

University of KwaZulu-Natal

**EXPLORING THE LIVED EXPERIENCES OF HIV-POSITIVE WOMEN ON
PMTCT OPTION B+ STRATEGY IN A SELECTED DISTRICT HOSPITAL IN
MALAWI**

ALIKO MMANGA

**EXPLORING THE LIVED EXPERIENCES OF HIV-POSITIVE WOMEN ON PMTCT
OPTION B+ STRATEGY IN A SELECTED DISTRICT HOSPITAL IN MALAWI**

**Dissertation submitted to the school of Nursing and Public Health
College of Health Sciences
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**In partial fulfilment for Coursework Master's in Nursing
(Advanced Midwifery, Maternal and Child Health Nursing)**

**by
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Declaration

I, Aliko Mmanga, declare that this research project: **“Exploring the lived experiences of HIV-positive women on PMTCT Option B+ Strategy in a selected district hospital in Malawi”** is my own unaided work. It is being submitted for the course work Master’s degree in Advanced Midwifery, Maternal and Child Health Nursing at the University of KwaZulu-Natal, Durban, South Africa. I have not submitted this work for any purpose. All sources of information that have been utilised or quoted have been acknowledged by a complete reference.

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Date: 02 APRIL 14

Abstract

Introduction: In July 2011, The Malawi government started implementing an innovative PMTCT policy known as Option B+ strategy that provides universal lifelong ART for all HIV-infected pregnant and breastfeeding women regardless of clinical or immunological stage. Even though Option B+ strategy is a good choice for Malawi, there is fear that the programme may be affected by poor access, utilisation, adherence and retention.

Aim: The aim of this study was to explore the lived experiences of HIV-positive women on Option B+ strategy in a selected district hospital in Malawi.

Methodology: A Hermeneutics phenomenological approach was used in this study to explore the lived experiences of HIV-positive women on Option B+ strategy through in-depth interviews of five purposely sampled information rich sources. Interviews were audio-taped and transcribed, then manual data analysis using Giorgi's approach was employed to identify meaningful segments and develop categories, themes and sub-themes.

Results: The lifelong commitment was described as the most challenging aspect of Option B+ strategy. Participants demonstrated lack of knowledge and understanding of Option B+ strategy and its implications which rendered them poorly prepared and unready for the task. The un optional Opt-out HIV testing resulted in participants feeling left out in their own care, as health professionals dominated the care from HIV testing throughout the process. The importance of male involvement in PMTCT was revealed in promoting partner HIV testing, disclosure, support, and prevention of further HIV spread. Barriers to participation were described in terms of attitudes of health care workers, stigma and discrimination. Despite the overemphasised need for women to be supported on Option B+ strategy participants were not willing to seek available sources of formal support.

Recommendations: Suggestions made included that; emphasise comprehensive Option B+ strategy information in the hospital and community; promote male involvement in PMTCT; implement Opt-out HIV testing in reality; facilitate policy change to include ART preparatory classes for women; ensure nurses' curricula reflect new responsibilities related to ART management and conduct a similar research study on a larger scale.

Dedication

This thesis is dedicated to all women and children infected and affected by HIV and AIDS and those involved in the prevention of mother-to-child transmission of HIV.

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Abbreviations

AIDS:	Acquired immunodeficiency syndrome
ANC:	Antenatal care
ART:	Antiretroviral Therapy
ARVs:	Antiretroviral drugs
AZT:	Zidovudine
BF:	Breastfeeding
CDC:	Centers for Disease Control
CD4:	Cluster difference 4
CPD:	Continual professional development
CPT:	Cotrimoxazole prophylaxis therapy
DOH:	Department of Health
HAART:	Highly active antiretroviral treatment
HCT:	HIV counselling and testing
HIV:	Human Immunodeficiency Virus
MCH:	Maternal and child health unit
MDGs:	Millennium Development Goals
MMWR:	Morbidity and mortality weekly report
MOH:	Ministry of Health
MSH	Management sciences for health
MTCT:	Mother-to-child transmission of HIV
NAC:	National AIDS commission
NVP:	Nevirapine
PACTG:	Paediatric AIDS clinical trials group
PEPFAR:	President's emergency plan for HIV relief
PMTCT:	Prevention of mother to child transmission of HIV
SD-NVP:	Single dose of Nevirapine
UN:	United Nations
UNAIDS:	United Nations Joint Programme on AIDS
UNDP:	United Nations development programme
UNICEF:	United National International Children's Emergency Fund
WHO:	World Health Organisation
3TC:	Lamivudine

Chapter 1 Introduction

1.1 Background

1.1.1 Global overview of HIV and Women

The HIV and AIDS pandemic continues to be a global public health concern. Of the estimated 35.3 million people worldwide living with HIV by 2012, 47% were women (United Nations Joint Programme on AIDS [UNAIDS], 2013) and half of all new infections occurred among women. The vulnerability of women to HIV remains particularly high in sub-Saharan Africa where 76% of all HIV-positive women live. In 2011, an estimated 92% of pregnant women living with HIV resided in this region. With the increasing evidence of HIV infection among women of reproductive age, there is high incidence of perinatal transmission. Mother-to-child transmission (MTCT) of HIV accounts for 14% of all new HIV infections worldwide (UNAIDS, 2012), and may occur during pregnancy, labour and delivery, or breastfeeding.

In September 2000, the Millennium Development Goals (MDG) framework was adopted by world leaders from 189 nations during the United Nations Millennium Summit, and three of its eight goals (goals 6, 5, 4) are concerned with combating HIV and AIDS and reducing the high rates of maternal and infant mortality attributed to HIV infection (United Nations Development Programme [UNDP], 2010). These goals were framed on the principle that primary health care must ensure access to health services for the most disadvantaged populations and focus on interventions that directly and significantly impact on the major causes of mortality, morbidity and disability for those populations (Kekki, 2003). Globally, there has been some progress towards achieving the MDGs. The incidence of new HIV infection was reduced from 3.3 million in mid-to late 1990s to 1.9 million in 2012, largely due to expansion of HIV prevention programmes (UNAIDS, 2013). In the absence of

prevention, rates of MTCT are estimated to be 25–35 percent (United Nations [UN], 2007). Prevention of mother to child transmission (PMTCT) is currently a global priority in the management of HIV. Since the programme was introduced in 2001 many countries have incorporated it into their HIV programmes (Druce and Nolan, 2007), one of them being Malawi.

1.1.2 The situation in Malawi

Malawi has one of the highest HIV prevalence rates in Africa. In 2011 prevalence among pregnant women was 12.6%, above that of the general population (10.6%), and approximately 63,500 pregnant women were living with HIV. Mother-to-child transmission was identified as the major route of transmission (Van Lettow, et al., 2011), and without intervention about 15% babies born to women living with HIV are infected at birth; an additional 15% acquire the virus through breastfeeding.

1.1.3 HIV and PMTCT in Malawi

Since 2003, the primary prophylaxis regimen in the WHO-recommended PMTCT programme has been the Option A ‘opt-in’ strategy. In the Option A programme, women attending antenatal care are advised to go for HIV testing should they so wish (Perez, Zvandaziva, Engelsmann, and Dabis, 2006); if found HIV-positive they were originally given single-dose Nevirapine (SD-NVP) to be taken when labour starts, and this has subsequently been revised to a short course of ARVs (Zidovudine) from 28 weeks gestation until 1 week after delivery and NVP syrup for the infant to minimise the risk of HIV transmission (Ministry of Health [MOH], 2008). In 2006, Malawi approved HIV testing and counselling (HTC) for all women in antenatal care clinics (ANC), with the option to refuse or ‘opt out’ (Center for Disease Control [CDC], 2004). The aim was to enable all pregnant women to be screened for HIV infection. The guidelines recommended that HIV-infected

women have their WHO clinical staging determined and that they be initiated in the national antiretroviral therapy (ART) programme on highly active antiretroviral treatment (HAART) if in stages III or IV, or if in stages I and II and CD4 count <350, (MOH, 2008). By 2010, PMTCT services were available in all ANC facilities (World Health Organization [WHO], UN and United Nations International Children Emergency Funds [UNICEF], 2011), but even though HIV testing coverage among pregnant women rose from 10% in 2005 to 66% in 2010 it still remains low. In 2011 only 53% of pregnant women received more efficacious ARV regimes for PMTCT (WHO, UN and UNICEF, 2011). According to the ACCESS year end project report (2010), despite the introduction and scale-up of PMTCT services, the number of women accessing these services has not come close to the estimated need. Policies have been updated, space created and supplied with medicine, supplies and equipment, providers have been trained, and yet women accessing high-quality services remain low. National statistics also indicated minimal progress in the reduction of MTCT, as evidenced by the increasing trend of HIV-positive children needing ART each year (MOH, 2009).

Van Lettow, et al. (2011) highlighted issues of the PMTCT programme uptake and outcomes in Malawi and concluded that there was low PMTCT programme efficiency and effectiveness under routine programme conditions in Malawi. Poor uptake may in part be related to an unwillingness of mothers to reveal their HIV status; in this study HIV-infected mothers who denied their status were among the least likely to comply with the recommended strategies. This is confirmed by other qualitative study findings by Chinkonde (2009) and O’Gorman, Nyirenda and Theobald (2010) which reveal that low uptake, or drop-out of PMTCT services in Malawi was related to avoidance of involuntary HIV disclosure, fear of negative community reactions and lack of support from husbands.

Since the initial publication of WHO guidelines in 2006, important new evidence has emerged on the value of antiretroviral (ARV) prophylaxis for prevention of mother to child transmission of HIV. The Kesho Bora randomised controlled clinical trial (2011) which was conducted in five sites in Burkina Faso, Kenya and South Africa is one of the studies that informed WHO on the use of triple ART prophylaxis during pregnancy and breastfeeding as compared to short-course ARV prophylaxis to prevent MTCT. The Kesho Bora results showed that in HIV-positive mothers with CD4 200–500 cells/mm³, triple-ARV prophylaxis given during pregnancy and continued during breastfeeding significantly reduces risk of HIV transmission to infants and improves HIV-free survival, compared with the standard recommended short-course regimen. These findings led the WHO to issue revised guidelines in 2010 to support a global scale-up of PMTCT interventions in resource-limited settings (WHO, 2010). These recommendations have two prophylaxis options;

Option A: Ante partum AZT (from 14 weeks), sd-NVP at onset of labour, AZT + 3TC during labour and delivery, and AZT + 3TC for 7 days postpartum

Option B: Triple ARV (from 14 weeks until one week after all exposure to breast milk has ended)

The 2010 guidelines recommend initiation of lifelong ART for all pregnant women with severe or advanced clinical disease (stage 3 or 4), or with a CD4 count at or below 350 cells/mm³, regardless of symptoms or gestation and continue throughout pregnancy, delivery, breastfeeding and thereafter. The new ART eligibility criteria emphasise the need for access to CD4 testing (WHO, 2010).

1.1.4 Changing from Option A to Option B+

Following WHO recommendations, and drawing on a decade of experience and monitoring data from the HIV programmes in Malawi, a group of physicians and researchers argued that practical realities in Malawi prevented widespread implementation of either Option A or

Option B (Schouten, Jahn, Midian, Makombe and Mthambalala, 2011). The team concluded that complicated protocols and reliance on CD4 counts created an obstacle for the majority of women trying to access PMTCT interventions, resulting in low uptake and high losses in follow-up. In July 2011, the Ministry of Health started implementing a modified version of WHO Option B, in which all HIV-positive pregnant women are initiated on lifelong treatment regardless of clinical or immunological stage. This new PMTCT approach is formally known as Option B+ strategy (Schouten, et al., 2011)

Table 1-1 Three options for PMTCT

	Treatment (for CD4 count < 350cells/mm ³)	Prophylaxis (for CD4 count > 350cells/mm ³)	Infant receives
Option A	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	<i>Antepartum:</i> AZT starting as early as 14 weeks gestation. <i>Intrapartum:</i> at onset of labour, single-dose NVP and first dose of AZT/ 3TC. <i>Postpartum:</i> daily AZT/3TC through 7 days	Daily NVP from birth until 1 week after cessation of all breastfeeding; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks
Option B	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	Triple ARVs starting as early as 14 weeks gestation and continued intrapartum and through childbirth if not breastfeeding or until 1 week after cessation of all breastfeeding	Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
Option B+	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	Triple ARVs starting as soon as diagnosed, <i>continued for life</i>	Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method

Source: WHO programmatic update, 2012

Malawi is the only country to have embarked in such a way on bold expansion of the established global guidelines. The Malawi Ministry of Health takes the view (MOH, 2010) that lifetime treatment is not very risky to the women, is practical and has far-reaching health

benefits. Although a feasibility appraisal conducted prior to policy implementation (MOH, 2009) recommended that the proposed implementation be done in phases, the actual implementation in fact took place on a massive country-wide scale, and the projected yearly increase of people to be started on ARVs has major implications for government's capacity to sustain the initiative - involving, as it does, a steep rise in requisite quantities of drugs and supplies and sharply intensified pressure on health personnel availability, infrastructure, transport and logistics. Notwithstanding these difficulties, the new measures will clearly benefit client health; more clients will have earlier access to more expensive ARVs, which will continue throughout their lives. For a woman initiated on lifetime ARVs there is protection in subsequent pregnancies and reduced HIV transmission to sexual partners.

According to UNICEF (2012), implementation of Option B+ strategy in Malawi has been positive, with a more than 5-fold increase since its commencement in the number of pregnant and breastfeeding women initiating ART. This research investigates the lived experiences of women who are on Option B+.

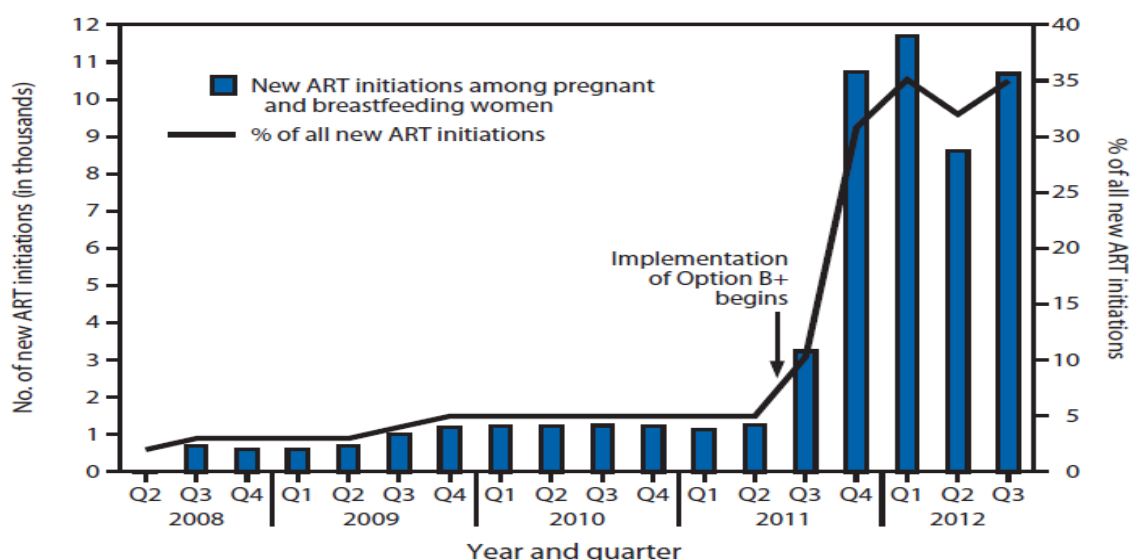


Figure 1-1 Number of new antiretroviral treatment (ART) initiations, 2008–2012

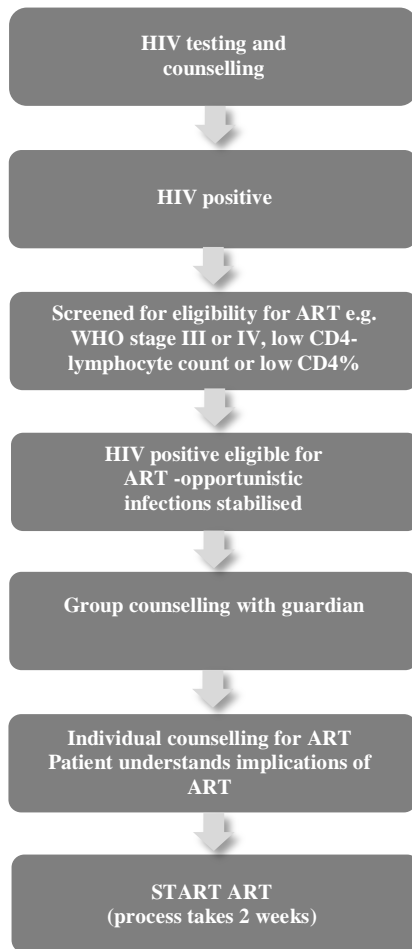
Source: Chimbwandira, Mhango, Makombe, Midiani, Mwansambo, et al. (2013)

The success of the Malawi initiative prompted the WHO to endorse Malawi's approach as a third PMTCT Option in its executive summary document, *Programmatic update: use of antiretroviral drugs for treating pregnant women and preventing HIV infection in infants*, released in April, 2012. So far, Uganda and Swaziland have adopted Option B+ strategy, while other countries like South Africa are still discussing it (Mnyani, 2012), but even though it is evident that Option B+ is a good choice for Malawi, there is fear that the programme may be affected by poor utilisation, adherence and retention. Currently all efforts are directed towards rolling out the programme to increase access, and less attention is being directed towards the primary user: pregnant and breastfeeding women. Nothing is known about the experiences of women on the programme so far.

1.1.5 Integration of ART and PMTCT services

Increasing access to ART among pregnant women has frequently been a challenge, mainly because PMTCT services and ART services have often functioned separately (UNICEF, 2012). Pregnant women were normally managed within family health units where routine antenatal care and ARV prophylaxis were provided to mothers and infants together with follow-up during postnatal care, while other HIV-infected individuals went through the national ART programme. The public approach to ARV provision taken by Malawi requires an integration of ART and PMTCT so that nurses administer ART to pregnant women in all health care facilities. Malawi's integrated guidelines for HIV service provision, issued in 2011, include antenatal care, maternity care, under-5 clinics, family planning clinics, exposed infant/pre-ART clinics and ART clinics (MOH, 2011). Although the national ART programme and PMTCT are integrated, their operating systems are still slightly different, leaving PMTCT with gaps for improvement.

Essential steps in ART



Essential steps in PMTCT

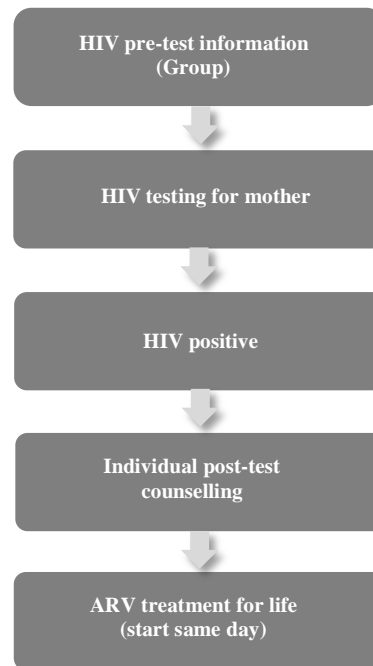


Figure 1-2 Essential steps in PMTCT and ART

Source: Ministry of Health (2008)

What happens in practice is that a pregnant woman who walks into an antenatal clinic for routine care is tested for HIV without much choice, and if tested positive she is started on lifelong ARV treatment immediately, an approach described by Dieffebach and Fauci (2009) as ‘test and treat’. The woman’s thoughts, fears and concerns are seldom addressed in this scenario, as clinic staff are trained to seize every opportunity for identifying and treating HIV-infected women.

Brinkhof, et al. (2008) give an insight on an existing problem with patient retention strategies on ART programmes in Africa. They carefully analysed 15 ART treatment centres and observed that early client loss was increasingly common when programmes were scaled up.

With the increased numbers of women enrolled on the Option B+ strategy, issues of loss to follow-up can be anticipated. On the other hand, ART preparatory classes that are prerequisite in the national ART programme have a major influence on the outcome of clients (only those who understand the implications, are started on treatment) which is not the case with PMTCT. This may result in initiation of a long-term treatment therapy to women who are not psychologically prepared. Chisha (2010) found that readiness for lifetime commitment taking ARVs was a determinant in adherence.

In the Option B+ strategy, healthy HIV-positive women are asked, without choice or preparation, to make a lifelong drug commitment. The practicality of this demand is debatable. Statistics indicate that out of 6,094 females who were pregnant from April to June 2012, 97% were started on Option B+ in WHO clinical stage 1 or 2 (MOH, 2012). Although these are healthy pregnant mothers who may not see the need for a lifelong treatment, the benefits of the Option B+ strategy may motivate them to access and adhere to the programme for their own health and that of their partners and children. With many pregnant and lactating women being enrolled on ART, and with ART requiring consistent adherence for the rest of one's life, it is essential to explore the experiences of these women on the programme to determine what lifelong treatment means to them. It is not known whether women taking the Option B+ strategy see it as a benefit for improvement of health, or as just another burden to be endured.

1.2 Problem statement

Worldwide, it is women rather than men who are the most affected by HIV and AIDS. With increasing evidence of HIV infection among women of reproductive age, incidence of mother-to-child transmission of HIV is high. At the same time, there has also been significant progress in the global scale-up of PMTCT of HIV, including in high-burden and resource-

limited settings (WHO, 2010) such as Malawi, and elimination of MTCT of HIV is now considered to be a realistic public health goal. In July 2011 the Department of HIV and AIDS in the Malawi Ministry of Health, began implementing an innovative policy for pregnant women living with HIV which came to be known as the Option B+ strategy, formally defined as “universal lifelong ART for all HIV-infected pregnant and breastfeeding women regardless of clinical or immunological stage” (MOH, 2011), and this resulted in an astounding 88% increase in the total number of all patients initiating ART in the national programme after implementation of the new strategy for just one quarter (MOH, 2012).

The benefits of the new protocol are undeniable both therapeutically and in terms of access, but it also has enormous consequences for the health system; and while major implications such as programme sustainability have been reported in the literature, but little attention has been given to how the programme is experienced by the participants themselves, even though this is a situation where healthy women are asked to make a lifelong drug commitment. Schouten et al. (2011) point out that PMTCT Option B+ is untried and untested as a public health model, and that no assessment has yet been made of community acceptability for this approach. Participating women’s experiences should be high on the list of issues still to be explored because they could well have a positive or negative influence on their participation.

A review by Graham and Hussein (2003) of HIV and AIDS and maternal mortality recommended assessment also of the effects of HIV and AIDS on the uptake of maternal health services. In areas where PMTCT is a component of maternity care, women might avoid maternal health facilities because of HIV-related fears, and a few studies have examined the impact of these fears on women’s decisions about where to deliver (Etiebet, Fransman, Forsyth, Goetzee, and Hussey, 2004). For maximum reduction in MTCT of HIV, the maternal regimen needs to commence antenatally and continue consistently throughout

breastfeeding (Chasela et al., 2010). If women's experiences on Option B+ strategy are negative it may lead to poor adherence (with increased MTCT) and avoidance of health facilities for antenatal care and delivery (with increased pregnancy complications and maternal and infant HIV morbidity and mortality). At this early stage of Option B+ implementation little or nothing is known about how pregnant women understand, accept, utilise or adhere to the long-term regime. Coutsooudis et al. (2013) argue that with there still being so many unknowns the push for countries to switch to Option B+ is premature. The purpose of the present study is to help build a fuller understanding of the public health potential of Option B+ strategy through an exploration of pregnant women's experiences in utilising the service.

1.3 Aims and objectives of the research

1.3.1 Aim of the study

To explore the lived experiences of HIV-positive women receiving care on PMTCT Option B+ strategy in a selected hospital in Malawi.

