greater challenge for people who are already trying to deal with their diagnosis (ZNNP+, 2014). In this study, stigma arose from the fact that HIV is sexually transmitted and many people still associate HIV with death. These findings are similar to many studies that have discussed stigma (Ekama et al., 2012; Ferguson & WHO, 2013; Gourlay et al., 2013; Patel et al., 2010). Some women reported participating in name-calling other people known to be HIV-positive in order to avoid suspicion about their status. Similarly, a study on stigma in Zimbabwe also found that 7.5% of the respondents had been discriminated against by other people living with HIV (ZNNP+, 2014). The fact that the women would participate in name-calling other HIV-positive people goes to show the extent these women will go to avoid being identified and stigmatised as HIV-positive.

The fear of anticipated stigma resulted in non-disclosure to family and friends/community. Non-disclosure due to stigma has also been identified in the literature as a barrier to adherence (Duffy, 2005; Medley et al., 2004). This study however found that the women were more reluctant to

disclose to their partner's family members compared to their own family members. They were concerned that they would be blamed for infecting their partners and that disclosure would disrupt their relationship with their partner's family. Similar findings in other studies have shown that women were shunned by their in-laws following disclosure and some were afraid that they would be sued by their partner's families for infecting their partners (Laher et al., 2012; Webb & Cullel, 2013). Therefore, the male partners' family have significant influence over the women, their relationships and even decisions regarding their health.

In this study, non-disclosure led to non-adherence particularly when the women travelled. Travel is an important barrier to adherence to consider with this sample because they are a highly migratory group. The two major reasons for travel are to firstly to attend funerals. It is common practice to travel back to the villages for funerals and to spend a few days there. Zimbabwe has a high HIV prevalence rate of 15% (ZIMSTAT & ICF, 2012). Zimbabwe also has a high adult mortality rate of 11.5 deaths/1000 years of exposure for women, and 11.4 deaths/1000 years of exposure for men (ZIMSTAT & ICF, 2012). The high HIV prevalence and high mortality rates may mean that funerals are a common occurrence. The second reason for migration is that there is an expectation for the women to live with their in-laws for extended periods of time, especially from planting to harvesting season and when they are pregnant for the first time. The literature also talks of urban-rural 'seasonal migration' that occurs during agricultural peak periods such as weeding and harvesting (Oucho & Gould, 1993). Since most women are reluctant to disclose to their partners families as discussed above, they are likely to be non-adherent during those times.

An interesting outcome of this study was the difference between the women's experiences with their diagnosis and treatment and the health worker's perception of the same. Health workers were of the opinion that stigma around HIV no longer existed and that the women readily accepted their diagnosis and treatment. The women's experiences were opposite, with stigma and difficulty in accepting diagnosis and treatment being frequently discussed. The significance of this finding is that the health worker's perception of stigma may influence their interaction and treatment with the women. This may also affect strategies or policies that are adopted at health facilities to address stigma. Delva et al. (2006) reported that a counsellors' sensitivity to the

women's fears about stigmatisation determines the success of counselling and adherence to ART on a PMTCT program.

5.8 Partner support

In this study, the researcher identified three experiences as reported by the women in terms of partner dynamics that had the potential to affect adherence for the women. These were the need to seek approval or permission before taking the medicine, non-disclosure to intimate partners and negative reaction from partners for those women that had disclosed their status. These will be discussed below.

In this study, the women did not necessarily set out to get tested for HIV, but it was offered as part of routine ANC. Once they tested HIV-positive, some of the women had little or no agency regarding their own health and both key informants and some of the women reported that they had to seek approval or permission from their partners before starting on ART. Several studies have discussed the patriarchal nature of Zimbabwean society where men and not women are decision makers, including decisions on health and sexual matters (Pearson & Makadzange, 2008; Shoola, 2014). In a study conducted in Malawi on the barriers to adherence on Option B Plus, some of the women faced difficulty in initiating treatment if they had attended ANC without their partners (Keehn & Karfakis, 2014).