1.3.2 Specific objectives in the study

- 1) Describe and interpret the experiences of HIV-positive women receiving care on PMTCT Option B+ strategy
- 2) Describe and interpret sociocultural factors that affect HIV-positive women receiving care on PMTCT Option B+ strategy.

1.3.3 Research questions

- 1) What are the experiences of HIV-positive women when participating on PMTCT Option B+ strategy?

- 2) What sociocultural factors affect HIV-positive women receiving care on PMTCT Option B+ strategy?

1.4 Significance of the study

The PMTCT Option B+ strategy is a bold initiative by the Malawi government to minimise mother-to-child transmission of HIV and prevent maternal and infant mortality by providing universal lifelong ARV drugs for all HIV-infected pregnant and breastfeeding women, regardless of clinical or immunological stage (MOH, 2011). According to Bobrow (2008), the PMTCT programme continues to face obstacles to participation by the women concerned, resulting in low uptake and loss to follow-up of women and their newborns at different stages of the programme (Peltzer, Jones, Weiss and Shikwane, 2011). Issues of participation are becoming more critical since there has been a huge increase in Malawi in the number of women being tested for HIV during pregnancy (Bobrow, 2008). Factors that affect participation in PMTCT programmes have been discussed but are not conclusive in predicting a similar trend in the Option B+ strategy. The purpose of this study is therefore to investigate how Option B+ strategy is experienced by HIV-positive pregnant and breastfeeding women and to understand the individual meanings attached to the experience. The findings of this research will highlight experiences of women on PMTCT in order to gain more insight on factors influencing their participation. These experiences will be a base for recommendations for improving programme performance, which is crucial for refining practice and predicting outcome as the programme fully rolls out. The findings and recommendations will influence policy change on HIV care in pregnancy to ensure that programme implementation meets women's needs. The recommendations will also be of service to educators in curriculum development for learning institutions and the study's

findings will contribute to the body of knowledge on the phenomena and serve as a baseline for future research.

1.5 Operational definitions

HIV and AIDS

HIV is the human immunodeficiency virus. It is the virus that can lead to acquired immune deficiency syndrome, or AIDS (CDC, 2012). AIDS is the late stage of HIV infection, when a person's immune system is severely damaged and has difficulty fighting diseases and certain cancers (CDC, 2012). HIV is spread through having unprotected sex with HIV-infected person and through babies being born to an HIV-infected mother whereby the virus can be passed from mother to child during pregnancy, birth, or breastfeeding.

Option A strategy

Option A is a WHO-advised PMTCT intervention that aims to provide longer antiretroviral (ARV) prophylaxis for HIV-positive pregnant women with relatively strong immune systems who do not need ART for their own health. This is believed to reduce the risk of HIV transmission from mother to child (WHO, 2010). In this study, *Option A strategy* refers to maternal antepartum AZT starting as early as 14 weeks gestation; intrapartum single-dose NVP and first dose of AZT/3TC, and daily AZT/3TC through 7 days postpartum, including daily NVP for the infant from birth until 1 week after cessation of all breastfeeding; or, if not breastfeeding or if mother is on treatment, through age 4–6 weeks (WHO, 2010).

Option B+ strategy

Since the publication of revised guidelines by the WHO in 2006, important new evidence has emerged on the use of antiretroviral (ARV) prophylaxis for the prevention of mother-to-child transmission of HIV (PMTCT), and on safe feeding practices for HIV-exposed infants.

Option B+ strategy is a PMTCT intervention that provides universal lifelong ART for all HIV-infected pregnant and breastfeeding women regardless of clinical or immunological stage (MOH, 2011). This is a basis for effective PMTCT interventions that will virtually eliminate the number of new paediatric HIV infections in resource-limited settings. In this study *Option B+* refers to the provision of triple ARVs to HIV-positive, pregnant and breastfeeding women starting as soon as diagnosed, continued for life including daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method (MOH, 2011).

PMTCT

PMTCT (prevention of mother-to-child transmission of HIV) are global interventions to minimise the risk of HIV infection from an infected mother to an infant. HIV is transmitted from a mother to an infant before, during, and after labour; MTCT of HIV can therefore be prevented by antiretroviral therapy, obstetric interventions, and changes in breastfeeding practices. ART is considered a priority for pregnant and breastfeeding women for effective reduction of mother-to-child transmission of HIV (MOH, 2008). In this study *PMTCT* refers to the primary interventions with voluntary testing and counselling of pregnant women in antenatal clinics, the use of antiretroviral drugs and adoption of appropriate infant feeding options (Department of Health [DOH], 2008).

HIV-Positive women

In this study *HIV-positive women* refers to women tested for HIV where antibodies against the virus were detected on a blood test.

Lived experiences

Lived experience is an individual's expression of how she views the everyday world, conveyed in words, personal feelings, attitudes, and behaviours (Colaizzi, 1978). This term

will be used to describe individuals who have lived through the experience of being HIV-positive and participating in the PMTCT Option B+ strategy.

1.6 Conclusion

In an overview of HIV and women, this chapter highlighted the situation in Malawi in relation to PMTCT. The efforts to minimise maternal and child morbidity and mortality in Malawi through the adoption of Option B+ strategy and other related issues were briefly indicated, and the aims and objectives of the study were identified as being to seek understanding and interpretation of the lived experiences of HIV-positive women on Option B+ strategy in order to inform changes in practice, policy, education and research.

Chapter 2 Research methodology

2.1 Introduction

In the previous chapter, the world, regional and country HIV and AIDS statistics in relation to women were discussed with the aim of putting a context to the research problem and objectives. This chapter therefore outlines the approach used in the research in seeking to answer the research questions for the purpose of gaining understanding of, and providing meaning to, the lived experiences of HIV-positive women receiving care on PMTCT Option B+ strategy. It indicates the research paradigm that informed the research approach and how it was applied in relation to the study setting, sampling and data management.

2.2 Research paradigm

This research study was based on the constructivist paradigm. Within this worldview, the qualitative approach was applicable. Constructivism as the mode of inquiry offers the possibility for a researcher to examine the unique experience of humans as they live and make sense of their social worlds, and paradigms for human inquiry are in turn characterised according to the ways in which they respond to certain primary philosophical assumptions: *ontological* assumptions, relating to the study of being; *epistemological*, assumptions, relating to how we know what we know, and *axiological* assumptions, concerning the role of values in the inquiry (Crotty, 1998).

The ontological nature of constructivist enquiry lies in the way that social reality is approached as the product of processes by which social actors together negotiate the meanings for action and situations (Crotty, 1998); on this premise, reality is considered to be multiple and mentally constructed by individuals. Constructivists thus take the position of relativism that assumes that different worlds constitute people with diverse ways of knowing,

distinguishable sets of meanings and separate realities (Crotty, 1998). This implies that reality is subjective and is the ontological assumption from which this study sets out to explore the lived experiences of HIV-positive women receiving care on PMTCT Option B+. Epistemologically, constructivists assume that meaning is not discovered, but constructed. According to Crotty (1998), knowledge is maximised when we engage with phenomena and make sense of them directly and immediately. The lived experiences of women on Option B+ will therefore be explored through an interaction between the researcher and the participants; hence, the findings will be the creation of this interactive process. In other words, the research will be conducted subjectively and in a value-laden context, this then representing the axiological dimension of the research project.

In this study, the ontological assumption was that HIV-positive women have individual unique experiences on Option B+ strategy, the meaning of which is constructed as they receive care. Epistemologically, these meanings were explored and understood by interacting with the women directly without prior assumptions, thoughts or feelings (axiologically), which was useful as a way of identifying and interpreting their experiences.

2.3 Philosophical framework

A phenomenology approach was chosen as the philosophical framework for this study, which also had an exploratory dimension in view of the paucity of existing research that could provide information on the lived experiences of HIV-positive women receiving care on PMTCT Option B+ strategy. Crotty (1998) discusses phenomenology, which is rooted in a philosophical tradition developed by Husserl and Heidegger, as an approach to discovering the meaning of people's life experiences. Phenomenologists investigate subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences. According to Polit and Beck (2004), the four aspects of lived experiences that

are of interest to the phenomenologist are: *lived space*, referring to the external environment of the subject (home, clinic, hospital, etc.); *lived body*, referring to the physiological or psychological changes that affect the individual (feelings, emotions); *lived time*, referring to the period of sickness or care (the period of pregnancy); and *lived human relations*, referring to the way a person relates to friends, family and community members.

The goal of phenomenological inquiry is to fully describe the lived experience, and the perceptions to which it gives rise, through prolonged engagement with a small group of participants which enables patterns and relationships to emerge (Creswell, 2009). Two schools of phenomenology which have been described are descriptive phenomenology and interpretive (hermeneutic) phenomenology.

2.3.1 Descriptive (transcendental or eidetic) phenomenology

Descriptive phenomenology was first developed by Husserl (1835-1938), and his philosophy emphasised descriptions of the meaning of human experience. Husserl's belief was that causal relationships cannot in themselves explain phenomena; there has to be a person to experience the phenomena, and the phenomena need to be described within the context in which they occur (Burns and Grove, 2001). Descriptive phenomenology thus asks, "what do we know as persons" with the emphasis on describing the experience. According to Crotty (1998), Husserlian phenomenologists believe that although self and worlds are mutually shaping; it is possible to bracket oneself from one's beliefs in order to let the experience of phenomena speak first hand. Polit and Beck (2004) describe bracketing as a "process of identifying and holding in abeyance any preconceived beliefs and opinions about the phenomena". This study proposed to explore the experiences of the participants going beyond Husserl's approach by understanding and interpreting the lived experiences; the descriptive phenomenology approach was therefore not considered appropriate.

2.3.2 Interpretive (hermeneutic) phenomenology

Interpretive (hermeneutic) phenomenology is based on the work of Husserl's student and critic, Heidegger (1889- 1976), who moved away from Husserl's philosophy into interpretive philosophy. Hermeneutics moves beyond the description or core concepts of the experience and seeks meanings that are embedded in everyday occurrences (Crotty, 1998). It uses lived experiences as a tool for better understanding of the social, cultural, political or historical context in which those experiences occur. Heidegger believed that people are shaped by the world in which they live; the world of each person is different and can thus only be understood in the context in which that person lives (Crotty, 1998). Differing from Husserlians, hermeneutic investigators do not believe bracketing can be achieved in totality; hence bracketing is seen not as a subtractive process of removing ones presuppositions but instead as a positive process, a way of seeing. Interpretative phenomenology asks "what is being", with the emphasis on understanding and interpreting, rather than not just describing the experience (Polit and Beck, 2004). This approach matched the study's aim and objectives in providing interpretation and meaning to the lived experiences of women on Option B+ strategy and is therefore used in the study.

Table 2-1 Comparison of phenomenological schools of thought

	Husserl (1859-1938): descriptive phenomenology	Heidegger (1889-1976): interpretive phenomenology
Research question	Descriptive	Interpretive
Assumptions	Epistemology “what do we know as persons”	Ontology “what is being”
Bracketing	Bracket biases to ensure neutrality	Eliminate bracketing- personal awareness is intrinsic to phenomenological research
Credibility	Member checking	No member checking
Data analysis approach	Colaizzi developed a method that involves observing human behaviour within its environment to examine experiences that cannot be communicated (Burns and Grove, 2009)	Giorgi considers it important to identify the relationships of the units to each other and to the whole “Hermeneutic circle” (Burns and Grove, 2009)
Data analysis process	<ol style="list-style-type: none"> 1. Read all the subjects’ description to acquire a feeling for them 2. Return to each protocol and extract significant elements 3. Spell out the meaning of each significant element 4. Organise the formulated meanings into clusters of themes 5. Results are integrated into an exhaustive description of the phenomena under study 6. Formulate the exhaustive description into statements of identification 7. Final validating step by returning to each subject 	<ol style="list-style-type: none"> 1. Reading the entire disclosure of the phenomenon straight through to obtain a sense of the whole. 2. Re-reading the same disclosure again in a purposeful manner to delineate each time that a transition in meaning occurs. 3. Examining the previous determined meaning units for redundancies, clarification, or elaboration by relating meaning units to each other and to a sense of the whole. 4. Reflecting on the meaning units and extrapolating the essence of the experience for each subject. 5. Formalising a consistent description of the structure of the phenomenon across subjects by synthesising and integrating the insights achieved in previous steps.

Source: Pallikkathayil and Morgan (1991); Burns and Grove (2009)

2.4 Research approach

The objectives of this research were to describe and interpret the lived experiences of HIV-positive women on PMTCT Option B+ strategy, adopting a Heideggerian hermeneutic

approach. Hermeneutics is a qualitative research tradition, drawing on interpretive phenomenology that focuses on the lived experiences of humans and on how they interpret those experiences. Heideggerian phenomenology takes an ontological approach, asking the question, “what is the essence of these phenomena as experienced by these people?” According to Crotty (1998), this philosophy regards reality as subjective, which means there is no single reality because each individual has his or her own unique reality; correspondingly, the Heideggerian concept of “being in the world” acknowledges peoples’ physical ties to their world, and their personal context will be integrated into the way they experience the world and provide meaning to their experiences.

As noted previously, the process of bracketing is not supported by Heideggerian phenomenologists because they regard it as impossible for the researcher to negate his or her own experiences related to the phenomenon under study (Crotty, 1998); presupposing prior understanding on the researcher’s part, they accordingly identify beliefs, assumptions and preconceptions about the research topic which are put in writing at the beginning of the study for self-reflection and external review.

Interpretive phenomenology is used when the research question asks for the meaning of the phenomenon – hence its use in this study. Heidegger’s process of understanding (also known as the historicity of understanding) and the hermeneutic circle are the two essential components of Heideggerian phenomenology, as outlined below.

2.4.1 Background

Heidegger emphasises the historicity of understanding of one’s background or situatedness in the world. According to Koch (1995) and Lavery (2003), a person’s history or background, includes what a culture gives a person from birth and is handed down, presenting ways of understanding the world. Through this understanding, one determines

what is 'real', yet Heidegger also believed that one's background cannot be made completely explicit. In the context of this study, participants were asked 'background' questions relating to their demographics, such as marital status and HIV diagnosis, which assisted in applying meaning to their experience on Option B+ strategy.

2.4.2 Pre-understanding

Pre-understanding is the meaning or organisation of a culture that is present before we understand and become part of our historicity of background (Lavery, 2003), and is not something a person can step outside of or put aside, as it is understood as already being with us in the world. According to Heidegger, pre-understanding is a structure for being in the world and he goes on to argue that nothing can be encountered without reference to a person's background understanding. In this study, the researcher's knowledge and experience working with HIV-positive women on Option B+ strategy was enhanced by understanding and interpreting their experiences. Koch (1995) and Lavery (2003) concur, arguing that meaning is found as we are constructed by the world, while at the same time we are constructing this world from our own background and experiences.

2.4.3 Co-constitution

According to Patterson and Williams (2002), *co-constitution*, as the term is used in hermeneutics, refers to a mutually defining inter-relationship between the persons and their world. It is thus impossible to separate the individual from his/her world. The authors go on to explain that co-constitution comprises activity from two sources, the individual orienting itself to the world, and the world revealing itself to the individual, thus co-constituting each other. Individuals therefore both construct their world and draw meanings from their experiences. During the interview process, data was collected through a series of co-created

questions, with main questions followed by probes that were influenced by preceding responses; in the context of PMTCT, common meanings will exist.

2.4.4 Interpretation

Heidegger describes a situation where nothing exists without reference to the background understanding, and claims that to be human is to interpret, because every encounter involves an interpretation influenced by an individual's background or historicity. According to Lavery (2003), interpretation is seen as critical to the process of understanding, and this interpretive process is achieved through a hermeneutic circle which moves from the parts of experience, to the whole experience and back and forth again and again to increase the depth of engagement with and the understanding of texts.

2.4.5 The hermeneutic circle

Hermeneutic circle theory posits that it is not possible to really understand any one part of a work until you understand the whole, but it is also not possible to understand the whole without understanding all of the parts. The researcher's pre-understanding of the phenomena is crucial in the context of hermeneutic approach to phenomenological research because it provides the background and frame of reference that provides meaning and understanding of the phenomena. Once interviews have been conducted and transcribed, an interpretive process of continuously relating a part of a text (transcribed interview) to the whole of the text known as hermeneutic circle or "circle of understanding" begins (Burns and Grove, 2009). In this study, my preconceptions in terms of experiences and emotions were acknowledged and recorded during the interview process by keeping a reflective journal which was utilised to understand and provide real meaning to the experiences.

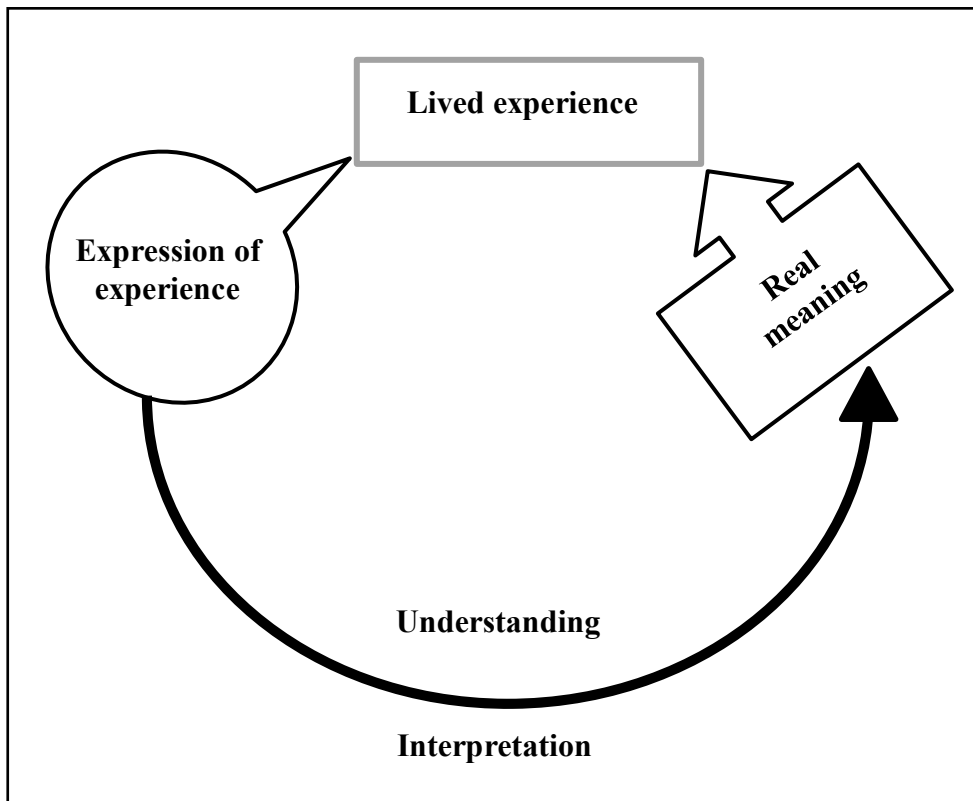


Figure 2-1 The hermeneutic circle

Source: Dummer, Brodewolf and Erath (2001)

Despite the major contribution it makes in illuminating details of seemingly trivial aspects of human experience that might be taken for granted in seeking creating meaning and achieving a sense of understanding, phenomenological inquiry nonetheless faces criticism. One objection is that phenomenology abandons the scientific procedures of verification which means that research findings cannot be generalised to other situations, putting the overall benefit of the research in question (Mack, 2010). The phenomenological approach is also criticised for its ontological assumption which is subjective in nature; critics argue that not using a hypothesis, and involving oneself in the research, may yield biased results.

2.5 Study setting

Lincoln and Guba (1985) mandate that a naturalistic study must be carried out in a natural setting, arguing that this increases subjectivity of the study and promotes engagement. For the purpose of this study, one district hospital in the central region of Malawi was selected. The

district covers an area of 3,356 km² and had a population of 511,792 as of 2012. It is the only government hospital in the district, is a referral hospital for 17 community health centres, and is conveniently situated within informal settlements. Services offered at the hospital include, but are not limited to, HIV and AIDS counselling and testing (HCT), an ARV clinic, and PMTCT.

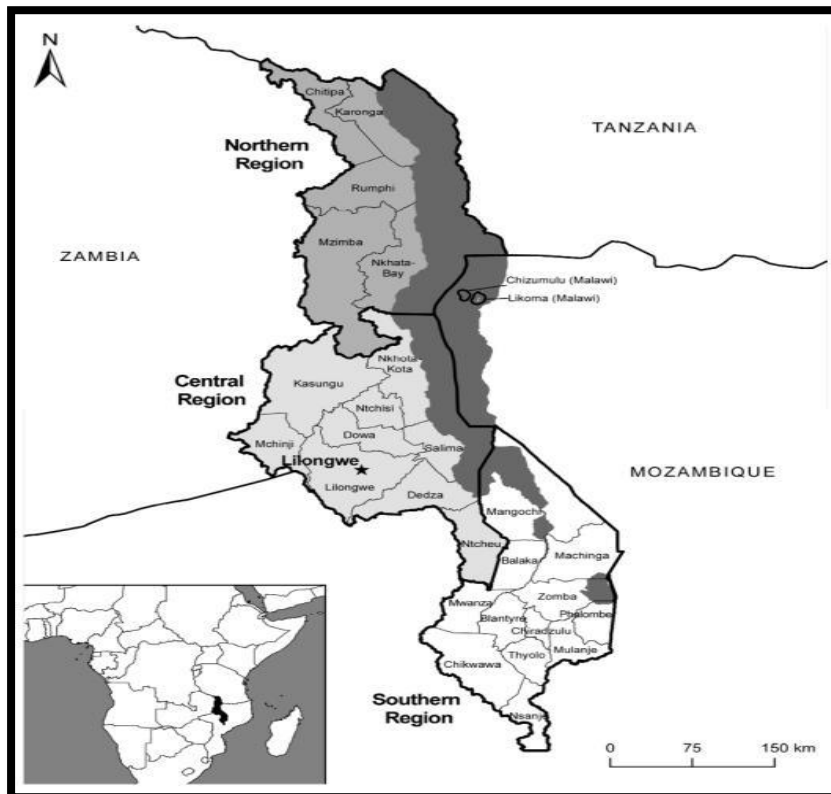


Figure 2-2 Malawi and its districts

Source: Malawi Demographic Health Survey (MDHS, 2010)

2.6 Study participants

The target population for the study was HIV-positive women, pregnant or breastfeeding, who were receiving care under the PMTCT Option B+. The selected district hospital serves an average of 190 women attending maternal and child health clinics each day.

2.7 Sampling

Purposive sampling was used in the study to invite participants on the basis of their being knowledgeable and informative about the phenomenon under study. According to Lincoln and Guba (1985), purposive sampling aims to detail the many specifications that give the context its uniqueness. Since very little is known about the lived experiences of women on Option B+, purposive sampling was ideal for this study in seeking insight into the new phenomena from selected information-rich cases. Babbie and Mouton (2001) acknowledge that “sometimes it is appropriate for a researcher to select his/her sample based on the knowledge of the population, its element and the nature of the research aims”.

2.7.1 Inclusion criteria

- HIV-positive women (pregnant or breastfeeding) within the district, , who were on the PMTCT Option B+ strategy
- HIV-positive women willing to participate in the study and have their interviews digitally recorded

2.7.2 Exclusion criteria

- HIV-positive women on their first antenatal visit because they are introduced to Option B+ strategy on the same day, hence not considered to be experienced with the phenomena
- HIV-positive women who did not want their interviews digitally recorded

2.8 Initial participant sample

The participant sample may be large or small, but it is considered sufficient when the amount of new information is scarce (Lincoln and Guba, 1985) – also known as data saturation. The study comprised five participants and data saturation was achieved.

2.9 Data collection process

Ethical clearance to conduct this research was obtained from the Research and Ethics Committee of the University of KwaZulu-Natal and Malawi, and permission to conduct the study was obtained from the District Health Office of the selected research setting.

Prior to the commencement of data collection for the study, the District Health Officer (DHO) and District Nursing Officer (DNO) of the selected district hospital was contacted in order to gain access to the Maternal and Child Health unit services. When permission was granted, an appointment was made to introduce myself to the clinic staff and explain my study purpose, objectives and procedures to the clinic in-charge, with whom I worked closely in identifying potential participants. Convenient days for the interviews were properly planned and coordinated with the clinic staff to avoid disturbing their routine work and patient flow.

Women on Option B+ were identified during registration process through documentation in their health cards, if they met the inclusion criteria they were approached individually in the consultation rooms informed about the research, its purpose, and confidentiality issues in order to obtain their informed consent. Since each interview took time to conduct, they were scheduled in between waiting times for women in the clinic and an arrangement was made with the clinic staff so that when a woman was taken out of the queue to complete an interview she returned to her position in the queue to avoid any delay in her management. Women who completed their interviews after they had attended their clinic appointment were offered a drink and a snack during the interview as compensation for the extra time they spent at the clinic. The length of interview varied between participants, and the interviews were conducted individually in a private room to avoid disturbances and allow free expression of experiences.

2.10 Data collection techniques

2.10.1 In-depth interviews

Data collection for this study relied primarily on in-depth interviews using an interview guide translated into the local language (Chichewa). Lincoln and Guba (1985) mention that collecting rich description of human experience is the researcher's responsibility, to be done through intensive interviews with a small number of people. In this study, the respondents were fully aware that they were being interviewed, and they understood the purpose of the interview and how the information would be used (i.e., overtly). All verbal data was collected in Chichewa, in a relaxed atmosphere, and sufficient time was provided to enable complete description of phenomena. Since it had been anticipated that the interviews would be lengthy, they were digitally recorded to avoid memory bias and error in written notes during verbatim transcription; women who agreed to participate in the research but refused to be recorded were therefore excluded from the study. Polit and Beck (2004) strongly encourage recording of interviews rather than written notes, if only to minimise bias from the interviewer's memory and personal views. This technique was chosen for the study to capture the detailed account of phenomena as lived by participants. This being my first qualitative research, two practice interviews were conducted to familiarise myself with the interview guide for more effective data collection; these two interviews have not been included in the analysis.

2.10.2 Participant observation

This form of unstructured data collection, according to Lincoln and Guba (1985), permits the researcher to use self as a data source (Polit and Beck, 2008) and see the world as the participant sees it. Participants' non-verbal cues during interview were observed to assess for affective responses. This technique helped to provide more insight into the participants'

world that would not have otherwise be described; these observations were recorded in field notes to enable meaningful interpretation of participants' experiences.

2.11 Data analysis

Data collection and analysis in this study occurred simultaneously so that the search for themes and concepts began from the moment data collection commenced (Lincoln and Guba 1985). Only one interview was conducted in a day to allow data analysis of each interview to identify emerging themes that were used in the proceeding interviews. In this study, the collected Chichewa information was translated back to English for analysis which also included language interpretation. Using the recorded interviews and written notes, translation and transcription verbatim, and analysis was done using Giorgi's approach (Pallikkathayil and Morgan, 1991):

- Reading the entire disclosure of the phenomenon straight through to obtain a sense of the whole.
- Re-reading the same disclosure again in a purposeful manner to delineate each time that a transition in meaning occurs. This is done with the intention of discovering the essence of the phenomenon under study. The end result is a series of meaning units or themes.
- Examining the previous determined meaning units for redundancies, clarification, or elaboration by relating meaning units to each other and to a sense of the whole.
- Reflecting on the meaning units and extrapolating the essence of the experience for each subject. Systematic interrogation of each unit is undertaken for what it reveals about the phenomena under study for each subject. During this process each unit is transformed into the language of psychological science if relevant.
- Formalising a consistent description of the structure of the phenomenon under study across subjects by synthesizing and integrating the insights achieved in the previous steps.

2.12 Data management

All recordings were downloaded on a computer protected by a password and labelled using participants' pseudo-details and interview date, with back-up copies stored on a memory stick. Data analysis is the systematic organisation and synthesis of research data (Polit and Beck, 2004). The data collection tools were stored under lock and key in the School of Nursing at the University of KwaZulu-Natal where they will be held for a period of 5 years, and only the researcher and research supervisor will have access to the data.

2.13 Trustworthiness

The criteria used in this study are outlined by Lincoln and Guba (1985), and have been described by Polit and Beck (2004) as the gold standard for qualitative research. Trustworthiness is the degree of confidence in qualitative research data which is assessed using the criteria of credibility, transferability, dependability and confirmability.

2.13.1 Credibility

According to Lincoln and Guba (1985) credibility involves carrying out the study in a way that makes the study findings believable and taking steps to demonstrate credibility to consumers. It refers to the confidence in the truth of the data and its interpretation. Due to the likelihood of participants discussing the study questions with others in the waiting queue, only one interview was conducted in a day therefore minimising the possibility that a person who already knows about the study would be sampled, hence preventing data contamination.

Member checking

Lincoln and Guba (1985) regard member checking as a crucial technique for establishing credibility of qualitative data but Giorgi argues against validation by the participants (Reiners, 2012). Giorgi regards it as inappropriate to ask participants or external judges for

validation since the researcher has not bracketed their biases, and according to Heidegger's philosophy, the depth of involvement of researchers confirms credibility. In this study, my personal engagement and reflection during the study and the interpretive nature of the data analysis method did not necessitate confirmation.

2.13.2 Transferability

Phenomenologists cannot specify the external validity of an enquiry (Lincoln and Guba, 1985) but the researcher can provide a thick description of the findings to enable someone interested to conclude whether to make a transfer. Transferability in this study was achieved by providing a rich and thorough description of study processes, in harmony. The authors note that the responsibility of the researcher is to provide a data base in the research report that makes transferability judgements to other contexts possible.

2.13.3 Dependability

Lincoln and Guba (1985) acknowledge that there is no credibility without dependability; this implies that it is possible to use techniques outlined in relation to credibility to demonstrate dependability. In this study dependability was also achieved through scrutiny of relevant supporting documents by an external reviewer.

2.13.4 Confirmability

In this study, inquiry audit was used to support dependability and credibility. Confirmability is the objectivity and neutrality of the data which ensures congruent opinions between two independent people about the data's accuracy, relevance or meaning. Collection of research materials and documentation such as raw data and reflexive notes were undertaken to allow an independent audit (Lincoln and Guba, 1985).

2.14 Ethical issues

Ethics is defined as a system of moral values concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants (Polit and Beck, 2004). This study was conducted ethically with due consideration given to the protection of the rights of human subjects; according to Brink (2006), a researcher is responsible for conducting research in an ethical manner and must pay attention to all such requirements.

The three main principles that helped guide this study were: beneficence, respect for persons, and justice.

Beneficence: Beneficence is a fundamental ethical principal in research which protects participants from physical and psychological harm (Polit and Beck, 2004). HIV and AIDS being a sensitive issue, inquiries in this study may lead women to reveal sensitive personal information that may have psychological consequences. To minimise this harm, questions were fully phrased and women were allowed to ask questions at the end of a session. The hospital's counsellor also arranged for a follow-up session to help the women deal with possible emotional discomfort, but none of the participants opted to take this opportunity. According to Polit and Beck (2004), the risks and benefits of participating in a research study should be communicated, and since the study aims to make recommendations that will inform education, practice and research in the care of HIV-positive women on Option B+ strategy, detailed information was provided to participants in advance.

Respect for persons: This principle is the foundation of the participant's right to self-determination and full disclosure (Polit and Beck, 2004). Participation in this study was voluntary and no incentives were given for participating. Participants were free to withdraw from the study at any point without penalty or risk to the treatment they were entitled to.

Information regarding this research study was offered to the participants in the study both verbally and in form of a document, and consent was obtained in writing or by thumb print for illiterate participants.

Justice: All participants in the research study were selected according to research requirements, and treated equally and fairly throughout their participation. According to Polit and Beck (2004), fair treatment includes access for participants to professional assistance and honouring of agreements between researcher and participant, all of which were taken into consideration. The right to privacy and anonymity was maintained by using pseudonyms in the data collection tool, not real names, so that information cannot be traced back to individuals.

2.15 Dissemination of results

Copies of the research findings are disseminated to the institution where the study was conducted, the Malawi Ministry of Health, for use in practice, policy making and education, the University of Kwazulu-Natal Library and the University of Kwazulu-Natal Nursing department. The findings will also be presented at conferences and be published.

2.16 Conclusion

This chapter outlined the methodology used for the study to seek understanding of, and provide meaning to, the lived experiences of HIV-positive women receiving care on PMTCT Option B+ strategy. It indicated the research paradigm that informed the research approach and its application in relation to the study setting, sampling and data management.

Chapter 3 Literature review

3.1 Introduction

The methodology discussed in the preceding chapter outlined the research approach used in the study, and this chapter, highlights the review of literature in relation to the phenomena. Literature review is a survey of what is known and what is not known about the research problem. The timing of a literature review in qualitative research varies (Burns and Grove, 2009); some phenomenologists believe that literature should not be reviewed until after the data have been collected and analysed so that the literature will not influence the researchers openness (Burns and Grove, 2009), while others prefer to review the literature at the outset of the study to seek out experiential descriptions of the phenomena and expand the researcher's understanding of the phenomena from multiple perspectives (Polit and Beck, 2004).

The review of literature for this study was done prior to data collection with the following purposes in mind:

- to establish what is already known about the phenomena under study
- to gain insight into what research has already been done in order to guide the research process
- to identify gaps in literature for further enquiry

The literature was sourced from databases such as Medline, Proquest, EBSCOhost, and Google scholar and from a number of text books. Very little literature was found which could provide information regarding the experiences of women on Option B+ strategy.

The review of literature is organised as follows:

- Global interventions to reduce MTCT and scaling-up of PMTCT
- PMTCT in Malawi

- Process of PMTCT
- Experiences on Option B+ strategy
- Implications for policy change

3.2 Global interventions to reduce MTCT and scaling-up of PMTCT

HIV is the leading cause of mortality among women of reproductive age worldwide and is a major contributor to maternal, infant and child morbidity and mortality (WHO, 2009; UNAIDS, 2009), making PMTCT a global priority. PMTCT is a key component of overall HIV prevention efforts and represents an opportunity to stem the tide of the HIV epidemic through improved maternal health and infant HIV-free survival. According to the PEPFAR independent expert panel which reported in terms of Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008 (“Lantos and Hyde United State Global Leadership,” 2008), comprehensive PMTCT involves a 4-pronged approach:

1. Primary prevention of HIV infection among women of childbearing age
2. Preventing unintended pregnancies among women living with HIV
3. Preventing HIV transmission from women living with HIV to their infants, and
4. Providing appropriate treatment, care and support to mothers living with HIV
and their children and families.

PMTCT has been the focus for the international HIV and AIDS response as reflected in the Declaration of Commitment on HIV and AIDS adopted at the United Nations General Assembly special session on HIV and AIDS in 2001 (UN General Assembly, 2001), the President's Emergency Plan for AIDS Relief (PEPFAR) in 2002 (AIDS Virus Education and Research Trust [AVERT], 2011), the Abuja Call to Action Towards an HIV-free and AIDS-free generation in 2005 (Inter-Agency Task Team [IATT], 2012), the political declaration of the United Nations General Assembly high-level meeting on AIDS to work towards universal

access to HIV prevention, treatment, care and support in 2006 (UN General Assembly Special Session [UNGASS], 2008), and numerous other high-level statements by multilateral organisations (PEPFAR, 2010). Scale-up of PMTCT services as an important aspect of access also falls in line with the Obama administration's strong support for empowerment of women and improving the health of women, children and families through the Global Health Initiative (GHI), and it contributes to Millennium Development Goal (MDG) 4 (Reduce Child Mortality), MDG 5 (Improve Maternal Health) and MDG 6 (Combat HIV and AIDS, Malaria and Other Diseases).

There have been significant achievements in PMTCT in a number of countries, with 70 of 123 reporting low- and middle-income countries having established a national PMTCT scale-up plan for implementation of provider-initiated ('opt-out') HIV testing in antenatal care (ANC) settings (Access to Clinical and Community Maternal, Neonatal and Women's Health Services [ACCESS] Report, 2010), with improved rates of HIV counselling and testing for pregnant women. According to the PEPFAR Independent Expert Panel report (PEPFAR, 2010), in six of the ten countries estimated to have the largest numbers of pregnant women living with HIV (Kenya, Malawi, Mozambique, South Africa, Tanzania and Zambia), rates of counselling and testing for pregnant women have risen to 60–80%, including provision of ARVs for PMTCT. In resource-rich countries like the United States, there has been dramatic reduction of MTCT since 1994, with a 67% drop since the introduction of Zidovudine (AZT) during pregnancy, labour and to the newborn, as reported in clinical findings on the Paediatric AIDS Clinical Trials Group (PACTG) 076 protocol. Early identification of HIV infection among pregnant women through routine antenatal HIV testing, provision of antiretroviral treatment to HIV-infected pregnant women, elective caesarean delivery, and avoidance of all breastfeeding, have reduced the risk of HIV transmission to infants in the

United States and Europe, and in other countries with well-resourced health systems, to approximately 1–2% (Townsend et al., 2008; PEPFAR, 2010).

In resource-limited countries, clinical trials have identified prophylactic antiretroviral drug regimens for use in treating pregnant women living with HIV infection and preventing HIV infections in infants. WHO (2010) guidelines emphasise the importance of providing ART for women who require it for their own health, and of regimens such as AZT plus single-dose intrapartum/newborn Nevirapine (SD-NVP) for PMTCT in women who do not require therapy for their own health. According to the WHO (2010), women who test positive must be assessed for treatment eligibility by CD4 test and clinical examination. Increased availability of CD4 tests in antenatal settings is critically needed but is not a reality for many countries, which is a serious challenge in efforts to extend PMTCT. Even though the majority of pregnant women are clinically well, many are likely to be eligible for treatment based on low CD4 count, which gives urgency to the need for intervention in provision of treatment or prophylaxis during the intrinsically limited time period of the pregnancy (PEPFAR, 2010). Implementation has nonetheless been slow.

The PEPFAR Independent Expert Panel (PEPFAR, 2010) reported that reasons for low rates of PMTCT utilisation among pregnant women include lack of availability or access to antenatal and PMTCT services, and difficulties in integrating PMTCT interventions within existing antiretroviral treatment and maternal and child health (MCH) services, but according to the same report even if all of the programmatic challenges of making services available are met, agreeing to testing, accepting HIV-positive status and following through on the recommended interventions nevertheless places a tremendous burden on the individual woman. In addition to other social barriers (including stigma) that may be detrimental to women's health, disclosure of HIV infection to a partner, family or community member can

be extremely daunting (and in some cases even dangerous) for a woman who culturally may have very little decision-making power or personal independence.

3.3 PMTCT in Malawi

In 2003, the Malawi Ministry of Health (MOH) set a target of at least 75% of women attending ANC with PMTCT services by the end of 2010 (MOH/NAC/UNICEF, 2003), and by 2007 PMTCT services were available in 64% of health facilities (MOH, 2008). Despite the expansion of the PMTCT services in the country in recent years, the efficiency and effectiveness of these interventions remain unknown (Van Lettow et al., 2011). In 2011, responding to the challenge of providing the requisite universal access to CD4 cell-count testing for successful implementation of either of the two WHO recommended options, the MOH proposed a modified Option B (called “Option B+ strategy”), in which all confirmed HIV-infected pregnant and breastfeeding women are offered lifelong ART regardless of CD4 count or clinical stage (MOH, 2011). This massive scaling up of testing and treatment has, however, given rise to an ethical debate on how best to prepare pregnant and breastfeeding women (Hardon et al., 2012). Some argue that there should be comprehensive pre-test counselling to help clients in consciously opting for testing, so that they are better prepared for subsequent issues of disclosure and compliance should they be HIV-positive (Yeatman, 2007). Advocates of comprehensive counselling believe that routine testing approaches expose HIV-positive women to severe stigma and discrimination, for which they are ill-prepared.

PMTCT studies in Malawi have shown very high rates of consent for HIV testing but attrition in follow-up continues to be a serious problem (Bwirire et al., 2008). Manzi et al. (2005) found that while 95% of pregnant women attending antenatal care in Malawi tested for HIV, only 45% of HIV-positive pregnant women and 34% of babies born to HIV-positive mothers

received ARV prophylaxis. These findings are similar to those from other African countries such as Côte d'Ivoire, where only 36% of 1,829 HIV-positive pregnant women in a PMTCT programme in Abidjan received prophylaxis (Coulibaly et al., 2005), and the question remains, why are so few HIV-positive women and their infants receiving ARVs? One especially notable reason for low uptake of PMTCT revealed in a qualitative study in Malawi by Bwirire et al. (2008) is that women visiting the antenatal clinic are unprepared beforehand for HIV testing and its implications. In Kenya (Delva, Mutunga, Quaghebeur and Temmerman, 2006), low quality of PMTCT counselling has been noted, with only haphazard attention to crucial topics such as partner involvement and follow-up support: in Botswana, post-testing counselling also neglected the psycho-social needs of HIV-positive women (Creek et al., 2007).

Option B+ strategy's process of ART initiation has the potential to improve maternal health, facilitate access to PMTCT and ART, reduce HIV transmission risk to uninfected male partners, and provide protection against vertical HIV transmission in future pregnancies (Schouten et al., 2011; Cohen et al., 2011), however the government's efforts in realising these goals would be in vain if HIV-positive women are not utilising the service; this leaves the researcher to wonder whether the lived experiences of these women would provide answers to its optimal provision and uptake. Is anyone listening to the HIV-positive women?

3.4 Process of prevention of mother-to-child transmission

This section outlines the PMTCT process as provided in maternal and child health care units, beginning with antenatal care, and continuing through labour and delivery services to postnatal care (MOH, 2011). These areas involve multiple activities that are crucial in the PMTCT process.

3.4.1 Antenatal

All pregnant women presenting for antenatal care receive HIV counselling and testing (HCT) with an “opt-out” option. For women who agree to be tested and are HIV-positive, a confirmatory HIV test is done to rule out any possibility of mix-up in results or fraudulent access to ART (MOH, 2011); individual post-test counselling then follows, with emphasis on adherence, disclosure, feeding options and follow-up care. HAART (Tenofovir/Lamivudine/Efavirenz), Cotrimoxazole preventive therapy (CPT), and NVP syrup for the baby are prescribed on the same day and given right in the ANC for HIV-positive women from 14 weeks’ gestation, irrespective of CD4 count. Unlike other persons starting ART, pregnant and breastfeeding women do not undergo the pre-ART readiness classes (known as literacy classes) which are intended to promote compliance. Each woman has a master card that is kept in the clinic to be used whenever she reports for follow-up; the ANC staff also records all new clients in the ART register. Integrated guidelines for HIV services provision also encourage women to bring sexual partners to attend HTC (MOH, 2011).

3.4.2 Labour and delivery

HIV status is confirmed from their antenatal records for all women presenting in labour ward. A labour ward resident HIV counsellor offers HIV counselling and testing for all women with unknown HIV status depending on the stage of labour; the women take prescribed HAART immediately as per protocol, and the next appointment date is given. If the woman is already on Option B+, she is then asked whether she took the day’s dosage before coming to the hospital. If she did not, she is reminded to do so or she is given the dose from the hospital supply. Women initiated on ART in labour ward are recorded in the ART register and also have a master card. Infant feeding method is discussed with the woman, together with other counselling as in ANC clinic.

3.4.3 Postpartum

HIV testing is offered for women whose HIV status is still unknown after delivery and ARVs are prescribed for mother and infant. The infant receives the first dose of NVP syrup after birth in the labour room and will continue for six weeks (MOH, 2012) regardless of infant feeding method. The next appointment date is recorded in the woman's antenatal card and she attends postnatal care at her nearest health facility. The woman and child continue receiving ARVs in the MCH unit until such time as they meet the relevant criterion for transfer to the national ART programme in which the mother will continue for the rest of her life. The interventions go beyond breastfeeding and the mother's commitment is thus crucial.

3.5 Experiences on Option B+ strategy

There are so far no research studies in the literature that consider the lived experiences of women themselves on Option B+ strategy; this section accordingly outlines Malawi's experience at national level in the implementation of Option B+. At the July 2012 international AIDS conference in Washington attention was given to Option B+ strategy and there was considerable discussion about a rapid scale-up of this programme. However, according to Thyssen, Lange, Thyssen, and Reddi (2013), studies on clinical and economic feasibility have yet to be done, and additional studies investigating adherence and resistance to ART are also needed before a global scale-up of Option B+ strategy is implemented. The study by Chimbwandira et al. (2013) is the first to summarise Malawi's experience in implementing Option B+, drawing on data collected through routine programme supervision under the direction of the MOH and supported by the office of the global AIDS coordinator (OGAC) through PEPFAR. Their report revealed that 8,877 (83%) of 10,734 women started under Option B+ strategy were retained at 6 months after ART initiation. Only 1% of those not retained were known to have stopped ART, 4% were known to have died, and the majority of the 1,762 women classified as lost to follow-up are likely to have stopped or

interrupted ART, giving an exceeding high 83% retention rate. This is a good result for the first quarterly cohort of women starting on Option B+ in Malawi, considering that there had been no previous experience at any of the sites with ART initiation from ANC and maternity (MOH, 2012).

Table 3-1 Six-month outcomes of women initiated on Option B+ strategy

ART cohort registration group outcomes		
Total alive on ART	8,877	83%
Total not retained	1,857	17%
Defaulted	1,762	95%
Stopped ART	22	1%
Died	73	4%

Source: Chimbwandira et al. (2013)

Under the new policy, of the 2,949 women who started ART under Option B+ in the third quarter of 2011 and did not transfer care, 2,267 (77%) continue to receive ART at 12 months; this indicates that the number of pregnant and breastfeeding women started on ART has increased and the retention rate has remained similar to the rate for adults continuing to receive ART at 12 months before Option B+ strategy implementation.

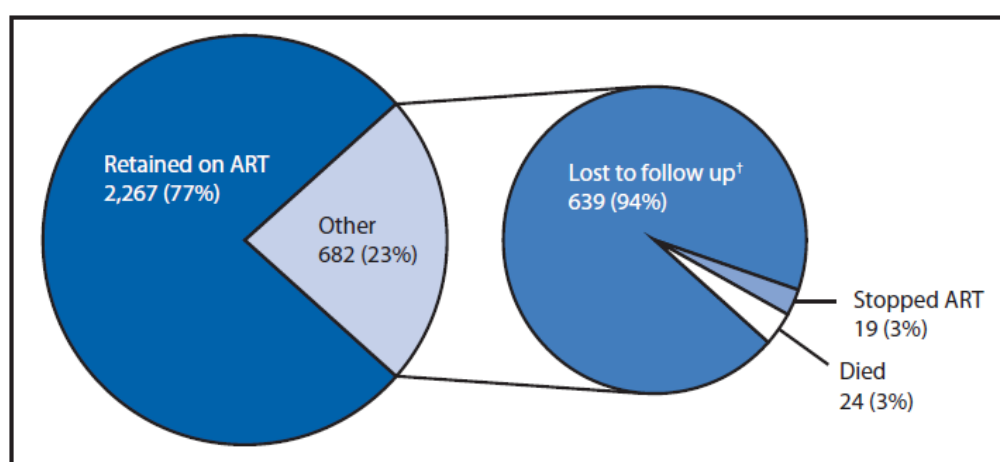


Figure 3-1 Twelve-month outcomes for women initiated on Option B+ strategy

Source: Chimbwandira et al. (2013)

According to MOH report (2012), the removal of the barrier represented by CD4 cell count in Option B+ strategy also minimised other barriers to ART provision for pregnant women, such as distance between ANC sites where HIV diagnosis is made and ART sites where treatment was started, transportation costs, and human resource constraints that lead to long waiting times and scheduling difficulties (Chi et al., 2012). Decentralisation of ART into all ANC sites, combined with training of nearly all nurses and clinical officers on the new integrated PMTCT/ART guidelines, helped to bring about a 748% increase in the number of pregnant and breastfeeding women started on ART (Chimbwandira et al., 2013). Implementation of Option B+ in Malawi has led to women receiving ANC and ART in the same clinic and by the same provider, a move that is believed to promote retention. This ART scale-up has also resulted in a growing proportion of HIV-infected women who are already on ART when they become pregnant (MOH, 2012) Despite all the successes, important challenges and questions nonetheless remain: the cost-effectiveness of this approach needs to be evaluated, and although 12-month retention rates are reassuring, lifelong ART adherence will need to be maintained (Chimbwandira et al., 2013), informed by lessons learnt from the women's own experiences.