Since their partner's acceptance and approval of both diagnosis and treatment appeared to be important for some of the women in order to be able to initiate treatment, if the women anticipated a negative reaction from their partner, they chose not to disclose their status. Some women in the study did disclose their status but experienced negative reactions from their partners, including being blamed for infecting their partners, as well as their partner withholding emotional and financial support. Similar negative partner reactions have been reported in other studies on barriers to adherence on ART (Duffy, 2005; Hardon et al., 2006; Laher et al., 2012; Webb & Cullel, 2013). In both scenarios, that is, not disclosing to partners, or experiencing negative partner reaction, the outcome was that there was little or no partner support. Partner support has been identified in the literature as aiding adherence by providing for example social

support and improving access to prevention and treatment services (Medley et al., 2004; Skovdal et al., 2011). Therefore, a lack of partner support will have the opposite effect and result in potential non-adherence.

In this study, a few of the women had resorted to living in the village with their in-laws due to a lack of partner support. This presented a barrier to ART adherence because the women did not always have transport money to travel to health facilities in Harare to collect their medicine. The women continued to access ART from clinics in Harare because they had not disclosed their status to their in-laws. In addition, living with their in-laws made it difficult for the women to take their ART in their presence if the women had not disclosed their status.

The women's lack of agency extended to condom use. Despite the women receiving counselling on the need to use condoms and being provided with free condoms, most times their partners refused to use these condoms. Their partners even refused to use female condoms. This was true for sero-discordant and sero-concordant couples, as well as couples where the male partner had refused to test for HIV. Several studies have also found that the use of condoms in sub-Saharan Africa is a male-controlled activity, with women having little control over condom use within relationships (Montgomery et al., 2012; Motsi et al., 2012). Several reasons have been put forward for this reluctance to use condoms, including interference with intimacy, reminding the couples of their discordant status and male machoism where men do not fear death and therefore HIV infection (Allen et al., 1992; McDonald, 2011).

5.9 Religion

In this study, for most of the women, their religious beliefs were a positive influence, providing a source of support and helping them deal with their diagnosis. It is probable that those women whose religion does not permit accessing health facilities or taking medicine would not have been engaging with the clinics and would not have been recruited for this study. Key informants reported however, that some women had defaulted on taking their medicine because they believed they had been miraculously healed. A study on the barriers to ART adherence in the general population conducted in Tanzania also reported that some of the respondents had stopped

taking their medicine because they had been prayed for and encouraged to stop treatment (Lyimo et al., 2012). The case study on Karen confirms the literature on religion in Zimbabwe which states that members of the Apostolic Faith do not believe in western medicine or in accessing health facilities (Maguranyanga & UNICEF, 2011).

5.10 Limitations

The sample consisted of women who were accessing health facilities, therefore the study missed non-adherent women who have stopped engaging with any health facility or support services. It is probable that the experiences of the women who were no longer accessing health services are quite different to those of the women interviewed for this study. The barriers to adherence as experienced by women no longer engaged in health facilities probably would have provided different or additional insights.

The sample size was small and this means that the results cannot be generalized to the wider population.

The participants were limited in terms of age to those over the age of 18 to prevent ethical implications. Given that the teenage pregnancy prevalence in Zimbabwe is 24%, and prevalence among 16 and 17 year olds is just under seven per cent and 20.1 % respectively (ZIMSTAT & ICF, 2012), the research might have missed a significant portion of the study population.

The nature of the topic, where women had to discuss behaviour that may be viewed as detrimental to their health and that of their children, means that the responses may have been subject to desirability bias. The women may have underrepresented the extent of their non-adherence to ART.

In instances where the women were interviewed in pairs, it is possible that some women may have withheld certain information from the researcher which they may have deemed too sensitive to share in the presence of someone else. The researcher minimised the risk of one woman dominating the conversation by allowing each woman to answer the question.

There is a risk that some of the study participants were among the most disadvantaged within an already marginalised group of women. Therefore they may have lacked agency and power and the barriers to adherence they experienced may be unique to their particular circumstances.