3.6 Implications for policy change

As a result of the policy change, the total numbers of all patients initiating ART in the national programme increased by an astounding 88% after implementation of Option B+ strategy for only one quarter (MOH, 2012). According to the same report, the number of pregnant women started on ART is expected to increase in the next few quarters and subsequently fall once the system is stabilised, It is not certain however, whether the numbers on paper really represent the number of women utilising the programme.

Coutsoudis, et al. (2013) raise a number of ethical, medical, programmatic and economic concerns in relation to the implementation of Option B+ strategy:

- Is it ethical to give women with high CD4 count treatment for life without fully understanding the long-term benefits and risks?
- Are the benefits for maternal health worth the potential increase in drug resistance?
- Will the necessary levels of adherence be maintained?

In its approval of Option B+ strategy, the WHO commented that even though the method demonstrates some clear benefits there is still a need to evaluate programme settings, systems and support requirements for an effective implementation. Actual experiences of women on Option B+ is one of the issues that need to be evaluated so that recommendations are made and programme modifications are done while the programme is still in its early implementation phase.

3.7 Conclusion

This chapter highlighted the global interventions to reduce MTCT in an effort to minimise maternal and child morbidity and mortality, and the scaling-up of PMTCT for improved maternal health and infant HIV-free survival. The current status of the PMTCT programme in Malawi with the introduction of Option B+ looks promising as discussed but loss to follow-up of women has already been identified along the crucial steps in the PMTCT process. A review of women's experiences on previous PMTCT strategy (Option A) and long-term ART programmes has been done and yet not conclusive to predict similar experiences in Option B+ strategy.

Chapter 4 Presentation of study findings

4.1 Introduction

The review of literature presented in the prior chapter accentuated the existing research studies on option B+, the PMTCT process and the experiences on the programme so far. The previous chapters overall broadened the scope of the study and guided the research process. This chapter sets out the study findings on the lived experiences of HIV-positive women on PMTCT Option B+ strategy and reflects the objectives of the study.

4.2 Research findings

The research findings are presented in two sections: participant profile data, followed by findings on views, thoughts and feelings expressed by the participants in the individual in-depth interviews.

4.2.1 Profile of participants

Five participants were involved in the study. All five were HIV-positive women on PMTCT Option B+ strategy; one was pregnant and four had delivered. Their ages ranged from 19 to 38, one participant was single, and the rest were married; the duration of their lived experiences on the PMTCT programme ranged from four months to four years. Their level of education ranged from primary to secondary education. Table 4.1 lists their demographic details.

Table 4-1 Profile of participants

Participant	Age	Marital status	No. of children	Experience on PMTCT	Level of education	General comment
Alinafe	24	Married	2	4 years	Standard 4	Been on Option A strategy before. Husband had unknown HIV status but believes to be HIV-positive. First child HIV-negative.
Febbie	28	Married	1	4 months	Form 4	New mother, Shortest experience on Option B+, not disclosed HIV status to partner.
Josephina	38	Married	3	2 years	Standard 5	Tested HIV-negative in two previous pregnancies. Physically abused by partner after HIV status disclosure. Partner HIV status unknown.
Monica	19	Single	0	6 months	Form 2	Youngest participant, still pregnant. Discarded medications on first visit and reinitiated a month later.
Rose	28	Married	2	1 year	Standard 8	Husband on ARV treatment already only disclosed when she was found HIV-positive.

4.2.2 Research findings according to categories, themes and sub-themes

This section presents the substantive findings of the study. The data were collected through in-depth interviews, and recorded, transcribed and analysed using manual data-analysis techniques.

In this analysis, categories, themes and sub-themes emerged, and the views of the respondents are presented here as direct quotations to support the identified themes and sub-themes.

The following categories of information emerged during the data analysis:

- A. Knowledge and understanding of Option B+ strategy
- B. Accepting the HIV-positive status
- C. Sociocultural factors affecting HIV-positive women on Option B+ strategy
- D. Adherence on Option B+ strategy

These categories were then subdivided into common themes and sub-themes.

Table 4-2 Categories, themes and sub-themes

Category	Theme	Sub-theme
Knowledge and understanding of Option B+ strategy	Source of information	
	To test or not to test	Timing 'Opt-out' an option?
	Moment of truth	Terrifying Depressing
	Preparation and readiness	Psychological readiness and Pre-treatment preparation
Accepting the positive HIV status	Silence best option?	
	Breaking the news	Who to tell The blame game
	Coping strategies	Talking about the experience Detachment Rationalisation
Sociocultural factors affecting HIV-positive women on Option B+ strategy	Participating on Option B+ strategy	Motivators vs. Deterrents Quality care Privacy
	Playing the role	Our opinions should count Preventing further spread
	Challenges	Attitudes of health care workers Distance to hospitals Availability of drugs Stigma and discrimination Men not going for testing
Adherence on Option B+ strategy	Till death do us part	Experience vs. Inexperience
	Support system	Informal support Formal support

Category 1: Knowledge and understanding of option B+ strategy & process

Theme 1: Source of information

All participants said that they knew about Option B+ strategy when they first tested HIV-positive, which happened either in the antenatal clinic, during labour and delivery, or during postnatal period. This was described as the beginning of the PMTCT process, which had different meanings for individual participants. It proved worthwhile to explore the theme incorporating the participant's experiences from the first stages of HIV testing to get a sense of the whole process.

Although they were broadly knowledgeable about HIV and details of its prevention and management, which is a routine education topic in the antenatal clinic, the study participants indicated that they had been much less well informed about the Option B+ strategy. During the interviews, all the participants said they were urged to go for testing when they attended the clinic, from which it can be concluded that HIV testing is available for all women receiving maternal and child health services in the hospital. The antenatal clinic was found to be the place where women first heard of Option B+ strategy and where it all began for them.

According to Rose:

When I came to start antenatal care for this baby's pregnancy, they taught us about HIV and we were told that all those coming for antenatal for the first time will be tested for HIV.

From the interviews it was noted that the issue of Option B+ was not discussed with all the women attending antenatal care; rather, the focus was on those coming for the first time, to whom HIV testing is also offered.

The process is the same, however, for women who had already tested positive but had no documentation. When asked how she started on the Option B+ strategy, Alinafe said:

It was when I came to start antenatal care for this pregnancy, they said all those who came for the first time should go for HIV testing. I had already been tested in previous pregnancies and knew my HIV status to be positive so I never went for the test [sighs]. However, the nurse told me that since I had no document that confirmed my status I had to do it again, so I did.

Another participant (Febbie) told a similar story:

I had not attended antenatal care throughout my pregnancy [Clears throat]... I discovered my pregnancy late and I had travelled to the village which was far from hospital.... I came to the hospital for delivery and that is the first time I ever heard of Option B+ strategy.... Umm, I had reported in labour ward with pains and guess what I got.

These are some of the statements made by participants which suggested that knowledge about Option B+ began when they presented themselves at the hospital where routine HIV testing is done. All women had no prior knowledge of the Option B+ strategy until their own diagnosis of positive HIV status. The issue of access to Option B+ was also explored in this theme and it was established that pregnant and postpartum women are able to access the service once they visit the hospital.

Theme 2: To test or not to test

Sub-theme 2.1: *Timing*

During the interviews it was obvious how the participants struggled with the decision whether to go through with the HIV testing or not. The participants felt that the HIV test was ill-timed, and that they needed to have been better prepared to go through with it. For Monica, a single woman with her first pregnancy, the decision was hard:

The truth is, I was not ready... By that time I had never been tested for HIV, it was my first time and I was scared yet there was nothing I could have done.

Some participants felt that they had not been given enough time to brace themselves for the possibility of a positive outcome as reported by Monica and Rose respectively.

I could have made the decision at that time but the only problem is that it came as a surprise.

If only there was a little more time to think about it, just some more time but there was none everything happened so fast.

For Josephina, who had tested negative in previous pregnancies, timing was never an obstacle and the decision to get tested came easily, as she reported:

Well I was tested for HIV with my previous pregnancies and I was found HIV-negative, that is why I did not think twice about testing this time, it felt normal. This time it was different and the results were shocking.

The experience however was different for women who started the process after they had delivered. Febbie, aged 28, who missed antenatal care and only reported for delivery of her first child, gave a graphic account of her experience:

I reported in labour ward in pain and frustration since I was sent back twice already saying I was not in labour, then one nurse asked whether I knew my status which I knew to be negative tested a year previously. She called for someone else who took me to a private room talked about HIV and tested me

Summing up, she expressed her frustration:

They couldn't have picked a better time.

Participants were asked how they thought the HIV testing should be done and they all agreed that they needed to be introduced to the idea and given time to decide. Ideally, the timing (for some participants) would allow for going back home and consulting friends, family and partners. Women who had delivered their babies thought labour and delivery period should be spared from the stress of HIV testing.

These contributions prompted the inclusion of the next theme to determine the possibility of a participant declining HIV testing.

Sub-theme 2.2: Opt-out an option?

Opt-out in the context of PMTCT means that any woman who is offered HIV counselling and testing has a choice to refuse the test; however, women believed this was not how the possibilities had been presented to them.

Rose, like some of the other participants, felt that she had not been given an option about whether to have the test. Asked to elaborate, she showed that she was upset:

I needed to get ready, it is not a decision you make in a rush, wish these people [health professionals] understood that.

Likewise, for Monica,

There was no choice, none whatsoever, not a chance. It was more like being told than asked.

Knowing from the interview how Rose had struggled with the decision to consent to testing, the interviewer wanted to find out if she could have gone for testing voluntarily:

[Laughed]...*Yes I could have gone for testing voluntarily, someday.*

Despite their ambivalence about going through with HIV testing, they all in the end did so, for a variety of reasons; some felt hopeless and knew that it was the only way out, others believed they would not get the necessary obstetric care if they declined the test, as in this statement:

Do you think there is a chance for someone to say I don't want to be tested? What would happen if someone refuses? I don't even want to speculate.

and some participants just decided to brave the test and get done with it.

Theme 3: Moment of truth

In describing their feelings after receiving their positive HIV results, words such as “disappointed”; “anger”; “grief”; “fear” often recurred in the participants’ accounts; “terrifying” and “depressing” were expressions used by all the participants. Reviewing the whole process through exploration of this theme of moment of truth, two sub-themes emerged:

Sub-theme 3.1: Terrifying

Febbie repeatedly described her experience as “terrifying”, more than three times in the course of the interview. These emotional terms, combined with the concerned look on their faces, showed what the impact had been for them of a positive HIV status:

The hardest part was receiving the results.

The same issue was therefore also explored with the other participants, from which *terrifying* and *depressing* emerged as sub-themes in their emotional reactions to getting a positive HIV test result. Febbie expressed a profound emotional reaction to the news:

Like I said, I was in labour pains when I was tested for HIV. It was my first child and everything else that was happening was new to me. I was highly anxious on the outcome of my labour and now that... Continued ... It was the worst feeling [gazing beyond the window] ... all I could think about was what my next move would be. All of a sudden the world seemed empty and my head grew bigger, it was terrifying.

Monica avoided eye contact when she related her experience on receiving her positive HIV test result. Clearly emotional, she corroborated Febbie’s story:

There is no better word to describe the feeling, it's almost unreal... terribly unreal. I thought the nurse was playing a sick joke on me.

...The terror came in as a realisation that life will never be the same again. For a moment my mind had a flight of ideas, almost getting me excited but none of it included curing the HIV... [Pause] ... Felt like reaching a dead end.

... I have seen HIV-positive patients before and that's how I pictured myself in a few weeks ahead. The faces of those sick AIDS patients I saw flashed in my mind [Pause]... it was absolute terror.

Sub-theme 3.2: Depressing

Josephina's experience on receiving the HIV test results was more depressive:

All of a sudden it dawned to me that I would die soon, and I will not live to see my baby grow. It was a depressing feeling, I felt angry towards the counsellor for putting me through that. I cried...it could be described like an out of body experience, when you know you are there and yet you are not. (Josephina)

Likewise, for Monica,

I was disappointed, I felt like I had disgraced my parents because there is no parent who wants to see their children suffering.

The interviews with participants who had other children and longer experience on Option B+ revealed their views on the importance of interaction with the health professionals. They felt that health professionals needed to have time with them when revealing their positive HIV status, describing the situation of failure to ask questions and learn more about their condition as pathetic and depressing:

There is not much time in the hospital to receive your HIV results and understand, no much time... [Pause] ...everything happens so fast.

Josephina summed up her emotions by saying,

It is like being given a death sentence. All plans, aspirations and goals crashed before your very eyes.

Participants with less experience on Option B+ expressed stronger emotions on receiving the HIV-positive test results, suggesting how recently the diagnosis had been made.

Theme 4: Preparation and readiness

Preparation, defined by the Oxford dictionary (2010) as “the act or process of getting ready for an undertaking” proved inadequate for most of the participants. Even though the benefits of testing were laid out before the actual testing took place, the participants unanimously agreed that they were not sufficiently prepared for the process.

Two sub-themes were used to explore the participant’s experiences with the theme: *psychological preparation* and *pre-treatment education*. These sub-themes were analysed concurrently in view of their mutual effect on one another. Participants believed that because they were not adequately prepared for their participation, it was psychologically taxing for them, and vice versa.

Sub-theme 4.1: *Psychological readiness and Pre-treatment preparation*

For Alinafe who had taken antiretroviral drugs for PMTCT in previous pregnancies under Option A, the preparation was more than adequate. She reported:

Yes, the preparatory education was enough and I understood very well. They taught me how to be taking my medications and also the main aim of taking the medication.

On the purpose of the taking the medications, she elaborated:

They said the main aim of taking my medication is that I have to protect my unborn child so that she should be born HIV-negative and also that I should still maintain my health and that I should not be getting sick often.

It was a different experience, however, for the rest of the participants who had no prior experience with PMTCT:

To tell the truth, the first time we were being educated on HIV and Option B+ strategy I had not tested for HIV so I was not paying much attention because I didn't think it was relevant to me. The second time it was right after I received my positive HIV results and honestly I was not listening because there were a lot of things going on in my mind.

(Monica)

You can just imagine knowing that you are HIV-positive, being fed a lot of information at one go and starting long life ARVs immediately. It is a lot to take for a day.

(Rose)

It is overwhelming, when I tested in labour ward I was given ARVs immediately and was told that they were for the rest of my life, soon after my baby was born she was also given ARV. It was hard to process but I had to go with the flow.

(Febbie)

For some, the preparation seemed adequate at the time because they had no expectations, but as time went on they had other suggestions:

At the time it seemed adequate but later I needed more explanations and I had questions I couldn't answer. There is need for more time to be dedicated when initiating the treatment because for me that is the crucial part about the whole process.

(Josephina)

The women acknowledged that ARV initiation was extremely important and helpful but had reservations on timing. They believed the ARVs should not be administered as urgent, but that the women should rather give time to come back at a later date following a positive HIV test, for proper preparatory instruction with initiation of ARVs. The worst case scenario was Monica's experience:

I did not take it well, you can imagine I went to the hospital and I am coming back with these bottles of medications. I did not even want to go home that day to avoid questions and suddenly an idea hit me, it seemed the only option at the point [Giggles]... so I got rid of the medications along the way and went home like nothing happened...

... I spent a month meditating on it until my next antenatal appointment. It all then sunk in, I realised the situation I was in and decided to act in the best interest of my baby. When I went back the next time I was more willing to start the medications, I was convinced I had made the right decision and I have not stopped ever since.

The issue of taking ARVs for the rest of their lives seemed troubling for many. Even though Alinafe had received ARVs for PMTCT before, the issue was puzzling:

I have received the ARVs for PMTCT before and I stopped sometime after giving birth to my child. That is what used to happen and my child was tested HIV-negative, so I really don't know where this is coming from. I guess that's why more time is necessary when the nurses communicate this you know

Participants initially believed the preparation was adequate because they were still in shock and did not know what to expect, but as time went on the gaps were obvious. If only the pre-treatment counselling took longer or scheduled on another day for initiation of treatment, they would be more prepared, they said.

Category 2: Accepting the positive HIV status

During the interviews it was clear that accepting the positive status was a process rather than a step, influenced by both intrinsic and extrinsic factors that helped them to understand and cope with their positive HIV status.

Theme 1: Silence the best option?

Some participants referred to non-disclosure of HIV status as “silence”, as one participant put it when describing the emotional toll of the period immediately after receiving positive HIV results:

It is an emotional bondage, you wonder if silence is the best option

The issue of “silence” was further explored with other participants to discover its true meaning; hence the emergence of the theme. For Febbie it proved to be the only option as she reveals in an expression of despair:

I cannot accept it, where do I start from?

Febbie is a married woman with four months experience on Option B+ strategy; this knowledge, and the revelation that she had not accepted her HIV status, prompted the interviewer to probe more about her home situation:

When I took my baby home, it was the best time for me and my husband, we had received our long awaited gift and I never wanted to spoil the mood with my positive HIV news.

... I am waiting to the best time to tell him, I know once I do that I will be relieved and in a way help me accept the diagnosis. [Sighs] As the days pass it is becoming harder and heavier on my heart but when I see his smiling face with our baby, that is all I want to see.

... Since he is working it is easier to keep the secret because most of the things to do with PMTCT like medications are done while he is away

... For now it is working but I do not know for how much longer. I will burden myself with the news until I am ready.

For some participants, the process is all about finding the inner strength, as summed up by Alinafe, the participant with the most years of experience on PMTCT:

It is easier when you realise that you cannot change everything in life. Embrace life situations positively and with support from significant others, the bumps along the way are less high than they appeared to be.

Theme 2: Breaking the news

Some of the participants seemed to be having problems disclosing their HIV status to others; this was evidenced by one participant from previous discussion staying “silent” after four months of diagnosis. For the rest of the participants, breaking the silence was strategic, with more of them feeling comfortable disclosing to a sibling or parent rather than their own husband or partner; none felt the need to disclose to the community. The participants’ disclosure circumstances varied, as did their experiences, and two sub-themes were explored to understand the theme better.

Sub-theme 2.1: *Who to tell*

When asked who they first told after being tested positive, Monica and others indicated that the decision did not come easy:

I will tell you the truth, I was scared to go home to start with. In my mind I knew I had to tell someone, talk to someone... Uum, I did not know who. On my way home I kept thinking who would be the best person to talk to. I had not made the decision when I got home so I stayed for a week before confiding in my best friend of 11 years and later I told my mum.
(Monica)

I told my mother first. She had escorted me to the hospital on the day I tested HIV-positive and on our way back I told her everything. I thought it was only appropriate to do so, we walked in silence back home and even

though she pretended not to have been affected, I knew she was hurt.

(Rose)

Probed further on what influenced her to tell her best friend first, Monica reported:

I was single, still am. [Laughs] I knew my mum would be critical because she was not happy that I got pregnant in the first place, I knew it was only my best friend who would understand you know, and I considered my privacy also. I trusted my best friend to keep my secret better than anyone. Later on I realised that my mum would support me as much if she knew so I told her.

The issue of difficulty in disclosing positive HIV status to the one's partner comes out in Josephina's experience:

My husband is a difficult man, major decisions in the family I have to discuss with him and yet I went for HIV testing and initiated on medications without consulting him and this made me so worried, however I convinced myself that it was not my fault and believed he would understand.

... I regretted telling him for sure. He beat me so hard that I cried all night, he called me all sorts of ugly names and the following day he left the house. I had nowhere to go to because if I complained to the marriage counsellors it meant disclosing my HIV status and possibly making him angrier. After sometime he came back. We are still together but life is never the same.

It came as a surprise during the interview to note that this dramatic reaction came from a partner who did not know his own HIV status, and the situation was similar with the other partners of the participants, with some actually refusing to be tested. Rose's situation brought her closure, however:

When I disclosed my HIV status to my husband he told me that he also tested HIV-positive few months before I delivered. He said he did not want

to worry me about it because of the pregnancy and he is already on ARVs. It was a shocking discovery, I was disappointed but what else could I have done.

The participants believed that the decision about who to tell brought them closer to accepting their HIV status, because that is when they get the sense of reality that helps them to deal with the consequences. The decision to disclose to community members, however, proves to be further from everybody's mind, as elaborated by Monica:

Our neighbour is very talkative and I feel if she knew my status I would have no peace, she would tell everyone in the village and beyond. I do not know anyone else other than my family to know. If they ever know, it will not be from me.

Sub-theme 2.2: The blame game

Another issue that emerged throughout the interviews was the blame game between the partners after disclosure of HIV status.

Josephina talked about her experience as follows in a sorrowful interview:

He didn't take it well as I explained before. He talked a lot, saying I am an ill-behaved person and it was me who brought the disease into our home. He left the house for a month now he is back but nothing has changed. He scolds me every chance he gets.

In the same interview, Josephina concluded:

My husband told me that since I was the one who had been found with the disease I had no one to blame but myself. He believes I got what I deserved. I never asked for this and God know that I had been faithful and now this is what I get.

For the partners the blame is almost self-evident because they convince themselves that the reason for the HIV-positive status is that when they leave home for work their wives have extramarital affairs. This suggested to the interviewer that it would be worth exploring the possible source of HIV infection in the participants' families.

Josephina threw back the blame ball to her husband, putting it like this:

Mmh, it is him, who else can it be. I always stay at home, he leaves me here and finds me when he comes back. I don't move around as he says. How can I even have a sexual relationship with all his spies around [Laughs].

For Rose the answer was already at hand:

After he confessed to me that he was also HIV-positive, it was obvious I did not look further for my answers... [Sighs]... I just don't understand why he would keep something like this from me, how is it different from killing someone.

The consequences of the blame game are far reaching; many participants commented that they lost a confidant and best friend:

We cannot trust each other anymore, there is a lot of finger pointing and before long violence will set in.

Theme 3: Coping strategies

In previous discussion the concept of accepting one's positive HIV status proved taxing for participants. Coping strategies that helped the participants to cope with their participation on PMTCT Option B+ strategy were identified as discussed in the sub-themes that follow.

Sub-theme 3.1: Talking about the experience

Monica described how she felt the decision to tell her mother and best friend about her HIV status had helped her to more fully accept her status; other participants agreed:

I feel good that I told my mother about my HIV status and participation in PMTCT Option B+. It gives me an opportunity to discuss with her issues that I would not have if she didn't know my status. I am able to communicate when I have a problem, she takes good care of me. She is also my treatment partner because she reminds me to take medications on daily basis so I never forget.

(Monica)

I can't imagine not telling anyone about my status up to this day, I would have gone insane. I couldn't wait to get it off my chest and once I did I felt relieved. Now we talk openly about the disease with those who know. They help me a lot and I get encouragement and that keeps me going.

(Josephina)

I was in constant fear of what would happen to me but once I started talking about it, a weight lifted off my shoulder. They encourage me to talk about my feelings and emotions. I get a lot of emotional support because it becomes overwhelming sometimes and I know that the situation would not be the same if I did not disclose my HIV status.

(Rose)

Febbie, who had not disclosed her HIV status to anyone as on the day of the interview, and had earlier in the interview described her conflict as to whether to disclose HIV status as emotional bondage, gave a controversial response:

I cope just fine. Not telling anyone actually makes me feel safer and at peace. The secret is safe with me. You can never trust anyone and before you know it your HIV status is top story in the newspaper. I don't have to be answerable to anyone and I can't stand anyone feeling pity for me.