5.11 Summary

This chapter discussed the findings of the study. Similarities were drawn between the research findings and the literature. Differences with the barriers to adherence described in the literature were also discussed. The most notable difference in this study was that women found adherence most difficult during the early days of treatment initiation, when the women are pregnant. The role that gender plays in being a barrier to adherence was highlighted, where applicable, throughout the discussion. The final chapter will conclude the research as a whole and provide recommendations.

In concluding this chapter it is important to reflect on the new ART guidelines that have been proposed and adopted by the WHO. In June 2016, the WHO published new ART guidelines for the general population. These guidelines recommended that all individuals who test positive for HIV should be initiated on ART as soon as possible, regardless of CD4 count or WHO clinical staging (WHO, 2016). This is commonly referred to as the ‘universal test and treat’ approach. These guidelines are similar to treatment guidelines on Option B Plus, which also follows a ‘test and treat’ approach for HIV-positive pregnant women. The rationale for adopting ‘universal test and treat’ guidelines is that early initiation of ART will result in better health outcomes for the individual and also help to reduce HIV transmission by suppressing viral replication early (Takarinda et al., 2016). In Zimbabwe it is not yet clear when these guidelines will be formally adopted but it is estimated that an additional 700,000 people will be initiated on ART, based on 2014 HIV prevalence data (Takarinda et al., 2016). Therefore the barriers to adherence associated with ‘test and treat’ regimens may potentially be experienced by the general population.

6.1 Conclusion

The introduction of anti-retroviral therapy (ART) has improved the lives of women and allowed them to pursue motherhood (Boehme et al., 2014). The success of ART however depends on adherence to the treatment regimen, therefore it is important to ensure that the women not only have access to ART and they take it in the prescribed manner (Bardeguet et al., 2008). In resource poor settings, the provision of free ART has significantly increased access to ART for women who otherwise may not be able to afford treatment (Hardon et al., 2006). Removing the requirement for CD4 count tests whose costs were prohibitive for both the women and health facilities, has also greatly improved access (UNICEF, 2012).

Despite these provisions to improve access, there remain many barriers to adherence on ART. Many of the findings of this study have been articulated in similar research regarding the barriers to adherence on ART for prevention of mother-to-child transmission (PMTCT) and ART in the general population. The fact that these barriers still remain shows that the barriers to adherence are varied and complex. Addressing these barriers will require more than simply providing free ART, but tackling social constraints such as stigma and gender roles that pose a significant barrier to adherence.

The findings of this study bear significance for two reasons. Firstly, there is very little data on adherence on Option B Plus in Zimbabwe, three years after adopting these guidelines (Takarinda et al., 2016). Therefore, the findings of this study will add to the body of knowledge. Secondly, it is likely that the barriers to adherence on Option B Plus will be similar to the barriers experienced by the general population following the new guidelines by the WHO to test and treat as soon as possible, regardless of CD4 count or WHO clinical staging. For example, it is estimated that an additional 700,000 people will potentially access ART in Zimbabwe once these new guidelines are adopted (Takarinda et al., 2016). This could put strain on an already under-resourced health system. Therefore, it is likely that health facility factors such as long waiting times, heavy workload and inadequate counselling may be experienced. Individuals may also

struggle with the immediacy of initiating treatment after testing. The occurrence of side-effects in asymptomatic individuals may also be a barrier to ART adherence. It is important to note that women are more likely to be more adversely affected by any barriers to adherence because they are generally not decision-makers regarding their health (Pearson & Makadzange, 2008; Shoola, 2014). For example, similar to this study, women may find it difficult to start treatment before consulting their partners. Therefore, the lessons learnt from this and other studies on barriers to ART adherence on Option B Plus should be applied to ensure improved adherence and retention in care with ‘universal test and treat’ guidelines.

6.2 Recommendations

Based on the findings of this study, the following recommendations are made:

The introduction of Option B Plus has increased workload since more women are eligible for ART. In addition, staff shortages are common largely as a result of the economic situation in Zimbabwe. Increased workload and staff shortages have led to long waiting times and poor quality and quantity counselling. Therefore, the Ministry of Health and Child Care (MoHCC) needs to increase the number of health workers employed in health facilities that provide Option B Plus. Nurses and counsellors play a pivotal role in ART provision on Option B Plus, therefore they need to be given priority. This could be achieved by firstly increasing the number of health workers recruited and trained at tertiary institutions. Improving the working conditions of health workers such as shorter working hours, providing incentives (both financial and non-financial) and enabling professional development (Dieleman & Harnmeijer, 2006) may assist in attracting and retaining health workers.

Use support groups and community health workers to encourage the women to carry food to the health facilities for them and their children to alleviate hunger while waiting at the health facilities. Increasing the number of health workers may take longer to achieve, therefore this strategy provides a short-term solution to the issues associated with long waiting times as identified by the women.

This study found that counselling did not take into account the psycho-social impact of being diagnosed HIV-positive as well as initiating treatment immediately. This may be due to time and staff constraints. It is recommended that counselling should focus on the impact the experience of diagnosis and treatment may have on the women's lives and equip them with strategies to cope.

Health workers in this study were perceived by the women as having a negative attitude. Training may need to be provided to health workers to equip them to deal with the women in a sensitive manner. In addition, the literature suggests that improving working conditions for health workers as discussed above can also help change negative attitudes (Mannava et al., 2015).

Health facilities and civic organisations should support the formation and utilisation of treatment support groups. This study found that the women struggled with accepting being initiated on treatment compared to diagnosis. According to the literature, the presence of HIV role models in the community may help in accepting diagnosis (Black et al., 2014). Therefore, treatment role models that can be identified and mentored through support groups may help the women better accept treatment and lead to greater adherence.

Partner support has been identified in the literature as aiding adherence (Medley et al., 2004). This study found that there was a general lack of partner support. Community engagement activities that encourage male partner support need to be implemented. This can be done through peer support or the use of opinion leaders in the community (van den Berg et al., 2015). One way of ensuring partner support is to actively recruit men to provide support to their partners as they access PMTCT services. This has been shown to improve the health of the mother, child and father, improve couple communication and allow the fathers to be more actively involved in their child's health (van den Berg et al., 2015).

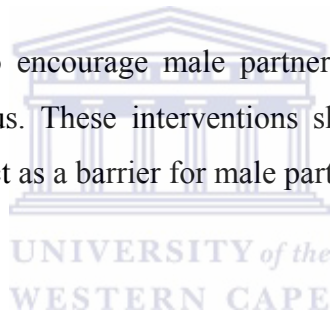
Stigma remains an issue and was identified as a significant barrier to adherence in this study. Women were reluctant to take their medicine in the presence of people they had not disclosed to. Therefore, public education on HIV in general and specifically ART needs to be conducted in

order to reduce the stigma associated with HIV and enable the women to take their medicine in any setting.

6.3 Recommendations for further research

In order to better understand the barriers to adherence on Option B Plus further research in the following areas will be required:

- An in-depth look at barriers to ART adherence during the early days of treatment.
- Barriers to ART adherence need to be investigated with women who are no longer engaged with health facilities.
- Investigate barriers to ART adherence in teenage mothers as a priority population who may have specific barriers.
- Research should be conducted on the enablers to ART adherence for pre-and post-partum women.
- Implement interventions to encourage male partner support for women initiated onto treatment on Option B Plus. These interventions should focus on challenging gender norms and roles that may act as a barrier for male partners to provide support.



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APPENDIX 1 INTERVIEW GUIDE -PREGNANT WOMEN AND MOTHERS

1. Can you tell me about the clinic/hospital you go to for your ante-/post-natal services?

Prompts

- Where is it?
- How do you feel about the service?

2. How did you find out about your HIV status?

Prompts

- At what stage during pregnancy?
- Where did you find out?

3. Can you tell me about your experience of starting treatment?

4. Can you tell me about what you were told about treatment?

Prompts

- Who told you?
- What information did they give you?