Sub-theme 3.2: Detachment

During the interviews it was apparent that some participants cope by separating themselves from reality. For Febbie the coping mechanism is very effective:

I know it, I do... but that is where you learn to detach yourself. I never knew but I guess it's a trade you learn with time ... [Laughs]... I have learnt not to carry it everywhere with me, I bury it somewhere in my brain maybe and it stays there.

And later in the interview:

Even when I attend antenatal clinic and I hear the HIV and AIDS education, it seems as if am not there. It takes a while to click back in my head that I am HIV-positive... [Smiles]... I sound crazy I know, but you know what I mean. That's the only way that keeps me sane I guess.

Monica also shared her tendency to detach herself from reality: unlike Febbie, she became emotional when an HIV issue was brought up in her presence:

It becomes so real when people are talking about it and you are thinking like, Hello I also have it here you know, but once the episode is over and I am home I am in a completely different set of mind. It doesn't bother me much, it's like I have switched off the power button for a while [makes a face] ...it works!

Other participants were not in consensus on this coping strategy, commenting that once you are diagnosed with HIV you can never take a break from the constant thoughts. It becomes a part of their lives. Rose experienced particular difficulty with suppressing her emotions:

I am an emotional person, always been. I become emotional about everything [clears throat] ... With HIV sometimes I can't stand people talking bad about HIV-positive people in my presence. I become emotional and once I am in the comfort of my home the memories come back. Asked how those feelings are dealt with she hesitated before responding ... I just keep myself busy and divert my concentration.

Sub-theme 3.3: Rationalisation

Most of the participants gained solace from rationalising the whole process. Josephina had an unusual way of understanding her situation:

It had to be me, who else? I mean if God planned for it to happen to me so let it be. I think it is selfish to be complaining why me, why me, you know,...
[Pause]... *if not you, then who?*

Because come to think about it, everyone is working hard to help me and my baby to be healthy, so why should I sit down and cry. I am grateful that I am getting all the support I get and there is nothing to worry me at all.

Alinafe agreed:

It all happens for a reason and the earlier you realise that, the easier it becomes. I am receiving the best care for myself and my child and that is all I need, I do not let my heart be troubled by things I cannot change.

Category 3: Sociocultural factors affecting HIV-positive women on Option B+ strategy

Theme 1: Participating on Option B+ strategy

Although all the participants reported that they were happy participating on Option B+ strategy, it became clear during the interviews that utilising the services gave different meanings to the experience. Sub-themes that emerged helped to understand the women's personal feelings as they receive care as discussed below.

Sub-theme 3.1: Motivation or deterrence

Participants' decision to participate on Option B+ strategy was influenced by various factors and there were various reasons why they continued to participate despite obstacles. Some considered that the strategy was for their own good while others prioritised their child's health

Josephina could not hide her happiness at inclusion in the programme:

I feel it is benefiting me because had it been that I was not on the Option B+ strategy I could have died a long time ago ... She continued ... It is helpful because before I started my medication I was getting sick more often, it got me worried. I had not tested for HIV then but once I did and started PMTCT Option B+ it's a whole new me. I wish I knew earlier I would be in perfect health now [Laughs].

Monica and Rose were equally ecstatic:

I am very happy because I know that my life and that of my child is protected, I get all the care and advice I need.

(Monica)

As long as my baby is protected from the virus I am happy because she does not deserve to be infected.

(Rose)

Alinafe who had received PMTCT previously under Option A strategy was also very approving:

It is all about protecting my child. I was found HIV-positive when I was carrying my first child, I did everything I was told from the hospital. It was my first experience so I was really sceptical but when my baby was tested negative I was thrilled, it was a good feeling.... and as if sensing the next question she continued... [Smiles]... well I thought I would not get pregnant again after that, but I got married later and he wanted my child, what would I have done? [Giggles]. I promise this is the last one.

All the participants promised that it was their last child, which the interview was inclined to doubt, not least from the look on their faces.

Making a comparison with the Option A strategy, Alinafe commented:

I like the attention I get, it is different from the previous strategy you know, at least I get to be included in the management other than the baby only.

Desire for a HIV-negative baby seemed to be the biggest motivator in the women's participation on Option B+ strategy, which made the interviewer curious as to whether they would continue on the strategy once their children stop breastfeeding.

Sub-theme 3.2: Quality care

The concept of quality care was explored from the participant's point of view. The participants differed in their experiences in the hands of the health professionals. The interviewer wanted to find out if they believe they receive quality care from the hospital and some participants had only kind words to say:

To say the truth, yes, they treat us well, or maybe they treat me well ...

Paused as if waiting for a confirmation, then continued ... Well when you have a problem, they spend their time to help you and for me I come back satisfied.

(Alinafe)

Most definitely they are helpful, they go up and beyond to get the help that you need.

(Febbie)

One frequent issue, however, was timing of health services, as Monica complained:

Sometimes the nurses and the doctors are late in attending to us, we come to the hospital very early but we return home late and sometimes they shout at us, without showing love and yet a doctor is supposed to be loving to us patients [smiles]... I wish they could be receiving patients with love so that we could also be coming here with open minds.

Probed further Monica then expressed how she felt about the unloving attitude of the health service carers:

It's like they are adding on more stresses in my life.

Since the timing issue appeared in all interviews, the interviewer wanted to establish whether the participants ever asked why they were kept waiting. Josephina was the only one who had an explanation:

When you are looking for help you don't ask questions... [Grins]... but sometimes we see that they start with a meeting that lasts long delaying the clinic since we use the same room.... and oh, there are a few nurses to help us so maybe that's another reason.

Rose had the same concern:

To me I really feel the main problem is the time they start attending to patients. We arrive at the hospital early and spend most of the time waiting. Sometimes we sing songs followed by education session. By the time we start receiving treatment it's almost 10:00 am which is too late so I feel if they can start treating us earlier it would be better so that we should reach home early too.

The other issue that arose from this conversation was follow-up care for the women after delivery, on which point Rose had this to say:

After I delivered I was not told where I should be getting my ARVs. So it was confusing you know what I mean, initially I was getting them from antenatal clinic but I wasn't going to the antenatal clinic anymore.

And following up her concern whether she got the necessary help:

Yes, I asked one nurse when I went for my first postnatal visit and it was clarified.

Sub-theme 3.3: Privacy

The issue of privacy came earlier in the interviews because participants felt comfortable participating on Option B+ strategy when they felt their privacy was guaranteed – a point related to disclosure of HIV status to close family and friends only, as outlined previously. Participants did however express concern when privacy issues went beyond their control.

You know there are a lot of people here in the hospital, you know, some from my own village. It is not easy to keep a secret for long you know what I mean. Soon they will start wondering why you go to the hospital so often or why you are treated differently.

(Josephina)

After a big sigh she continued:

The clinic that we receive medications is just behind the antenatal clinic here and sometimes you are sent there for different reasons. Everyone knows around here that whoever goes there is HIV-positive or is a guardian to an HIV-positive patient but when you are alone the implication is obvious. I can't control who sees me and it is frustrating sometimes

Asked how that made her feel and how she dealt with the emotion, she skipped the first part and quickly commented:

It is one of those things you tell yourself whatever you know, the most important thing is that I am receiving treatment and that's what matters.

Monica, who complained about her talkative neighbour earlier in the interview, thought that the neighbour suspected something because she might have seen her at the ARV clinic. Asked whether they felt the hospital maintained their privacy participants unanimously agreed that hospital personnel do maintain their privacy:

I don't have any problems because I know they receive a lot of patients and they can't remember everyone.

(Alinafe)

Absolutely, there is privacy here. But maybe since the counsellors come from the same communities we do... [Laughs] ... we can never be too sure, but really, I don't think that is the case.

(Monica)

... unless you have a personal grudge with a health personnel but I don't think they are allowed to be discussing patients with other people.

(Rose)

Theme 2: Playing the role

This theme was explored as a result of women feeling left out when participating in Option B+ strategy. They referred to the situation as a role play where they are used to fulfil a part without their emotional involvement.

Sub-theme 2.1: Our opinions should count

Febbie gave an interesting description of Option B+ strategy when her experiences on the sub-theme were explored:

It's a play that we are starring in, all the parts have been laid out already and we just follow the script as per director's vision... [Laughs]... you are laughing? but seriously that's how it feels. We are taken for a ride, destination unknown.

Asked how that made her feel she hesitated for a while ... Powerless, it is the systems fault though not an individual... wish it was easy to change a system.

Alinafe could not agree more:

I was on PMTCT programme before, I learnt about it from here then and when I came back with this child's pregnancy, everything had changed. I

never knew anything about the change and it seems many more women didn't. Aren't we supposed to know when these changes are implemented? Who makes them anyway? Maybe am asking the wrong person... [Smiles]... and everything that happens during the PMTCT process from testing to medications, we do not have a say. It is all planned out, we are just playing the part.

Febbie presented a different view altogether:

It is too much about the baby, everyone focuses on the baby, your baby this, your baby that. Don't get me wrong, I am concerned about my baby too... [gazing straight into interviewer's eyes as she continued]... but it seems that nobody realises that I am the one carrying the baby, she is my child and I am just as concerned.

Probed on how she thought it would be done Febbie reported:

I wish I could be involved, more like a partner and not like an invisible participant. Making the decisions for myself and my baby and not listening to them all the time. Because there is one thing they forget [Clears throat] ...at the end of the day, I leave them here [referring to health professionals] ... and I go home alone, u know what I mean. I can do whatever I want without them knowing so it only makes sense that I am happy with the management also.

Participants felt that they could contribute to their own health and that of their children if they were involved more by health professionals and taken as mature individuals capable of making sound decisions pertaining to their health, while on the other hand a few participants felt that health professionals knew what was best and were more than willing to let them make all the decisions.

Sub-theme 2.2: Preventing further spread

One role that the participants were happy playing was that of preventing further spread of HIV. They were more than happy to be on Option B+ for the sake of their husbands and children. For some it was one of the reasons they disclosed their status to their partners, because they believed they had a responsibility.

I told him, I had to tell him. Not only did I want the weight off my shoulder but I knew that if I didn't I would be putting my life, his life and our child's life in danger. It took a lot of courage because I did not know how he would react but it had to be done. I am glad that we are all focussing on staying healthy and preventing further spread of HIV.

(Alinafe)

At the hospital the nurse told me to use a condom during the pregnancy to prevent re-infections since my husband's HIV status is not known. She said that will help to minimise the risk of infecting my baby with the virus... [long pause] ... so you see the situation I was in, it was difficult to talk about condoms with my husband because we have never used them in our marriage not even as a contraceptive method, so talking about them could have brought suspicious on me... [Laughs] what would be the justification if I did not disclose my status? I told him, he was reluctant at first but we use sometimes.

(Josephina)

During an interview with Febbie, the interviewer was compelled to explore the sensitive sub-theme to document her experience since she had not disclosed the HIV status to husband. Asked how she felt about keeping her husband in the dark, she said that she was only worried about her marriage and she gave these responses to follow-up questions:

I feel sorry for him but I am afraid that my marriage will collapse if I tell him.

For now we are not using any protection but soon we will, once I tell him.

At that point she brought the interview to a halt, visibly upset, and did not want to answer any further questions on the issue.

Theme 3: Challenges

Throughout the interviews, participants themselves raised what they regarded as challenging issues without being asked. Challenges faced by women on Option B+ strategy will be discussed in relation to five sub-themes: attitudes of health care workers distance to hospital, availability of drugs, stigma and discrimination, and men declining HIV testing.

Sub-theme 3.1: Attitudes of health care workers

Participants expressed concern over judgemental treatment they received from some of health care workers at the hospital. According to some participants it almost felt like they were being blamed for the infection, and worse, that they got pregnant while knowing their HIV status.

For all participants except Alinafe who already knew her HIV status, this assumption left a bitter taste:

I think it is unfair to judge, because they do not know how we became infected. I believe it can happen to anyone.

(Febbie)

If I knew my HIV status before I wouldn't have gotten pregnant in the first place, but I knew after I was pregnant and there was no way out. They need to be more understanding.

(Monica)

Probed further, the women failed to pinpoint a particular attitude or behaviour that validated the accusation but nonetheless persisted in this criticism:

I don't know how to explain it you know, it is not a specific thing... [Silent gaze] ... it is general; the way they talk to you, look at you, behave in front of you, you know, you can clearly read their state of mind.

Alinafe reported that she had more than twice been asked why she got pregnant when she knew her HIV status. She remorsefully narrated her story:

After I delivered my last child, she was my second child so really as a family we were prepared not to have any more children. I was on PMTCT Option A then and did all I could to protect my child. Luckily at 18 months she tested negative, anyway that was not the story... [Laughs]... When I delivered my child I wanted to put a permanent family planning method right away and I consulted the hospital and they inserted Norplant which was to be effective for five years. I had the Norplant for a year and suddenly I started menstruating heavily and I noticed that I was growing thinner, it don't know whether it was related though... [Pause]... I was scared and then I came back to the hospital and the doctor gave me some family planning pills to be taking to control the bleeding. I was taking the pills everyday but it didn't help. I came back to the hospital and the doctors said with the way things were they would give me some more pills but firstly to remove the Norplant for a while. Eventually when the bleeding was controlled the doctor asked me to choose another family planning method and I chose injections. Three months after starting the injections I found out that I was pregnant.

After a long pause as if giving interviewer time to process she continued:

So you see what I mean, even though I knew my status I did not plan this pregnancy you know, but they do not even want to listen to my story before they conclude.

Asked how the particular experience made her feel, she said that she was frustrated but could do nothing about it so she let it pass.

Sub-theme 3.2: Distance to hospital

All participants that were interviewed lived within the hospital catchment area but some were still a long distance from the hospital and had to use “Kabaza” [a bicycle taxi] or a minibus to get there. On whether distance to hospital hindered them from getting the necessary medical attention, Rose, who lived furthest from hospital provided an insight:

Yes it's a bit far, it is about two hours or more of walking. I have walked before but now I can't so I use a taxi. This means I have to have transport money all the time.

Clarifying how she dealt with the issue, she added:

I try to keep all my appointments but it is not easy. Sometimes I fail to go to the hospital to receive treatment for other ailments because am thinking there is an appointment coming that will also need money. So sometimes I just wait to do everything on the same day.

Sub-theme 3.3: Availability of drugs

In all the interviews it emerged that there was no problem with the availability of drugs at the hospital and no difficulty whenever anyone wanted to replenish her drug supply.

Alinafe, Josephina, Monica and Rose all agreed that it had never happened to them that they went to the hospital for their medication and found that medication was out of stock:

No it doesn't happen or maybe it has not happened to me yet.

Sub-theme 3.4: Stigma and discrimination

Stigma and discrimination proved to be the chief obstacle in participants' utilisation of Option B+ strategy. Contrary to the interviewer's belief that stigma and discrimination no longer happened, the reality was very different.

Josephina said she worried most about fellow villagers knowing her status because she felt she would be stigmatised:

My fellow villagers, I feel they might be saying bad things about me and discriminate me.

Asked if these things really happen in the village, she said:

Yes, sometimes it happens, like a certain woman in our village disclosed her HIV status and the whole village knows. She motivates people to go for testing in the village and visits the sick. But when she is not around people always talk about her ... [Pause]... it just makes me wonder if they don't do the same with me when I turn my back.

When asked whether this was mere talk or included acts of stigma and discrimination she elaborated further:

Of course it is more of the talk, they say she is an ill behaved person but I think it's not like that, I am not ill behaved and yet I am HIV-positive.

OK so the other time, the same lady I am talking about ... she is in our church, right? I sing in a choir and she also wanted to join the choir but the leaders did all they could to prevent her. In smaller groups people were discussing how she will not be attending most choir practices due to sickness. I did not say much because if they knew I was also HIV-positive I would be kicked out of the choir possibly or they would start avoiding me.

Alinafe who has been HIV-positive for the longest time had not told anyone in the community, even though her suspicions were almost palpable:

When you pass by people talking, you just know from the look on their faces that they are talking about you. Asked how she feels about other people knowing her status she said.....There is nothing I can do, the only thing I have done is accepting my status and I hope those people will get used to the fact and stop talking about it.

Febbie and Monica had a different opinion; in their view it was not the community but they themselves who were to blame:

Sometimes I feel like the problem is not them but us. Well I am talking in general because it has never happened to me but I get the feeling that people are talking about me sometimes. I become suspicious and eventually I withdraw myself, so it's not anybody's fault really. It's more like discriminating yourself [Laughs].

Alinafe said that she wished she could help her community know more about HIV and motivate them to go for testing, but she felt that doing so would be disclosing her HIV status publicly and she was not ready to put her husband and children in that position yet. She believed that more HIV knowledge would mean less stigma and discrimination

Sub-theme 3.5: Men not going for testing

Male involvement was the hottest topic in all the interviews. Almost all the participants complained about their partners not being involved in the process of HIV testing, education and controlling HIV spread. It seemed as if the women had always wanted to share their opinions on this issue.

Men should be on the fore front just like they head their families because they are the ones with the problem and yet they refuse to accept reality. They do not want to get tested, I don't know whether they believe they cannot get the virus.

And referring to her husband she continued ... *He believes I infected him and yet he refuses to go for testing. It really makes me wonder whether he really doesn't know or he feels guilty to admit that he is also HIV-positive.*
(Josephina)

According to another participant:

My husband believes he is already infected since I tested HIV-positive myself, for him, there is no point going for the test because it is obvious. How can you convince such a person? These men are cowards I tell you, they pretend to be tough but inside they are like babies...

Participants do realise that the success of their own participation on Option B+ strategy is directly affected by their partners' failure to get tested.

It makes no difference being on PMTCT programme and the partners status is unknown because we still sleep [referring to sex] together as a family and most times are very reluctant to use protection. We are just infecting and re-infecting each other, it can't work like that...

Continued... I have tried my best to explain to him and make him understand that he needs to get tested but to no avail.

(Josephina)

Seeking to understand how the women saw the men's behaviour, the interviewer asked if they felt the hospital set-up made men shun maternal and health care services. Josephina responded with a proverb:

[Laughing] *Mbewa ya manyazi inafela kuuna* [literarily, Cowardice results in loss of opportunities]

Enlarging on her comment, Josephine insisted that if men were truly concerned about their families they needed to take the initiative of going to the hospital to get tested for HIV. Asked how she felt men could be encouraged to go to hospitals she remained optimistic about leaving the responsibility to women who know their partners better. Speaking of the man as a "baby" she commented:

You can pamper him, praise him, manipulate him or trick him if that's what it would take to get him to the hospital for the HIV test.

Category 4: Adherence on Option B+ strategy

When participants were asked to express their feeling regarding their adherence to Option B+ and factors affecting their adherence, the frequently occurring themes in this category were the impact of lifelong treatment and the support system. These themes and emergent sub-themes were discussed.

Theme 1: Till death do us part

Sub-theme 4.1: *Experience and inexperience*

The notion “Till death do us part” was regarded with derision in participants’ reference to PMTCT Option B+ being a lifelong commitment like marriage. All participants showed anxiety when talking about the lifelong commitment, but there was a remarkable difference between those with longer HIV diagnosis and those with less experience.

During interviews with Alinafe and Josephina who were more experienced than the rest of the participants, there was a sense of calmness when they talked about the lifelong commitment which comes through in their remarks:

I was told from the very beginning, Umm, I was told that once I started on the Option B+ strategy it will be for the rest of my life...

Asked how she felt about it she continued.. it was not easy at first, I thought it was unrealistic but with time it sunk and I am ready for the commitment.

(Josephina)

When I heard that I will be on the Option B+ strategy for the rest of my life my heart sunk. I was like, how can this be, I struggled at first but not anymore.

(Alinafe)

Alinafe had an afterthought:

Mmh it is very different I must say, in Option A strategy I stopped the medication soon after I delivered my last child. It was only the baby who took medications for some time. I didn't understand why it was happening that I had to take the medication for the rest of my life. During one of my visits to the hospital I asked the nurse about it she told me the process had changed but didn't explain, I pressured on until I got closure and from then on I accepted Option B-plus strategy as my life partner [Giggles].

The less inexperienced participants regarded their commitment much more equivocally. They felt that it was unrealistic to demand this much from them, and some participants sounded more defeated than the rest. Monica, the single mother and the youngest participant, had this to say:

Mmh it is difficult my sister, look at me now, just take a good look... [Pause] ... do I look sick? Perfectly healthy, Well is do understand that we need to protect the baby from the infection blah blah blah, I get that but why me? why do I have to take the medication for the rest of my life,... feeling the need to convince the interviewer she continued ... I am 19 years old I would want to get married later, Uum, I would surely disclose my HIV status to the future partner but telling him am on lifelong treatment too?

And elaborating further:

He will believe I am that sick that they had to put me on medications forever. No one would want to marry me. Option B+ may just as well be my partner for life.... Sensing lack of commitment, Monica was asked whether she will make it through to the end ... Mmh I don't know for now, will see when I get there [Both laugh].

In the interesting case of Febbie not having disclosed her status to her partner, her experiences on the sub-theme were probed further, with careful rephrasing of the question to avoid upsetting her. She responded with a short unelaborated comment:

That has to be the hardest part in the whole process, knowing once you are in it is forever.

Febbie and Rose's sentiments were also shared by Monica, but none of them admitted the possibility of withdrawing from the programme any time soon, although they worried about their privacy.

The frequent hospital visits, the procedures and the medications will get people suspicious... yes there is a chance that people might know about my status because the care is different from another mother who is HIV negative.

Drug adherence

Drug adherence was explored in the same sub-theme because participants expressed anxiety on this issue. The key element of Option B+ strategy is the medication, on which depends the health of mother and HIV-free status for the child. The women's experiences with drug adherence, keeping in mind the lifelong commitment, took a variety of forms.

For Alinafe it was an easy go:

There are no major problems, I must say, only that, umm, at first after taking the medications I was feeling dizzy so the doctors told me to be taking the medications at night and go to sleep so at least now its better off

Asked whether she understood the purpose of the medications, she explained:

*well I do like I said before, please don't tell me to explain again [Laughed]
... and sensing the response she continued... well I don't know like specifics
but what I know is that the medications will help to prevent the virus from
multiplying that much and hence I won't be getting sick so often and oh... if
the virus is not multiplying there is a chance that I may not pass it to my
child... [Pause]... Correct? See I can even teach you [Both laugh].*

Level of knowledge on medications varied among the participants, and taking a different position to Alinafe Rose brought up the issue of poor preparation at the initial stage of medication:

There were a lot of things that were discussed that day but I only remember a few things like I said I wasn't in the best state of mind and I wasn't listening. They said will start ARV medication [Coughs] so that I should protect my unborn child from getting the disease and that I will take that medication for the rest of my life.

Clarifying her point, she added:

I can tell you that I did not start taking my medications right away because I did not even understand how I was supposed to take them... [Smiles]... I had to ask on the next visit and then I started.

Taking these reservations further, Monica commented:

I am worried at the thought that my life will depend on medications for the rest of my life, what kind of life is that? and I always think what would happen if I forgot to take the medication...

Asked whether she meant forgetting to take her medication or stopping altogether she clarified... *No, I can't stop taking the medication because I want to protect my unborn child..*

Asked if she will stop when her child is born she hesitated... *It's not like that, but the child is my number one priority at the moment"*

Monica's reasoning was shared by Rose and Josephina:

I do not want my child to go through what I am going through now I will do everything in my power to save my baby. They [health professionals] explained everything to me and I thought it is better that my child should be protected.

(Rose)

I feel blessed that I am benefiting from these medications, some months ago I met a friend who has been coming here and she told me that she gave birth to an HIV negative child so I feel it will also happen to me if I stick to what I have been advised.