5. How do you feel about this treatment you have been started on?

6. Can you tell me about some times when you started missing or stopped taking your medicines?

7. What do you think were the main reasons that might have made it difficult for you to take your medicines?

Prompts

- What was going on in your life when you started missing or stopped taking your medicines?
- Health providers?
- Support from family, friends, support group i.e. did they disclose to anyone, do they receive any support, reminders from any family members, friends, support group?
- Stigma from society?

8. How do you feel when you miss taking your medicines?

9. What do you think could be done to support you in taking your medicines?

Prompts

From family, friends, support group, health services.



APPENDIX 2 INTERVIEW GUIDE – KEY INFORMANTS

1. Describe your role in this facility.
2. How do you tell women about their HIV status?

Prompts

- At what stage during the pregnancy?
 - What process do you go through?
3. What is your involvement with Option B Plus?
 4. What information regarding treatment is provided to the women?
 5. Who provides this information?
 6. How do the women react when they are told about this treatment?
 7. How do the women feel about treatment in general?
 8. How much counselling and support is provided by the health facility?
 9. Who provides this counselling?
 10. What process do you follow before initiating the women on treatment?
 11. When do actually initiate Option Plus B treatment?
 12. What are some of the challenges you have faced in providing ART on Option B Plus

Prompts

- Health provider personal challenges
 - Health facility-related challenges
13. How do you/ health facility address these challenges?
 14. Are you aware of any challenges experienced by your patients that might have led to non-adherence?
 15. How does your facility help patients address these challenges?
 16. What is your facility's view on non-adherence?

Prompts

- Do you collect data – e.g. how many, reasons for non-adherence

- Is your facility concerned about non-adherence?



APPENDIX 3 PARTICIPATION INFORMATION SHEET AND CONSENT FORM – PREGNANT WOMEN AND MOTHERS

Principal Investigator

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School of Public Health

University of the Western Cape

Private Bag X17

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tanya1.dube@gmail.com

Local Performance sites

Edith Opperman Polyclinic

Kuwadzana Polyclinic



MRCZ No. _____

INFORMED CONSENT FORM – PREGNANT WOMEN AND MOTHERS

UNIVERSITY OF THE WESTERN CAPE



Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872

E-mail: soph-comm@uwc.ac.za

Exploring pre-and post-partum barriers to ART adherence for HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe.

Principal Investigator: Tanya Dube B.Pharm (Rhodes), PGDPH (UWC)

Phone number(s): (+27) 813441114 or (+263)774460785

What you should know about this research study:

- We give you this consent so that you may read about the purpose, risks, and benefits of this research study.
- Routine care is based upon the best known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.
- We cannot promise that this research will benefit you. Just like regular care, this research can have side effects that can be serious or minor.
- You have the right to refuse to take part, or agree to take part now and change your mind later.
- Whatever you decide, it will not affect your regular care.
- Please review this consent form carefully. Ask any questions before you make a decision.

- Your participation is voluntary.

PURPOSE

You are being asked to participate in a research study being conducted by Tanya Dube. The research is being conducted for a mini-thesis for a Master's in Public Health at the University of the Western Cape. The purpose of the study is to find out some of the reasons that make it difficult for pregnant women and mothers from always taking their HIV medication. It is hoped that this research will provide recommendations on how to make it easier for pregnant women and mothers to take their HIV medication. You were selected as a possible participant in this study because I value your knowledge and experiences. Your participation will help me understand some of the reasons that may have made it difficult for women like you to take your HIV medication. In total, 20 pregnant women and mothers and four health workers will be interviewed. Please read this information sheet carefully before you decide whether or not to take part in the project. Feel free to ask any questions about the project or information in the document.

PROCEDURES AND DURATION

If you decide to participate, you will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be one hour long. The interview will be conducted where your support group meets or at any other location that is convenient for you. You will be asked questions about how you have been taking your medication and any challenges you have experienced in taking your medication.

The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide. The recording will then be used to write out what

we have discussed in the interview. The recording will only be accessible to the researcher. At the end of the research, the recording will be erased from the voice recorder.

I understand that audio recordings will be taken during the study.

- I agree to **being audio recorded**

Yes

No

Name of Participant (please print)

Signature

Date



UNIVERSITY of the
WESTERN CAPE

RISKS AND DISCOMFORTS

There may be some risks from participating in this research study. You may feel upset or sad talking about your HIV status, pregnancy or children. It is possible that you may feel embarrassed by some of the questions. I will however minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance.

BENEFITS AND/OR COMPENSATION

This research is not designed to help you personally, but the results may help me learn more about some of the challenges that prevent HIV-positive pregnant women and mothers like you from taking their medicine. It is hoped that this research will help identify ways to help pregnant women and mothers take their HIV medication in the correct manner and at the right time. This will help to keep them healthy.

CONFIDENTIALITY

I will protect your identity and the nature of your contribution. To ensure your anonymity, a code will be placed on the typed interview notes. Through the use of an identification key, I will be able to link your data to your identity. I will be the only person with access to the identification key.

To ensure your confidentiality, I will be the only one with access to the voice recording and you will not be personally identified. All voice recorded interviews and hand-written notes will be kept in a locked cabinet and will be destroyed by erasing at the end of the research. I will keep a copy of your signed consent form in a locked cabinet and will destroy it by shredding at the end of the research. All typed notes will be kept on a password protected computer. These will also be deleted at the end of the research.

If a report or article is written about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to my attention concerning child abuse or neglect or potential harm to you or others. In this event, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the designated authorities.

ADDITIONAL COSTS

It is not anticipated that you will incur any additional costs, other than transport costs to travel to your support group meeting or the venue of your choice.

IN THE EVENT OF INJURY

In the event of injury resulting from your participation in this study, treatment shall be offered by the study.

In the event of injury, contact Tanya Dube on 0774460785.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with Edith Opperman or Kuwadzana Polyclinic (as applicable), its personnel, and associated hospitals. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.



SIGNATURE PAGE

PROJECT TITLE

Exploring pre-and post-partum barriers to ART adherence for HIV-positive women initiated onto Option B Plus in Harare, Zimbabwe.

Protocol Version Number/date

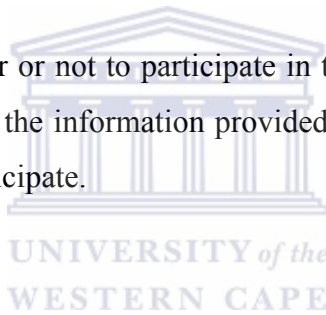
V01/11/2015

OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

AUTHORISATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.



Name of Research Participant (please print)

Date

Signature of Participant or legally authorised representative

Time

Relationship to the Participant

Name of Staff Obtaining Consent

Signature

Date

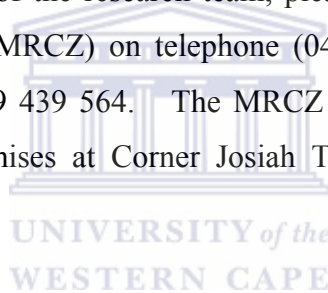
Name of Witness (*if required*)

Signature

Date

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0772 433 166 or 0779 439 564. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.



APPENDIX 4 PARTICIPANT INFORMATION SHEET AND CONSENT FORM – KEY INFORMANTS

Principal Investigator

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Local Performance sites

Edith Opperman Polyclinic

Kuwadzana Polyclinic



MRCZ No. _____

INFORMED CONSENT FORM – KEY INFORMANTS



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Principal Investigator: Tanya Dube B.Pharm (Rhodes), PGDPH (UWC)

Phone number(s): (+27) 813441114 or (+263)774460785

What you should know about this research study:

- We give you this consent so that you may read about the purpose, risks, and benefits of this research study.
- Routine care is based upon the best known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.
- We cannot promise that this research will benefit you. Just like regular care, this research can have side effects that can be serious or minor.
- You have the right to refuse to take part, or agree to take part now and change your mind later.
- Whatever you decide, it will not affect your regular care.
- Please review this consent form carefully. Ask any questions before you make a decision.