(Josephina)

For some participants, however, it was the fear of consequences that drove them to drug compliance:

I was told to take the medication for the rest of my life and that if I stop the viruses that were weak will become active and affect my immunity which can cause diseases or other problems and I may die earlier than expected, so I feel it's good for me to continue taking my medication as advised.

(Alinafe)

This revelation prompted the interviewer to find out whether participants are taking their drugs every day, as instructed at the hospital. Interestingly, Febbie was willing to share her experience.

I definitely keep my medications in the house, where else can I keep them?

[Laughs] *...I just make sure I take my medications without my husband knowing.*

Asked her what would happen if he saw the medications, she responded with an unusual grin ... *He saw them once before, I think it was the second month after delivering my baby, I was careless, I guess I was overwhelmed with the baby and all.*

Seemingly enjoying the conversation she continued:

He asked me about the medications and I was scared, I told him they were vitamins I was given at the hospital. Luckily I had removed the prescription note from the bottles so he fell for it and you know, even if the prescription was there, he wouldn't have known. They don't know about these things. Later in the conversation she concluded ... I am more careful now.

Rose, on the other hand, admitted that she surprised herself in still taking the medications up to that day. She hadn't thought she would make it that far, but time had helped her get stronger each passing day and she was hoping to continue for the rest of her life. Asked about their future plans almost all participants forgot that earlier in the interview they had said it was their last child – as evidenced by the following admission from Rose:

I feel if this baby is HIV negative I will give birth to another one [Laughs] because they told me that the baby can be HIV negative, if it really happens that she is negative I will give birth to another baby, just one more.

Theme 2: Support system

Provision of psychological support emerged strongly as an issue in the course of the interviews. Support systems that were explored were both informal and formal, along with their impact on the experiences of the participants on Option B+ strategy.

Sub-theme 4.1: Informal support

Important sources of support of informal support were family and friends. This was particularly the case where family and friends knew the participants HIV status but was also true in general. According to the women, this support needed to be present throughout the whole process, right from the initial HIV.

Participants felt that absence of support systems at the hospital when they were diagnosed HIV-positive made their experience more unbearable than it need have been:

Yes the presence of my mother on that day helped me, I don't know what I could have done if I was alone, she gave me strength in different ways and she encouraged me to start my medication and up to now I feel free and comfortable to discuss with her other things and problems that I face as I

am taking my medication.

(Rose)

A different scenario was recounted by other participants:

I came alone to the hospital that day. Much as it was my first time and my first experience I didn't think it was a big deal. My mum wanted to escort me but I declined, anyway, I didn't realise how much I would need her after the diagnosis, it was so heavy on me. I needed someone to be there and help me through.

(Monica)

Monica, who reported that she threw away the PMTCT medications she had been given on the first day, commented:

If there was someone with me that time I wouldn't have done what I did, am sure that someone would have talked sense into me.

A participant who wished her partner had escorted her to the hospital said that in addition to the emotional support this would have given her it would also have been an opportunity for the partner to get tested, in this way both getting mutual support from one another:

If I was with my husband that day he would have gotten tested to start with [Laughs] ...but most importantly it could have been easier for him to hear the advice from the hospital personnel and their explanations about condom use and everything and it could have been easier for him to support me. Explaining further, she added: I told you at the beginning that I missed some information that day and I couldn't really understand some of what they were saying so if we were together [Coughs] if we were together, we could be reminding each other where the other one has forgotten. But now how can he support me if he doesn't even know what is happening.

(Josephina)

Josephina, who was physically abused by her husband after she disclosed her HIV status, thought that if her husband had escorted her to the clinic it wouldn't have ended in violence.

She commented later:

I heard that in other hospitals like at the central hospital, I heard that women go with their husbands to the antenatal clinic. They talk about it here sometimes but it is not emphasised and I think I have never seen a husband doing that here.

For some husbands and partners it was not that they failed to come to the clinic but that they did not want to get involved. They took their wives by bicycle, dropping them at the hospital, waited outside the gate until they were finished and then headed home together.

Taking a very different position, Febbie much preferred to be on her own:

I am glad I was alone the day this happened [HIV testing] otherwise I wouldn't have been able to keep the secret, now I make sure I go to the hospital alone for my follow-up post-delivery visits.

Asked whether they felt they received necessary support from their friends and family participants commented as follows:

We both know our HIV status now, we help each other because we have all accepted it. He gives me the support because he also needs it. I couldn't have asked for more really...

Asked if she feels the support could have been different had it been that her husband was HIV negative, she said, ... *It could have probably been the same.*

(Rose)

I do not receive the necessary support from him, but of course I haven't told him so he wouldn't know what I need and I can't explain, if my marriage resolves I won't be able to take care of myself that's why I don't

really get worried with such support.

(Febbie)

Mmh sometimes but not always, the issue of the virus is always brought up and am just used to it now.

(Josephina)

Asked how she dealt with this Josephina said:

I just leave him to be talking, after he gets tired he stops. At least the physical abuse stopped and I can stand the rest. I just feel sorry for him because he doesn't know his HIV status. He could have been receiving proper care himself.

During the discussions it was determined that all the participants truly valued informal support, and at least each one of them had a trusted friend or relative whom they could share their emotions and experiences.

Sub-theme 4.2: Formal support

Formal support as discussed represented structures within the hospital and the community that provide women on Option B+ strategy the opportunity for physical, social and psychological help as needed.

One participant was unaware that there were any services of that sort and only realised during the interview of their possible availability.

It also emerged in the interviews that there were community support groups to which none of the participants belonged, as reported by Monica:

I know there is a support group for HIV people in my community but I am not a member, I am not ready to disclose my HIV status to people who have nothing to do with it. Maybe time will tell.

One NGO that was familiar to all participants was the organisation that keeps a record of all women registered on PMTCT Option B+ strategy. Located on the premises of the hospital, the staff of the organisation meets all women who have been diagnosed and visit them in their homes if the women are willing. Alinafe was the only participant who had accepted the home visiting and she gave this account of her experience:

I did not have any problem for them to visit me at home so they do come by once in a while just to see how I am doing.

The hospital also gives the women some food items if an assessment has revealed nutritional inadequacies in the mother or the child. Formal support is readily available but the women need to step out and access the services for their emotional support

4.3 Conclusion

This chapter reviewed and provided a discussion of the findings of the study in line with the objectives. The discussions focussed on HIV-positive women on different aspects, knowledge and understanding of Option B+ process, accepting their HIV status, utilisation and also adherence on Option B+ strategy. It looked at the overall lived experiences of HIV-positive women on PMCTCT Option B+ strategy.

Chapter 5 Discussion: study findings, conclusions, limitations and recommendations

5.1 Introduction

The lived experiences of the participants in the study as presented in the previous chapter are discussed herein, conclusions made and recommendations drawn. There are various research studies which have given an insight into experiences of women in ART programmes including PMTCT, both in Malawi and in Africa as a whole. Issues that have emerged and are outlined in this chapter may help to illuminate similar experiences on Option B+ strategy. The findings will be discussed according to the following four major categories and their themes and sub-themes that emerged in the course of the in-depth interviews with the participants (see Table 4.2)

Knowledge and understanding of Option B+ strategy

Accepting the HIV-positive status

Sociocultural factors affecting HIV-positive women on Option B+ strategy

Adherence on Option B+ strategy

Study limitations will also be discussed at the end of the chapter.

5.2 Knowledge and understanding of Option B+ strategy

5.2.1 Source of information

Knowledge of HIV and AIDS among women in Malawi stands at 99.4%, according to the Malawi Demographic Health Survey (MDHS, 2010). For pregnant and post-partum women, the source of such information is the hospital where they access maternal and child health services including antenatal care. Antenatal care includes all of the extra care going beyond medication and tests that women receive during pregnancy and preparation for child birth.

Since the introduction of routine HIV counselling and testing within antenatal care in Malawi, HIV and AIDS information assumes a greater proportion of the education offered to all women attending maternal and child health services in hospitals, and this is evidenced by all the participants in the study agreeing that they had some knowledge and understanding of Option B+ strategy irrespective of their level of education.

The knowledge and understanding differed among the participants, with none demonstrating adequate knowledge of Option B+ strategy. This may be supported by an estimated 41% proportion of women with comprehensive knowledge of AIDS (MDHS, 2010) notwithstanding the 99.4% general knowledge of AIDS in the same population, or it may actually reflect how comprehensively the education is offered to the women. In Uganda, one of the countries implementing Option B+ strategy, similar findings were presented through focus group discussions concerning Option B+ strategy with communities living with HIV, which highlighted varied and limited understanding of what Option B+ entails (Ahmed, Kim and Abrams, 2013). Limited knowledge on Option B+ strategy may yield to the fact that women are exposed to comprehensive Option B+ education just once, when reporting to the ANC for the first time. Assuming this comprehensive education was offered to all the women accessing maternal and child health services at the hospital, many women would be conversant with Option B+ strategy before they even get pregnant, hence maximising their knowledge and understanding.

Even though it was not feasible to determine access to HIV counselling and testing by all women in the population, since women in the study were already found in the hospital, it can be concluded that the service is offered to all women who come to the hospital. Option B+ strategy has promoted the target of universal access to HIV treatment for mothers in a setting where it is difficult to effectively distinguish between those mothers eligible for treatment

and those needing prophylaxis (Fasawe et al., 2013). Such knowledge and understanding is crucial to success however, and hence the need to increase exposure to comprehensive information through education and ongoing counselling. The first exposure to Option B+ strategy may be the same for all HIV-positive women, but their experiences differ from that point on.

5.2.2 To test or not to test

During the interviews it was obvious how the participants struggled with the decision to go through with the HIV testing. The emotional toll exacted on them was revealed in detail through the sub-themes that emerged during the analysis.

5.2.2.1 Timing

HIV counselling and testing should be an individual decision, but in settings like Malawi where there is a generalised epidemic all pregnant women are tested as early as possible in each pregnancy, with health providers recommending the testing as part of routine antenatal care. This means that it is the health provider who initiates the HIV test rather than the women themselves. The impact of this approach was evident throughout the interviews with participants feeling that the HIV testing was ill timed. This feeling was the same for women who were tested while pregnant and for those who had their first encounter with Option B+ strategy at labour and delivery. These encounters are consistent with WHO (2010) recommendations that women who test HIV-negative in their first or second trimesters of pregnancy should be re-tested in their third trimester of pregnancy, and if a woman does not return for testing during her third trimester, she should be recommended to test at labour or, if that is not possible, immediately after delivery. Despite the protocol, participants expressed concern that they were not given time to decide whether they wanted the HIV test or not.

The participants believed that they would have been in a position to make the decision independently only if they had been given adequate time to think it through, their fear being the outcome of an HIV-positive result. From the interviews it was noted that negative experiences on Option B+ strategy mostly arose from this uncontested HIV test. For some participants, the timing needed to include an opportunity to go home and consult with partners, as it could otherwise be a source of potential misunderstanding in their families. It is easy to say that women as self-determined individuals are capable of making their own decisions regarding their health, but it can also be argued that, with voluntary HIV testing criticised as overly simplistic (Lange, 2011) and potentially delaying early detection of HIV and initiation of ART, women need to be tested and treated on contact if the elimination of HIV infection is to become a reality.

5.2.2.2 ‘Opt-out’ an option?

The ‘opt-out’ HIV testing approach adopted in Malawi is meant to enable all pregnant women to be screened for HIV infection. Testing should be conducted after a woman is notified that HIV screening is recommended for all pregnant women and that she will receive an HIV test as part of the routine panel of prenatal tests unless she declines (WHO, 2007). This was found in the study to run counter to the preferences of the participating women, who felt strongly, and with a degree of hopelessness, that the ‘opt-out’ possibility had not been adequately available to them HIV testing. All participants expressed their concern that they were not given an opportunity to make a decision on whether to test or not. Test-and-treat models which allow health professionals to diagnose and treat HIV infection in pregnant women, minimise missed opportunities, and promote early initiation of ARVs, however reports have also shown an increased rate of loss to follow-up of mothers and their babies particularly after the first clinical visit (Coulborn et al.2013). It can be speculated that failure of women to ‘opt out’ of HIV testing results in initiation of women on Option B+ strategy

who are not ready to commit to the process; hence the increase in drop-out. Some participants expressed fear that they would not receive the necessary care if they declined the test, which made the women feel vulnerable the health system and induced them to withdraw.

5.2.3 Moment of truth

“Moment of truth” was the point when women learnt that they were HIV-positive. It was described as the most difficult time throughout the whole process. With the global emphasis on ‘test and treat’ this step in the HIV testing process has become a critical component of the spectrum of HIV care (Corwin, 2013). The news was received in various ways by the participants, but the common emotions were anger, grief and fear. Some of the participants felt angry and disappointed at themselves, some directed their anger towards their partners/husbands, grieving at the realisation that life would never be the same, while others feared isolation from their friends and family facing the prospect of disease progression and death. The extreme emotions fell into the pattern reflected by the sub-themes.

5.2.3.1 Terrifying and depressing

Regardless of the person’s sex or behaviour, a diagnosis of HIV (or any chronic illness) is likely to be felt as a shock. Shock and disorientation are commonly reported reactions to life-changing news of this nature, as are terror, sorrow, anger, fear, depression or shame – even for patients who already suspected that they were infected (Corwin, 2013). Human emotions are complex and varied, and while a small number of test providers indicated that they felt little or no impact when disclosing the HIV-positive result – because the diagnosis is ‘not the end of the world’ (Myers et al., 2007) – most indicated that it was difficult because they anticipated that the test recipient would (or did) find the news distressing, as was the case in the study. The psychological impact on the participants of HIV-positive results was explored and what came through from all the emotive words was that they felt terrified and depressed

at the prospects of dying. This impact abated, however, over time, with those less experienced exhibiting more extreme emotions than those with longer experience – an indication that the HIV diagnosis can become a lesser burden than it is at first.

Participant responses indicated a need for health professionals to spend time with them in the initial stages to help them understand and have their concerns resolved which does not always happen. Participants complained that it all happened so fast, in disregard of the recommendation that disclosure of positive test result should be followed by time for patients to react and process the news before further information is thrust upon them (Corwin, 2013). Corwin (2013) also advises that even if the patient does not display negative reactions, too much information should not be given at this particular visit as she may still be unable to adequately process long explanations at this time – thus rendering the service ineffective. It is therefore no surprise that women failed to show adequately comprehensive knowledge of Option B+ strategy despite having been given the information. Health care workers need to understand the grieving process that women go through at this stage and provide the emotional and psychological support they need.

5.2.4 Preparation and readiness

5.2.4.1 Emotional preparation and pre-treatment education

It is commonly acknowledged that being HIV-positive is difficult and stressful for anyone, but the experience of pregnant and postpartum women may have further dimensions. In prevention of mother to child transmission, the concern is not with the mother alone, but extends also to the unborn or newborn baby. The pregnant and postpartum mother is therefore in constant contact with the health professionals for management of the HIV infection – a task which in the view of the participants needed psychological preparation and comprehensive education. The focus of HIV counselling is to provide emotional support to

help the newly diagnosed patient cope with the diagnosis, access treatment and other care services, disclose status to sexual partners, remain safe during the initial phase of dealing with a new diagnosis, and prevent further transmission of HIV (Corwin, 2013). How much of this information is incorporated in the counselling of the participants is not known. A ground breaking presentation at the 7th Annual AIDS conference by Tenthani, et al. (2013) substantiates the poor preparation and support of women on Option B+. It was established that patients who were lost to follow up started ART on the day of their diagnosis and never came back, unsurprisingly these women were less likely to return to clinics.

Participants reported that there was information overload on the day of diagnosis; not only had they come unprepared for an HIV test but they also were found to be HIV-positive, counselled, and initiated on lifelong treatment, all on the same day. The participants questioned why the ARVs were administered as a matter of urgency, rather than making sure that they were ready first. Corwin (2013) agrees that risk behaviour assessment for the HIV-positive should not be done in haste but rather when the patient is ready (for some, this may be the same day as receiving the test results, for others it may be the next visit after they have had a chance to process the diagnosis). For some participants this proved tragic, with one participant throwing away all the medications she had received for PMTCT on that day. This corresponds with the preliminary findings of a routine PMTCT Option B+ programme in a rural district in Malawi (Coulborn et al., 2013) which revealed that the mothers and babies who are lost to follow-up, particularly after first visit, are not necessarily defaulters but may actually have failed to start ARVs at all. Poor preparation may result in poor compliance, as shown by one participant who had previously been on PMTCT Option A strategy in an earlier pregnancy and was not convinced as to why she needed to take the ARVs for the rest of her life, since she had previously taken the same ARVs for a short period of time and her child then had tested HIV-negative.

The integrated guidelines for provision of HIV services in Malawi that were implemented from July 2011 replaced all earlier editions of the Malawi antiretroviral therapy programme and PMTCT guidelines which had previously functioned separately (MOH, 2011). Even though the services are thus integrated, the ART programme which initiates lifelong ARV treatment for HIV-positive men, women and children in the general population continues, independently of the PMTCT programme, to conduct ART preparatory classes which are prerequisite for ART initiation. These classes have a major influence on the outcome for clients because only those who understand the implications of treatment are initiated. Men and women undergo 2–3 class sessions on ART after initial diagnosis, accompanied by a guardian of their choice, to prepare them for the same task that pregnant and postpartum women embark on without formal preparation. The participants' wish for better preparation may be valid, considering that this is provided for other HIV-positive people, but in the relatively inflexible 'test and treat' approach health professionals would be reluctant to let HIV-positive mothers come back later for education and initiation, for fear of missed opportunities should they fail to return. This may raise the question as to why only pregnant women are targeted for the 'test and treat' model and not the general population if the country's aim is to eliminate HIV.

5.3 Accepting HIV-positive status

5.3.1 Silence best option?

Whereas hearing about their HIV-positive result had been a single, dire step for them, participants regarded acceptance of the positive status as a long process that hinged on individual characteristics and environmental factors. Participants unanimously reported that it was only when they accepted their positive HIV status in their hearts that they started living a healthy life. Even though that may have been true for all of them, the realisation was not

necessarily enough to compel disclosure of HIV status, as some believed that silence was the best choice. Issues of HIV status disclosure need to be discussed during post-test counselling of an HIV-positive result, and if a patient is frightened or unwilling to notify the sexual partner of an HIV diagnosis, the reasons for this must be explored. Should there be real concern about abuse or harm to the patient, it is important to help them through those issues first (Corwin, 2013) and continue with ongoing counselling on disclosure.

As “golden” as Silence may seem, it has been cited as a major culprit in continued HIV transmission and deficient care for people living with HIV and AIDS. This was borne out by one participant who – despite having known for over four months that she was HIV-positive, with an active sexual partner, and being in contact with health professionals – still remained silent. For this participant, efforts to save her marriage took precedence over the risk of infecting others. This projects a gloomy and pessimistic scenario for the war against AIDS since prevention efforts should offer us a window of hope for mitigation and curtailing of the pandemic. Another factor cited in the spread of HIV is low and inconsistent condom use in a sexual relationship where one partner is HIV-positive – an issue also acknowledged in the Malawi national response to HIV and AIDS (Malawi Government, 2012). This also emerged in the conversations with the study participant who failed to bring up the issue of condom use in the family for fear of suspicion, since she had not disclosed her HIV status to partner.

Silence should not be encouraged in the era of HIV as it impedes the efforts in curbing the pandemic, not only does it put their sexual partners at risk but re-infections will prove detrimental to their own health and increase the risk of infecting their breastfeeding children. Women who are having difficulties in disclosing their HIV status should receive ongoing counselling and health professionals should be involved in bringing the woman to understand the consequences and help her with disclosure.

5.3.2 Breaking the news

5.3.2.1 Who to tell

For the participants who made the decision to disclose their HIV status, the circumstances and the experiences of disclosure varied. Decisions tended to be strategic, weighing the possible outcomes and in most cases influenced by other people's thoughts and perceptions. Nor was it likely to be an easy decision, although participants agreed that disclosing the results to someone was advantageous in more ways than one – consistent with literature reporting that disclosure of HIV status to partners and family has many benefits, including decreased anxiety, increased social support, increased access to PMTCT and care, treatment and support programmes, ability to plan for the future, opportunity for partners to be tested, and opportunity to reduce risky behaviours (Medley, Garcia-Moreno, McGill and Maman, 2004). In the study, women who believed they were infected by their partners were more likely to disclose their HIV status, and although barriers presented themselves to women, they did not match the actuality of disclosure experiences. Findings by Bobrow (2008) reported that even though majority of women reported positive responses to disclosing their HIV status to their partners, 14.6% of women experience a violent reaction to their disclosure (Medley et al., 2004) and this was reflected in the present study, with one participant being subjected to physical and verbal abuse after disclosure.

One participant raised a persistent issue that is often ignored when it comes to disclosure, citing the problem of disclosing HIV status that she had discovered through being tested for HIV without her husband's consent. In Malawi, the traditional value system, especially in rural settings, assigns limited power women within their marriages (Musopole, 2006; White, Kachika and Banda, 2005). In such cases women do not make independent decisions such as

choosing to be tested for HIV. Failure to include men in these matters therefore puts women in a difficult position when it comes to disclosure.

5.3.2.2 The blame game

The *blame game* sub-theme also arises in relation to the previous *who to tell* sub-theme, as women were more likely to disclose their HIV status to a partner if they felt they had been infected by that partner, thereby shedding some of the burden of self-blame. On closer analysis, these feelings could be interpreted as unacknowledged guilt. Participants indicated that it was more usually partners rather than family and friends who (they felt) blamed them unjustly, yet attempts to disclose were not always welcome. Partner disclosure is a central concept in most PMTCT programmes. Studies on PMTCT often cite the problems associated with a mother's voluntary or involuntary disclosure of HIV-positive status as an obstacle to minimisation, and the few studies that have specifically explored local experiences with partner disclosure in a PMTCT context tend to confirm the findings in the present study. Being the first in the partnership to be diagnosed HIV-positive was hard for women, yet reason enough for men to regard them as the source of the infection – regardless of their own unknown HIV status.

In the instance of the participant who suffered physical and verbal abuse at the hands of her partner after HIV disclosure, the spousal reaction was consistent with literature that cites negative reactions from partners of HIV-positive women. A study by Njunga and Blystad (2010) mentions that a PMTCT programme was sometimes called the “divorce programme”, suggesting how the programme's emphasis on partner disclosure played up fears among men facing accusations of infidelity from wives and relatives – a situation that sometimes led men to abandon their families. This puts the woman in a double-bind situation: potential transmission of the virus to the infant set against potential loss of income and support through

departure of the husband. Even though women may appreciate the social responsibility of disclosing their HIV status to partners, fears of blame still make disclosure a challenge.

Since the present study focussed exclusively on women, men's experiences on the sub-theme which could have been useful in understanding the situation were not solicited. Women's need for support in disclosure is important, since feelings of blame may entirely defeat the purpose of disclosure so that the programme ends up causing more harm rather good to those it is meant to serve. Male involvement in PMTCT programme may be the solution to the dilemma, but men's response to the programme needs to be analysed and this falls outside the scope of the study.

5.3.3 Coping strategies

Numerous studies have explored coping. The term refers to 'constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman, 1984). The stress associated with HIV disease has been found to be a major influence on quality of life as those who are infected try to find ways to buffer the impact of HIV. Participants in this study used a number of different coping mechanisms which they believed worked for them, such as talking about the experience, detachment and rationalisation, and, as pointed out by Lazarus and Folkman (1984), no one coping strategy emerged as inherently good or bad; coping can only be judged by its effectiveness in meeting the demands of the particular situation in each case. All participants realised that HIV was not curable and that Option B+ was a long-term commitment; they accordingly prepared themselves psychologically for the challenge one day at a time.

5.3.3.1 Talking about the experience

All participants except for one who had not yet disclosed her HIV status found partners, family and friends as a major source of support in the form of informal discussions concerning their experiences. They emphasised that talking about what they were going through was a way to obtain encouragement and reassurance which helped them to cope with their feelings, and they deliberately chose to talk to those who would offer just that. One of the participants said that talking to her mother about her experiences brings her a sense of serenity, while for some the same comfort is obtained from talking to a health professional about issues of concern. This confirms the concerns of some participants who wanted health professionals to be more empathetic with them so that their interactions help them to cope rather than adding more stress.

Talking about the HIV experience, and interpersonal relationships in general (to prevent social isolation), have been reported in literature. It has been found that mothers living with HIV who did not have social support were significantly more likely to have high psychological distress than those who had social support (Blaney et al., 2004). Hence the need to encourage women on Option B+ strategy to maintain social bonds.

5.3.3.2 Detachment

Coping is cited as an important aspect of adaptation outcomes such as psychological well-being, especially in the long term (Lazarus and Folkman, 1984). Some coping strategies such as detachment, also referred to as avoidance coping mechanisms, are indicators of passive coping as opposed to active coping. Active coping strategies focus on managing the illness, seeking social support, and spiritual activities, whereas avoidance coping strategies result in negative emotions such as depression and anxiety (Degenova, Patton, Jurich, and McDermid, 1994; Fleishman and Fogel, 1994). The findings in the study suggest however that while

avoidance may not be positively protective it may also not necessarily be harmful in terms of giving rise to emotional distress, since none of the participants who used this coping strategy exhibited such emotions. These findings are consistent with an extensive body of literature, but since none of the participants had been on Option B+ strategy for long it was difficult to determine what the long-term effects would be of the coping mechanism.

5.3.3.3 Rationalisation

Confirming that living with HIV has serious psychological and social ramifications in addition to being a physiological and medical concern, participants sought to rationalise the psychological stresses of being on Option B+ strategy. It was apparent from their responses that the psychological resources they drew upon were linked to issues of meaningfulness and psychological resilience. As with the detachment response, concealing their real emotions through attempts to rationalise their situation was a coping response through which they sought to establish a more stable emotional environment, avoiding more direct confrontation with the stressor.

The findings in relation to this sub-theme confirmed that coping is not something static and needs to be understood as a lifelong process in which individuals resort to different coping strategies for different situations. This provides an understanding of the role of coping in the outcomes of women with HIV disease and suggests possibilities for designing interventions in support of psychological adaptation to the illness. The evidence on adaptational outcomes for active or passive coping strategies suggests that avoidance coping may be more effective during the earlier stages of HIV disease, whereas active strategies may be more effective when the disease becomes physically manifest (Kotze, 2011) and should at that stage be emphasised as the recommended coping strategy for women on Option B+.

5.4 Sociocultural factors affecting women on Option B+ strategy

Issues of Option B+ participation and utilisation by HIV-positive women in Malawi are becoming more critical as a measure of programme success in view of the huge increase in the numbers being initiated on the programme, in relation to which a number of sociocultural factors come into play that are explored in this theme. No generalisable studies have been done to determine women's experiences on Option B+ strategy in Malawi, but if retention on the programme is taken to be a direct indicator of their satisfaction then the outcomes, according to statistics, are not promising. A study conducted in one of the district hospitals in Malawi by Coulborn et al. (2013), showed an approximated 16.5% of women lost to follow-up at month three and 21.5% lost at month six, including breastfeeding women. The study was based on patient charts and hospital records but its recommendations took no account of any input by the patients themselves; hence the need, as previously indicated, to focus more directly on the affected women's own experiences for deeper understanding of patient continuation (and continuation challenges) on Option B+ strategy. Contrary to the statistics, participants in the study expressed gratitude for the benefits they derived from the strategy, although it also emerged that various sociocultural factors affected them in one way or another – as highlighted further in the related sub-themes.

5.4.1 Participating on Option B+ strategy

5.4.1.1 Motivators and deterrents

Motivators, as deduced from the participants' experiences, were factors that promoted continued participation on Option B+ strategy while deterrents did the opposite. All the participants agreed that the strategy was helpful because their own health and that of their unborn or newborn children were taken care of and because the risk of HIV transmission to partners was reduced. This assessment by them is consistent with the goal set out in the

Malawi Integrated Guidelines for Clinical Management of HIV (MOH, 2011) of optimal protection for HIV-positive women during pregnancy, delivery, breastfeeding and subsequent pregnancies, taking account of the high fertility rates in Malawi, and with reduction of transmission to sexual partners being a further objective in the strategy. Participants' responses indicated, however, that the overriding incentive for them was the prospect of having an HIV-free child – persuasive enough, as they saw it, for them to adhere to the strategy recommendations whatever obstacles they might encounter. One woman who gave birth to an HIV-negative child seemed to prove the point.

The reasoning did not necessarily play out in the same way for all participants. Belief that PMTCT was exclusively for the child drove some women to the edge because they thought that their own need was being ignored. In a qualitative study by Bwirire et al. (2008), a woman declared that PMTCT was too much about the baby and not enough about the mother, echoing the feelings of some of the participants in the present study. In Option A strategy the focus was primarily on preventing HIV infection in the child, and women therefore stopped taking ARVs once the child was born; managing the child took priority over helping the mother. With Option B+ strategy the scenario is different: lifelong ART benefits the mother, with a substantive possibility of improvement to health, as in the case of one woman who reported being sick before being initiated on Option B+ and then responding positively to treatment. It has been suggested that recent trends to reposition start of ART at higher CD4 counts than previously might have a beneficial effect on the programme's acceptability to mothers (Braithwaite et al., 2008). Women who see Option B+ as advantageous for their own health may have a more positive overall experience than those who do not. Sadly, it is still the same poorly prepared women who are need to understand these complexities.

Feelings of guilt on the part of the interview participants were evident in the way they stressed their responsibility for protecting their child from the infection. The focus on the child was almost disturbing, inviting some doubt that the women would be equally motivated to remain on the programme once breastfeeding had ended. The one participant who had come to the end of breastfeeding insisted that she was continuing with the programme, so the possibility of some women discontinuing with Option B+ strategy could not be established.

5.4.1.2 Quality care

Although there was consensus among the participants that the care they received from the health professionals had been a significant incentive in persuading them to participate on Option B+, there was much more variation as to which individual factors or programme characteristics had the greatest influence on their experiences. Most of the participants felt satisfied with the care, with no bias against Option B+ strategy, and they commended health professionals in some cases for going out of their way to help them, although this could unfortunately not be said for all. The attitude of health care workers which emerged under this theme was also an issue under the *challenges* theme, where it is discussed in further detail.

Timing of health care services also drew reaction from the participants. They complained that the clinic starts operating late, making patients wait even longer to receive care, a problem also recorded by Bwilire et al. (2008), who reported long waiting times at the ANC as one factor in poor PMTCT programme participation. Some participants mentioned worry about having to leave other children at home while they spent hours waiting at the clinic. In the researcher's experience, this is a fair reflection of many ANC clinics which handle huge numbers of PMTCT women (as many as 200) with only two or three midwives on duty. These complaints were already being made in the Option A period when nurses only needed

to document ANC activities in client's health book; now, with Option B+, there has been a huge increase in the number of women started on ART, and with record keeping a vital element in the programme a lot more time is spent on documentation and lengthy counselling. With this increased workload it is no surprise that waiting times have also increased, and a way needs to be found to reduce the waiting times so that women are not eventually discouraged from coming to the clinic.

Despite mounting evidence that women on Option B+ will benefit from early treatment (Hargrove and Humphrey, 2010) and with less likelihood of negative consequences from treatment interruptions, some participants expressed anxieties about the programme that might ultimately affect their participation. They were troubled both by the prospect of lifelong treatment and by the idea of a drug-dependent existence which was hard to reconcile with their idea of quality life. Retention rates for long-term treatment programmes in Malawi remain unsatisfactory, and this is likely due to late ART initiation in the early stages of ART scale-up; Option B+ is also in the early stage of scale-up, but early initiation of ART would reduce the mortality rate significantly and possibly enhance participation.

A particularly important point that emerged from the interviews was that health care workers need to be familiar with protocols and procedures of Option B+ at all levels of care, especially nurses who are in constant contact with the patients, so that they give proper care, advice and guidance. One participant complained that health care workers failed to tell her where she needed to go for the next Option B+ services following delivery. Health care worker training sessions were prioritised ahead of Option B+ strategy implementation, so with time it can be expected that all health workers will deliver the same message in helping patients for continued participation.

5.4.1.3 Privacy

One reason frequently adduced in literature as a hindrance to PMTCT participation is fear related to HIV status disclosure and its consequences. Chinkonde, Sundby and Martinson (2009) note that fear of involuntary HIV disclosure and negative community reactions discourages women from participating fully in PMTCT. This corresponds with the findings from this study that women were fearful that Option B+ participation would automatically reveal their HIV status, mainly because of the medications and the point of care location. Women felt at ease with Option B+ when they thought their privacy was guaranteed and they all agreed that the fear had nothing to do with mistrust of the health professionals, with whom they felt their privacy was secure, but rather with the wider environmental circumstances. The integration of ART and PMTCT in Option B+ strategy meant that ARVs are dispensed to the HIV-positive women during their routine antenatal care, using the same consultation rooms as any antenatal woman, and fear of being treated differently, thereby arousing the suspicions of curious neighbours, does not arise; the problem, however, was that sometimes they were required to visit the adjacent ARV clinic to see the doctor there, and this gave rise to anxiety about who would see them and what they would think. This concern for privacy may affect women's attendance on Option B+ strategy, and indicates a need for better design of management arrangements that would instil confidence.

Postpartum women are faced with a dilemma when it comes to privacy and feeding options for their children. Breastfeeding poses a major risk for MTCT; it is reported that 5–20% of babies born to HIV-positive women will become infected during this time (De Cock et al., 2000), but PMTCT Option B+ postnatal women found themselves having to juggle protection for their child with protection of their privacy. One woman reported failing to maintain formula feeding her baby in fear of people's reactions. Breastfeeding is accepted as a norm in Malawi and failure to breastfeed so raises eyebrows; hence HIV-positive women who choose

to formula feed waver between the two feeding options depending on the situation, a practice that has been reported to increase MTCT in the long run. Option B+ women are expected to frequently come to the hospital for health monitoring, drug supply and routine care, hence they need to be treated in an environment where they can feel safe and protected for their continued participation. More importantly, ongoing feeding counselling for HIV-positive mothers need to be emphasised and women need to be supported as necessary with their feeding option to avoid mixed feeding that increases the chance of HIV transmission to the child.

5.4.2 Playing the role

5.4.2.1 Our opinions should count

This sub-theme proved to be emotionally taxing for the participants. In their participation on Option B+ strategy, participants saw themselves more as invisible partners than as active partners in care. Women equated themselves to actors in a movie where they fulfil a role with a laid-out script. The women had troubling questions about their involvement in their own care, and this supports the need for patients to be included in decision making so that they become more visible and empowered. This theme is not found in the Malawian literature, but a report on focus group discussions in Uganda concerning Option B+ strategy with communities living with HIV highlighted varied and limited understanding of what Option B+ entails, concerns about side effects, and a general feeling of lack of participation in their country's decision-making process in the adoption of Option B+ (Ahmed et al., 2013). This scenario mirrors the situation in Malawi, where the participants cited both failure of government to consult them on the adoption of Option B+ and failure of the programme to cater for their opinions.

Issues on which the participants felt they had been ignored included choice to get tested, recruitment on Option B+ strategy without preparation, initiation of lifelong treatment without being offered alternatives, and the expected follow-up route for their infants. The question on participants' minds was why it is called 'Option' when there is no option – a concern that is not clearly addressed in literature. Health workers and women on Option B+ need ongoing interaction focussed on what is working and what is not with regard to practical measures that could ensure sustained programme participation, where failure could render the programme ineffective. Having had no opportunity for input, participants expressed a sense of hopelessness in the face of the scenario of being tested without a choice, started on ART and left to deal with the community that still stigmatises the HIV-infected. MMWR (2002, cited in Bwirire et al., 2008) noted that women perceive HIV testing as an obligatory procedure. Although 'opt-out' may result in a high rate of HIV testing, if women are not involved at this early stage and perceive it as obligatory it might adversely influence participation.

Participants who believed the programme is all about the baby were particularly concerned that health professionals fail to realise that they cannot target the baby without the mother's involvement, and felt that they should be the ones to make the final decision. Regardless of national policy, respect for individual choice and human rights require that for true informed consent the risks, benefits, and alternatives in a recommended course of treatment must be communicated to patients (IATT, 2012). Participants seemed to echo this in holding that their capacity for positive participation in their own care should be taken seriously – although for some, leaving the decisions to the health professionals was the best choice.

The report by the interagency task team (IATT, 2012) on the implementation of Option B/B+ programmes emphasised that the success of transition to Option B/B+ is critically dependent

on its acceptability to women living with HIV. In cases where two options may have similar efficacy for an individual woman (e.g., Option B / Option B+), understanding the relative acceptability of the options becomes especially significant from a human rights perspective. It is important to hear at first hand from women living with HIV regarding their preferences and whether they would like to have the opportunity to choose between the two options. This implies that HIV-positive women would be given an opportunity to choose either unless they need treatment for their own health. Assuming women had the option to choose between Option B or Option B+ strategy it would mean that the treatment guidelines would not be standardised and there would be a crucial need for CD4 count to decide whether to discontinue ARVs on Option B – a long standing issue that was resolved with adoption of Option B+ strategy. Somehow Options B+ has cleared up the major potential area of confusion by employing one simplified regimen for all women so that each person can easily comprehend their role in the effort to reach an AIDS-free generation, but this may not be justification for not involving women in their care.

5.4.2.2 Preventing further spread

Participants exhibited a sense of social responsibility in dealing with their own emotional burden which was apparent in their willingness to take precautions to protect their partners and babies from the HIV infection. According to the Malawi government AIDS response report (2012), most new infections occur within long-term stable sexual relationships and the report identified the current drivers of HIV and AIDS epidemic in Malawi as low and inconsistent condom use and sub-optimal implementation of HIV prevention interventions, including the use of ARVs. Even for a participant not actively committed to preventing further spread, like the one who had not yet disclosed her status, the subject was excessively emotional – implying that with the right support she could be willing to join the race.

Failure to incorporate men in the care regime put women in a difficult situation however. Men expressed strong concerns that they might re-infect their partners, or might not bother to attend the clinic if they knew they will not be getting the same treatment (Ahmed et al., 2013). There is some evidence that these concerns have been alleviated in Malawi by sensitive approaches to disclosure and messaging, couples counselling, and support groups, giving some cause for optimism about active participation by men in Option B+ strategy and acceptance by them of their role in the preventing further spread of HIV.

5.4.3 Challenges

Although the lived experiences of pregnant women on Option B+ strategy seem positive, they are also faced with challenges and issues that affect their participation. HIV-infected women not only feel isolated and discriminated against by the community but they also have to contend with bad-attitude health care workers in the hospital, distance to hospital, availability of drugs, and men who fail to play their part in HIV prevention and decline testing – all of which gives unique and varied colouring to the experiences of each individual.

5.4.3.1 Attitudes of health care workers

The attitude of healthcare workers is not infrequently a cause of frustration for women on Option B+. As reported, judgemental behaviour by healthcare workers gave rise to helplessness, lack of confidence and loss of trust in the face of betrayal by those whom participants most relied upon for help, though this was not always the case; some participants had no problem in this regard, saying that healthcare workers gave them the information they needed, treated them well and kept their privacy. Bad attitude on the part of health care workers, especially nurses, is not uncommon in Malawi, and is often cited in platform discussions. The problem has also been reported from other African countries such as in South Africa where the Department of Health (DOH, 2011) has established National Core

Standards for Health as a benchmark of care quality against which delivery of services can be monitored to card the problem. Health care attitude being the priority, the Core Standards ensure that patients are respected and their rights upheld, including getting access to needed care and to respectful, informed and dignified attention as seen from the point of view of the patient. Service improvements to meet these standards could be achieved through patient satisfaction surveys and input from patient complaints. Malawi might learn from this programme to its advantage in seeking to promote positive attitudes that will attract women to participate on Option B+ strategy.

Muula, Misiri and Tadesse (2007) found that in general attitudes of health workers towards HIV-infected women were favourable but that some of the nurses/midwives were themselves not sure what advice to give to HIV-positive antenatal women on Option B+ strategy. Lack of knowledge among health care workers can be stressful, especially when they have to deal with large number of patients as in Option B+ strategy. One participant put the blame for bad attitude on shortage of staff that makes nurses feel overwhelmed. Although Option B+ strategy is actually simpler to administer from a provider perspective, it may be reasonable to assume that nurses already providing PMTCT prophylaxis could switch to providing ART without additional human resources. However, nurses initiating pregnant women on ART may need more time to provide adherence counselling, which is lengthier for patients starting ART than for PMTCT (IATT, 2012). This should force the government to redefine strategies so that there are sufficient trained health care workers to manage the workload while at the same time motivating them to prevent burn-out and encourage provision of continuous positive care.

5.4.3.2 Distance to hospitals

In this study it emerged that distance to hospitals may significantly affect a patient's access to Option B+ strategy. Although none of the participants specifically cited distance as hindrance, some who lived further from the hospital mentioned financial constraints but were quick to insist that this had nothing to do with missing any hospital appointments. Participants in this situation, always devised solutions that would allow them to receive the necessary care, which might include borrowing money or combining hospital visits.

Successful implementation of Option B+ strategy usually requires initiation of ART by nurses and clinical officers in MNCH settings (IATT, 2012). In Malawi, this has ensured that the same unified and simplified ART regime is also administered in remote health care centres, thus bringing ART to the women and children who need it and giving support to extended ART access, as has been confirmed in the findings of this study.

5.4.3.3 Availability of drugs

A feasibility appraisal conducted by Malawi's Ministry of Health, HIV and AIDS unit (2009) prior to Option B+ strategy implementation recommended that the proposed implementation be done in phases. But what happened instead was massive country-wide policy implementation that achieved total programme roll-out in less than one year. The projected increase of people to be started on ARVs yearly had major implications for the Malawi government's capacity to sustain effective implementation of the initiative, not least in view of the obvious sharp increases in required quantities of drugs and supplies, numbers of health personnel, infrastructure, transport and logistics. Sustaining the increased number of women on lifelong treatment was a major concern at every level, especially for a donor-dependent country like Malawi.

Similarly in Uganda, serious concern was expressed that the country was not ready for Option B+ because the government could not sustain a secure supply of ARVs and was dependent on donor funding (Hsieh et al., 2013). In focus group discussions with women on Option B+ strategy in Uganda and Malawi, less concern was expressed about drug shortage in the latter country, where treatment is “always available”. A few Malawians did however express concern that aid to the country might be cut off at some time in the future, or that newer, better ARV regimes might not be universally available as promised. This is consistent with the findings of the present study, where none of the participants had ever experienced drug stock-outs.

5.4.3.4 Stigma and discrimination

Stigma and discrimination proved to be the most significant challenge to utilisation of Option B+ strategy for the participants and was directly related to the unrequested disclosure to them of their HIV status. The women felt stigmatised by health professionals while they were accessing HIV care, and it also appeared that they were more likely to be targets of stigma and discriminatory practices from healthcare workers during labour and delivery. They also felt stigmatized by partners on assumptions about their moral integrity, such as accusations that they became infected with HIV because of risky behaviours, on top of which they also had to contend with community stigma and discrimination. In the end stigma and discrimination continue to undermine prevention treatment and care of people living with HIV, hinder those with the virus from disclosing their status to their partners, and threaten their access to health care. On the other hand, healthier appearance from being on treatment, and breastfeeding their children for longer, could also mean that Option B+ strategy would reduce the stigma and discrimination they have to contend with (Hsieh et al., 2013).

Stigma and discrimination exist in our societies in Malawi but evidence has shown that there is continuing decrease (Malawi government, 2012), supporting the picture that emerged in this study where it was roughly half of the respondents who reported being gossiped about and only a minority who suffered verbal and physical insults. Stigma and discrimination being a long-standing issue, collective effort is called for from politicians, policy makers, civil societies, opinion leaders and the general public, including PLWHIV, to eliminate stigma and discrimination if the Option B+ goal of eliminating HIV is to be realised.

5.4.3.5 Men not going for testing

Participants believed that their partners were part of the HIV problem and therefore needed to be part of the solution too. All participants mentioned that their partners did not accompany them when they went for HIV testing and even though they knew the women's HIV status, none had gone for HIV testing. They realised however that their efforts to prevent further spread of the virus would not be effective if the HIV status of their partners remains unknown. One participant suggested that men choose not to get tested because they think there is no point if they have already been infected by the woman. These possibilities differ from reported reasons in the literature such as low perceived risk of infection and fear of being tested (MacKellar et al., 2011). ANC and PMTCT settings are an ideal entry point to offer HIV counselling and testing for partners and family members of pregnant women living with HIV. Inviting male partners to get tested for HIV can influence the uptake of PMTCT services by promoting communication and disclosure of HIV status and yet this doesn't seem to happen.

As heads of households men need to play an active role in PMTCT as was illustrated in the case of the study participant who considered consulting her husband about HIV testing. Targeting men with HIV and AIDS education, including instruction on PMTCT, and

encouraging them to become more involved in the health of their partners and children could bring about a dramatic improvement in the success of the strategy. It is also possible that some men do go for HIV testing but find disclosure as difficult as the women do. This proved the case for one participant, whose husband had been on ART without her knowledge and only disclosed when she did. Men may also be in desperate need of counselling to promote disclosure; hence the need to promote couple counselling in PMTCT.

The benefits of testing heterosexual couples have also been highlighted by research: testing couples together facilitates mutual disclosure, can increase uptake and adherence with antiretroviral interventions for PMTCT, promotes condom use within the family (Farquhar et al., 2004), strengthens links with care facilities, and can increase the preventive benefits of testing.

5.5 Adherence on Option B+ strategy

Adherence among HIV-infected pregnant and postpartum women is probably the most challenging issue, and has significant implications for the success of the lifelong treatment (Besada et al., 2012) that is recommended with Option B+ strategy.

5.5.1 Till death do us part

5.5.1.1 Experience vs. Inexperience

Option B+ strategy is a long process involving both medications and a cascade of interventions that include health monitoring for mother and child through CD4 count testing, WHO staging, HIV testing for the child at different stages, monitoring side effects of ARVs, changing ARVs from first line if need be, referrals, and ongoing counselling on nutrition. When women are recruited under the PMTCT Option B+ programme, they accept a lifelong partnership with the health professionals who take them through the whole process. “Till

death do us part” was derived as a theme in this study from the reference made by participants to PMTCT Option B+ strategy as being a lifelong commitment like marriage. All participants showed anxiety when talking about the lifelong commitment but there was a remarkable difference between those with longer experience of an HIV diagnosis (amounting to as much as four years in one case) and those with less experience (just a few months). There was a corresponding range in their experience of the treatment regime, with some having only recently been initiated on Option B+ strategy and some who also had prior experience on Option A.

When the participants initially were told that Option B+ strategy was a lifelong commitment the meaning did not always sink in immediately, but as time went on the full implications aroused more and more emotional stress. Even those with more experience to draw on were not convinced that it had to be lifelong treatment. This confirms how poorly these women are prepared: despite their willingness to participate they lack vital information on Option B+ strategy. The less experienced women had a tougher time dealing with the reality; for one woman it was impossible to grasp the notion that she needed to go on lifelong treatment while she was still healthy. It is important to note that for patients in resource-limited settings like Malawi, there is radical departure in messaging where the previous advice to patients had been to wait until their CD4 cell count was low before they started ARVs (Ahmed et al., 2013). Public consultation and education has not been sufficient in clarifying the need for this shift of strategy.

Participants said that the hardest part of Option B+ adherence for them was accepting the notion of a drug dependent life. Most seemed to find this distressful, with one feeling she might have no chance of getting married if a man found out that she was on life-long ARVs. In Uganda most women on Option B+ revealed during focus group discussions that after the

birth of their children they would stop the medication because their only reason for agreeing to start ARVs had been to protect their children, while others planned to stop when their CD4 cell count was sufficiently high (Hsieh et al., 2013). Although there is no literature supporting this finding for Malawi, adherence issues were obvious in the study and the current statistics on loss to follow-up may well point to the same conclusion. Reversing the situation will require adherence support mechanisms, including task shifting for ART initiation.