- Your participation is voluntary.

PURPOSE

You are being asked to participate in a research study on adherence on Option B Plus. The study is being conducted by Tanya Dube for a mini-thesis for a Master's in Public Health. The purpose of the study is to explore the barriers to adherence for HIV-positive pregnant women and mothers. It is hoped that this research will provide recommendations on how to make it easier for pregnant women and mothers to take their medication. You were selected as a possible participant in this study because I value your knowledge and experiences. Your participation will help me understand some of the health facility related factors that may affect adherence on Option B Plus. Your participation will also help me understand some of the reasons given by women about why they have been or are non-adherent. A total of 24 participants (20 pregnant women and mothers and four health workers) will be interviewed for this study. Please read this information carefully before you decide whether or not to take part in the project. Feel free to ask any questions about the project or information in the document

PROCEDURES AND DURATION

If you decide to participate, you will be given a participant information sheet which explains what the project is about. If you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read or what has been read to you and you agree to take part in the research project. You will be given a copy of the participant information and consent form to keep for your records.

You will be asked to participate in a face-to-face interview with the researcher. The interview will be one hour long. The interview will be conducted at your health facility or at any other location that is convenient for you. You will be asked questions about how your facility has been providing ART on Option B Plus and any challenges the facility or the women have experienced.

The interview will be recorded using a voice recorder. The interview will be recorded to ensure that I capture all the information you provide. The recording will then be used to

transcribe the interview. The interview will only be accessible to the researcher. At the end of the research, the recording will be erased from the voice recorder.

I understand that audio recordings will be taken during the study.

- I agree to **being audio recorded**

Yes

No

Name of Participant (please print)

Signature

Date

RISKS AND DISCOMFORTS

All human interactions and talking about self or others carry some amount of risks. I will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

BENEFITS AND/OR COMPENSATION

This research is not designed to help you personally, but the results may help me learn more about some of the challenges that prevent HIV-positive pregnant women and mothers from adhering to their medicine. It is hoped that this research will help identify ways to help pregnant women and mothers take their HIV medication in the correct manner and at the right time. This will help to keep them healthy.

CONFIDENTIALITY

I will protect your identity and the nature of your contribution. To ensure your anonymity, a code will be placed on the typed interview notes. Through the use of an identification key, I

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If a report or article is written about this research project, your identity will be protected.

In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to my attention concerning potential harm to you or others. In this event, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the designated authorities.

ADDITIONAL COSTS

It is not anticipated that you will incur any additional costs except for transport costs to travel to work or the interview venue of your choice.

IN THE EVENT OF INJURY

In the event of injury resulting from your participation in this study, treatment shall be offered by the study. In the event of injury, contact Tanya Dube on 0774460785.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with Kuwadzana or Edith Opperman Polyclinic (as applicable) its personnel, and associated hospital. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

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Protocol Version Number/date

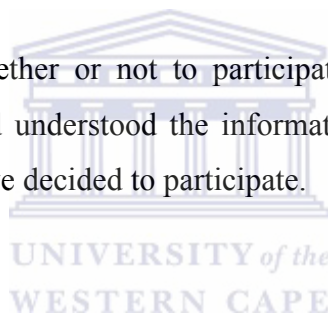
V01/11/2015

OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

AUTHORISATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.



Name of Research Participant (please print)

Date

Signature of Participant or legally authorized representative

Time

Relationship to the Participant

Name of Staff Obtaining Consent

Signature

Date

Name of Witness (*if required*)

Signature

Date

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0772 433 166 or 0779 439 564. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.



APPENDIX 5 LIST OF REFERRAL SERVICES

Dr. Walter Mangezi (MBChB (UZ), M.Med Psych, (UZ))

91 Josiah Chinamano Avenue

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Belvedere

Harare

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Christian Counselling Centre

8 Coltman Road

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CBD

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The Samaritans

60 Livingstone Avenue

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