5.5.2 Support systems

Support systems are important in the coping strategies that participants use for handling the psychological stress of being on Option B+ strategy, as discussed previously, and also in the provision of necessary physical care and advice. It has been found that psychological distress can be associated with behavioural problems in children as well as impairment of physical and cognitive development (Avan, Richter, Ramchandani, Norris and Stein, 2010); in the context of HIV it has been suggested that support systems have a positive influence on health behaviour outcomes, adherence, and safer sexual behaviour. For this reason women should be encouraged to seek support in order to minimise the level of psychological distress they experience. Sources of support reported by participants included more informal support from partners, family and friends as well as formal support generated from the health care system.

5.5.2.1 Informal support

Most participants spoke in very positive terms about informal support, with broad consensus that friends and family gave them courage and strength to move on. Informal discussions and simply talking about their feelings and experiences were much valued. Family were a source of both psychological and physical support, which could be nutrition or it could be someone to remind them to take medications – although this could not always be said of participants' partners. Some women reported that their husbands failed to provide for their basic needs

because of mistrust and overall disturbance in the family structure due to the infection. Participants who did not have support from partners exhibited more stress behaviour than their counterparts. Contrary to the findings in this study, literature has also identified contact and interaction with other HIV-infected individuals as a valuable source of informal support (Moneyham et al., 1998) for combatting the isolation that often results from the stigmatising aspects of the disease. This form of support relies on individual women actively seeking the support from others; women in this study would consequently not appreciate this form of support, as disclosure of HIV status was their major concern.

The participants stressed the necessity of a support system when they went for HIV testing, believing that more support would have made the experience less traumatic and would have helped them to absorb the education, instruction and advice from the hospital, much of which they had not understood.

5.5.2.2 Formal support

The presence of formal support structures in the hospital and in the community was confirmed from the study. What also emerged, however, was that even though participants craved support, they were not making use the already established sources of support within reach. Apart from the normal scheduled hospital visits where support was given by health professionals, not all participants knew that additional support structures existed. An NGO located on the premises of the hospital meets with women as soon as they are enrolled on Option B+ strategy but the continued support it offers depends on commitment by the patient, which was a problem for the women in the study. Community support groups to cater for their psychological, social and physical needs had also not been utilised by the women, and reluctance to access and utilise support services usually had at its root the problem of disclosure of HIV status.

Information about the range of support possibilities available within the hospital and community should be included in post-test counselling and ongoing counselling to HIV-positive women with particular focus on help with disclosure. Failure to disclose HIV status has profound consequences and the importance of supporting women in the acute dilemma they often face in this regard cannot be overemphasised

5.6 Conclusions of the study

Data to explore the objectives of this study was obtained through in-depth interviews conducted with five HIV-positive women on Option B+ strategy. The challenges they faced and their coping strategies were revealed, and what most notably emerged was the emotional toll on women participating on Option B+ strategy. Participants identified the lifelong commitment as the most challenging part of the PMTCT Option B+ process, which made worse by failure (as they saw it) to involve them in their own care.

This study indicated the importance of adequate knowledge and understanding of Option B+ strategy on the part of the women involved. Lack of knowledge seemed to be the biggest setback in the PMTCT process; the less the women understood about Option B+ strategy, the less likely they were to accept their HIV status, participate, adhere and cope throughout the process. The effectiveness of Option B+ strategy depended on how prepared the women were both psychologically and through education. The women in the study who had longer experience of PMTCT expressed less anxiety about the programme, which underlines the importance of knowledge, understanding, preparation and readiness for all women on Option B+ strategy.

This study revealed that the 'opt-out' option in Option B+ strategy places women in a vulnerable position that significantly affects their participation. Provider-initiated HIV testing without preparation and choice on the side of the mothers brings with it issues of human

rights conflict and no real conclusion could be drawn regarding the approach to testing. Irrespective of problems associated with the approach to HIV testing, women nonetheless appreciated additional time spent with health professionals helping them to accept and cope with their participation on Option B+ strategy.

Disclosure was found to be the major obstacle on Option B+ strategy. Not only did it determine whether the participants got the necessary psychological, social and physical support but it also affected efforts to minimise further spread of HIV. Fear of involuntary disclosure was indicative of failure on the part of the health care system to protect the privacy of women participating on Option B+ strategy. Lack of male involvement in PMTCT was an additional discouragement to disclosure, and gave rise to violence and blame within families.

Particularly highlighted by the findings was women's commitment to protecting their children from getting infected with HIV, but fixation on the children's welfare as the sole motivator points yet again to a gap in their preparedness to deal with the phenomena and leaves room for doubt whether they would adhere on Option B+ strategy in long-term. Notwithstanding the sociocultural factors identified, women nonetheless gave proof of their sense of social responsibility in the endeavour to prevent further spread of HIV.

Factors identified as affecting participation on Option B+ strategy included attitudes of health care workers, distance to hospitals, availability of drugs, men declining HIV testing, stigma and discrimination.

Formal support within the hospital and community was not being utilised by participants on Option B+ strategy, who mostly relied on informal sources of support such as friends and family as they struggle with the commitment to stay on Option B+ strategy.

5.7 Recommendations

The recommendations presented in this chapter are based on the findings from this study and other published studies in literature that informed the study discussion. The recommendations highlight gaps in education, practice and policy, as well as possible areas for future research.

5.7.1 Knowledge and understanding of Option B+ strategy

During the interview process, participants showed inadequate knowledge and understanding of Option B+ strategy. This was found to be partly because comprehensive education on Option B+ strategy is focussed on women attending antenatal care for the first time and targeted for HIV testing, meaning that women have just a single exposure to the rich information. Nurses need to make the comprehensive Option B+ strategy a routine education topic, so that all women accessing the hospital for other services too, such as family planning or under-five clinic, have an opportunity to learn about the new PMTCT option, thus disseminating generalised knowledge and understand of the Option B+ strategy within the community. Women on Option B+ strategy need ongoing counselling to address issues they are going through and there needs to be an emphasis on information-giving sessions for empowerment.

The ‘opt-out’ approach in Option B+ strategy needs to be practised as per recommendations. The participants expressed concern that being tested for HIV without being given a choice was untimely and stressful. Nurses committed to the ‘test and treat’ model for preventing missed opportunities also need to respect the women’s choices and rights. With adequate information women will be in a better position to make an informed decision on getting tested, which may enhance adherence to the programme.

Preparatory classes need to be considered in Option B+ strategy as is done for ART. Women who are tested for HIV need to be given a further date to return for comprehensive education

and initiation of ART. This will also give them more time to accept their HIV status and prepare themselves psychologically for the commitment. Women who come back for education and initiation would thereby show their commitment to start the medications and go through with the Option B+ process, creating greater confidence within the system that the women being recruited understand what the implications are. It can be recommended that as the Option B+ strategy programme rolls out, a principal target should be retention, otherwise women who are unwilling to participate will eventually default and be lost to follow-up, rendering the programme ineffective.

5.7.2 Accepting the HIV-positive status

Disclosure of HIV status by women on Option B+ strategy proved to be a challenge. There is need for disclosure education to be emphasised during post-test and ongoing counselling to women on Option B+ strategy. The culture of silence as far as HIV is concerned need to be discouraged because it challenges the efforts in HIV prevention. Disclosure for many women proved effective in obtaining the necessary support from friends and family, and those who did not disclose their status craved for support with disclosure highlighting the need for health professional to spend time with the women educating, counselling and supporting them with disclosure.

Male involvement in Option B+ strategy is a very important component that needs to be critically analysed. National policies and procedures for testing and treatment of male partners of pregnant and lactating women should be clarified as part of the process of Option B+ strategy. Equal treatment of men and women on Option B+ strategy will encourage more partners to come to the hospital. If 'test and treat' is the approach for Malawi then it needs to be standardised to include both men and women, since men have an equal chance of re-infecting their partner. Partner counselling and testing should be emphasised for antenatal

women because it will encourage both disclosure and acceptance of HIV status, it will promote preventive strategies and it will minimise partner violence.

Although adequate preparation of women on Option B+ strategy would help them in coping with their HIV status and participation, health professionals also need to promote active coping strategies such as seeking social support among women. Active coping mechanisms will also minimise psychological effects on the women and promote their health.

5.7.3 Sociocultural factors affecting HIV-positive women on Option B+ strategy

The lack of knowledge that women showed in the study suggests lack of knowledge on the part of the health care workers as well, since Option B+ strategy is a new phenomenon and in-service trainings are also needed for updating nurses, clinical officers and other cadres on ART management. Well-informed health professionals will be in a better position to support women on the programme, and the continuing professional development (CPD) programme in Malawi will promote this process. Other than the in-service training, new responsibilities related to ART management need to be included by educators in the nurses training curricula. ART initiation is a new task for nurses in Malawi and pre-service training curricula need to be updated to reflect Option B+ strategy guidelines, policies and protocols.

The Ministry of Health may benefit from adopting South Africa's National Core Standards to improve attitudes of healthcare workers dealing with women on Option B+ strategy. The National Core Standards, which is a benchmark of quality care against which delivery of services can be monitored, would ensure that patients are respected and their rights upheld, including access to needed care and to respectful, informed and dignified attention as seen from the point of view of the patient. The government can achieve this through patient satisfaction surveys and dialogue to establish what concerns they have for improvement of Option B+ strategy services.

The government needs to consider investing in additional human resources, especially nurses that would enable the PMTCT programme to deal with Option B+ strategy workload. It was discovered from literature that although the health professionals who were initially working on PMTCT initially easily switched to Option B+ strategy, the support that women require on Option B+ strategy may be more than for Option A. Lengthy counselling, ART initiation and ongoing support all require more human resources to eliminate long hospital waiting times that may eventually affect women's participation.

Participants' concerns about not being involved in their own care poses a major challenge for Option B+ strategy. According to the participants, this began with Government's initial failure to consult the service users before adoption of the service and it continues throughout the continuum of care. Even though Option B+ strategy is already in implementation, Government needs to engage with the community, consulting and educating them on Option B+ strategy. Targeting the community and its leaders will help to spread grass-roots awareness of Option B+ strategy and enhance acceptability. Women also need to be given an opportunity to evaluate the programme's effectiveness in their own terms. Hospitals need to devise ways of seeking feedback from the women who are utilising the service, which could include surveys, anonymous comments and meetings with stakeholders. This would help to deal with women's major concern: not being involved in their own care.

Empowerment of communities and their leaders will motivate them to take action on issues such as reducing the stigma and stigmatisation reported in the study, motivating men to go for testing and be actively involved in PMTCT, promoting disclosure of HIV status, speaking against gender-based violence, and backing support for women on Option B+ strategy.

5.7.4 Adherence on Option B+ strategy

Women on Option B+ strategy need to be introduced to formal support available within the hospital and community. Better linkage to support and care structures would enhance overall psychological, social and physical support for women as they cope with their participation on Option B+ strategy.

5.8 Recommendations for further research

This research was a small-scale study conducted in a single rural district hospital; a similar study in another setting could give a more extended picture of how widespread the views and experiences recounted here might be.

Male involvement was found to be an important component on Option B+ strategy but men's experiences with Option B+ strategy have never been explored. There is a strong case for further research targeting partners of women on Option B+ strategy to explore their knowledge, understanding and experiences with the Option B+ programme.

All the women who were interviewed were still on the Option B+ strategy. A study would be recommended to follow those women classified as lost to follow-up to get experiences and reasons of dropping out of the programme. These results would give a true picture of the experiences that would eventually collapse the Option B+ strategy.

5.9 Limitations

This study reflects the experiences of only five volunteer participants. The data obtained from the interviews were limited to what the participants were willing to share about their experiences on Option B+ strategy.

The interviews were conducted within the hospital premises, which might have been a bit intimidating for some participants since their experiences involved criticising the healthcare workers and healthcare system as a whole while they were still receiving care. This fear may have influenced the responses from participants.

The experiences in this study may therefore not be representative of all HIV-positive women on Option B+ strategy and cannot be generalised beyond the context of the study.

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Annexure A: Participants' Information Sheet and Informed Consent

Greetings,

My name is Aliko Mmanga; I am a student at the University of KwaZulu-Natal, undertaking a Master's degree in Nursing (Maternal and child health). One of the requirements for the degree is to conduct a research project.

This letter serves to ask consent from you to take part in this research. The purpose of the research is exploring the lived experiences of HIV-positive women on PMTCT Option B+ Strategy. This will help to understand the experiences that women go through while receiving PMTCT care on Option B+ strategy will the purpose of providing recommendations for improved programme performance.

Your participation is completely voluntary and you are free to withdraw from the study at any point without any consequences. You will not be paid for your participation in the study and you will not be required to pay anything in order for you to participate. If you agree to participate you will take part in an in-depth interview lasting 30-45minutes, the interview will be recorded. Your privacy will be maintained at all times and only the researcher and supervisor will have access to the information you provide. The anonymity will be ensured by having pseudo identification on the data collection tool so that information cannot be traced back to you. The confidentiality will be guaranteed through secure storage of the filled in data collection tools in a safe and locked place for a period of 5 years, in the School of Nursing at the University of KwaZulu-Natal and only the researcher and research supervisor will have access to the data collected.

If you do decide to participate there will be no direct benefits to you, however, your contribution will help the PMTCT programme in future. If there are any questions that you do not feel comfortable with, you are free to not answer. In addition, if after the interview any questions made you uncomfortable we will have a counsellor available to talk with you to help you through any stress you may have experienced. You will be required to sign two letters of declaration consent form if you agree to take part and you will keep one copy while I keep the other for my records.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (Protocol number BE260/13) and National Research Council of Malawi (Protocol number NHSRC 1186).

In the event of any problems or concerns/questions you may contact the researcher or researcher at the following contact details:

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Tel: +27312603311. Email:debeej@ukzn.ac.za

Research ethics: Biomedical Research Ethics Administration
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban, 4000. KwaZulu-Natal, SOUTH AFRICA
Tel: +27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
National health sciences research committee
P.O Box 30377
Lilongwe 3,
MALAWI.

DECLARATION OF CONSENT TO PARTICIPATE IN THE RESEARCH

I _____ have been informed about the study entitled exploring the lived experiences of HIV-positive women on PMTCT Option B+ Strategy by Miss Aliko Mmanga.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have given permission to the researcher to audiotape the interview.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact the researchers on the details provided.

Signature of participant

Date

Signature of witness

Date

Annexure B: Participant Interview Guide

Participant demographics

1. How old are you?
2. Are you married?
3. When did you know your HIV status?
4. How long have you been on Option B+ strategy?
5. Who else knows your HIV status?

Essential questions

Variations of the following questions will be used to solicit views and experiences from participants

- Tell me about your experience related to prevention of mother to child transmission of HIV on Option B+ strategy
- How do you feel about your participation in Option B+ PMTCT strategy?
- What are some of the issues and concerns that you have on Option B+ strategy?

Probes and prompts

Probing questions and probes will be used during the interview process based on participant responses

- How does that make you feel?
- So how do you handle that?
- Is there anything further you would like to tell me?

Annexure C: Mfundo zogwiritsa ntchito pokambirana ndiotenga nawo mbali

Mbiri ya otenga nawo mbali

1. Kodi muli ndi zaka zingati?
2. Kodi muli pa banja?
3. Kodi munadziwa liti kuti muli ndi kachiroombo koyambitsa matenda a edzi?
4. Kodi mwakhala nthawi yayitali bwanji pa ndondomeko ya mankhwala ama ARV?
5. Pali wina amene akudziwa zoti muli ndi kachiroomboka?

Mafunso ofunikira

Mafunso otsatirawa agwiritsidwa ntchito kufuna kudziwa zovuta ndi zinthu zomwe otenga nawo mbali akukumana nazo?

- Tandiuzeni zomwe mukudziwa zokhudza njira zotetezera mwana ku kachiroombo ka HIV zokhudza ndondomeko ya mankhwala ama ARV?
- Kodi inu mukunva bwanji pakutenga nawo mbali kwanu mu ndondomekoyi?
- Nanga ndi zinthu ziti komanso zovuta zANJI zomwe mumakumanazo pa ndondomekoyi?

KUFUFUZA NDI KUFUNA KUDZIWA

Mafunso ofufuza ndi kufunsa zizagwiritsidwa ntchito kutengera ndi momwe otenga nawo mbali akuyankhira

- Kodi zinthuzi zimakupangitsani kunva bwanji
- Kodi nanga munachivomereza bwanji?
- Kodi pali mau ena amene mugafunenso kundiuza?

Annexure D: Request letter for ethical clearance to Research Committee, University of KwaZulu-Natal

The Research Committee
University of KwaZulu-Natal
May 2013

APPLICATION FOR APPROBATION OF A RESEARCH PROPOSAL

I hereby apply for an ethical clearance for my research proposal titled:

“Exploring the lived experiences of HIV-positive women on PMTCT Option B+ Strategy in a selected district hospital in Malawi”.

I am a Malawian student, undertaking studies to obtain a Master’s in Nursing: Advanced midwifery, maternal and child health at the University of KwaZulu-Natal in the School of Nursing and public health. One of the requirements for the degree is to conduct a research project.

The district hospital was purposively chosen to be the setting for this study. Data will be collected from pregnant and breastfeeding women receiving care on PMTCT Option B+ strategy. Participants will be required to provide an account of their experiences through an in-depth interview with the researcher. This protocol will also be submitted for ethical clearance in Malawi for approval and permission will be sought from the selected hospital.

The research protocol, the data collection tools and the consent form for participants are enclosed herein. The informed consent for participants shows that participation is voluntary and how the rights and identity of the patients will be protected in the research process. The process will not interfere with daily work and flow of patients at the hospital.

Your consideration will be greatly appreciated.

Yours faithfully

Aliko Mmanga

Cell: +27748089722

Email: alimmanga@yahoo.com

Research Supervisor: Dr. J. de Beer (University of KwaZulu-Natal)

Tel: +27312603311

Email: debeej@ukzn.ac.za

Annexure E: Letter of approval from Biomedical Research Ethics Committee, University Of KwaZulu-Natal



29 August 2013

Ms AR M'Manga
140 Evans Road
Glenwood
Durban
4001
alimmanga@gmail.com

Dear Ms M'Manga

PROTOCOL: Exploring the Lived Experiences of HIV Positive Woman on Prevention of Mother to Child Transmission (PMTCT) Option B+ Strategy in a Selected District Hospital in Malawi. REF: BE260/13.

EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 11 July 2013.

The study was provisionally approved pending appropriate responses to queries raised. Your responses dated 17 August 2013 to queries raised on 14 August 2013 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 29 August 2013.

This approval is valid for one year from 29 August 2013. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its next meeting taking place on **08 October 2013**.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor D.R. Wassenaar
Chair: Biomedical Research Ethics Committee

Professor D Wassenaar (Chair)
Biomedical Research Ethics Committee
Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 2384 Facsimile: +27 (0)31 260 4609 Email: brec@ukzn.ac.za

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

Founding Campuses: Iligweod Howard College Medical School Pietermaritzburg Westville

INSPIRING GREATNESS



Annexure F: Request letter for ethical clearance to National Health Sciences Research Committee, Malawi

The Chairman
National Health Sciences Research Committee
P.O Box 30377
LILONGWE, MALAWI

University of KwaZulu-Natal,
Howard College Campus,
School of Nursing and Public Health
Desmond Clarence Building, 5th Floor
4041, DURBAN,
SOUTH AFRICA

May, 2013

Dear Sir

APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH STUDY

Research Topic: Exploring the lived experiences of HIV-positive women on PMTCT

Option B+ strategy in a selected district hospital in Malawi

I wish to request permission to conduct a research project at Mchinji District Hospital.

I am a 29 year old Malawian female who is currently studying Masters in Nursing: Maternal and Child Health –Coursework in South Africa. Part of the requirement for my studies requires that I conduct a research project in my area of my interest.

Mchinji District Hospital was purposively chosen to be the setting for this study. Data will be collected from pregnant and breastfeeding women receiving care on PMTCT Option B+ strategy. Participants will be required to provide an account of their experiences through an in-depth interview with the researcher. This protocol has been submitted to the Research Ethics Committee of the University of KwaZulu-Natal and upon your approval permission to conduct the study will also be sought from Mchinji District Hospital.

The research protocol, the data collection tools and the consent form for participants are enclosed herein. The informed consent for participants shows that participation is voluntary and how the rights and identity of the patients will be protected in the research process. The process will not interfere with routine work and flow of patients at the hospital.

Your consideration will be greatly appreciated.

Researcher: Miss Aliko Mmanga

Cell: +2774 808 9722

Email: alimmanga@yahoo.com

Research Supervisor: Dr. Jennifer de Beer

Tel: +27312603311

Email: debeej@ukzn.ac.za

Annexure G: Letter of approval from the National Health Sciences Research Committee, Malawi

Telephone: + 265 789 400
Facsimile: + 265 789 431
e-mail doccentre@malawi.net
**All Communications should be addressed to:
The Secretary for Health**



In reply please quote No. MED/4/36c

MINISTRY OF HEALTH
P.O. BOX 30377
LILONGWE 3
MALAWI

9th July 2013

Aliko Rose Mmanga
University of KwaZulu-Natal

Dear Sir/Madam,

Re: Protocol # 1186: Exploring the lived experiences of HIV positive women on PMTCT Option B+ strategy in a selected district hospital in Malawi

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER** : NHSRC # 1186
The above details should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : 9/07/2013
- **EXPIRATION DATE** : This approval expires 08/07/14
After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING** : All serious problems having to do with subject safety must be reported to the National Health Sciences Research Committee within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using standard forms obtainable from the NHSRC Secretariat is required before implementing any changes in the Protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on Telephone No. (01) 724418, 0888344443 or by e-mail on moh@gmail.com
- **Other**:
Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database.

Kind regards from the NHSRC Secretariat.


.....
FOR CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

PROMOTING THE ETHICAL CONDUCT OF RESEARCH
Executive Committee: *Dr. C. Mwansambo (Chairman), Prof. E. Molynux (Vice Chairperson)*
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
(IRB Number IRB00003905 FWA00005976)

Annexure H: Request letter to conduct study at Mchinji District Hospital

The District Health Officer
Mchinji District Hospital
P.O Box 36
MCHINJI, MALAWI

University of KwaZulu-Natal
Howard College Campus, School of Nursing
and Public Health
Desmond Clarence Building, 5th Floor
4041, DURBAN
SOUTH AFRICA.

May 2013

Dear Sir:

Application for approbation of a research proposal

I hereby request the approbation of my research proposal by Mchinji district health office.

I am a Malawian student, undertaking studies to obtain a Master's in Nursing: Advanced Midwifery, Maternal and Child Health at the University of KwaZulu-Natal in the School of Nursing and public health. One of the requirements for the degree is to conduct a research project.

The title of the research is "Exploring the lived experiences of HIV-positive women on PMTCT Option B+ Strategy in a selected district hospital, Malawi".

The district hospital was purposively chosen to be the setting for this study. Data will be collected from pregnant and breastfeeding women receiving care on PMTCT Option B+ strategy. Participants will be required to provide an account of their experiences through an in-depth interview with the researcher. This protocol has been submitted to the Research Ethics Committee of the University of KwaZulu-Natal and the Ministry of Health research unit for approval.

The research protocol, the data collection tools and the consent form for participants are enclosed herein. The informed consent for participants shows that participation is voluntary and how the rights and identity of the patients will be protected in the research process. The process will not interfere with daily work and flow of patients at the hospital.

Your consideration will be greatly appreciated.

Yours faithfully

Aliko Mmanga

Cell: +27748089722

Email: alimmanga@yahoo.com

Research Supervisor: Dr. J. de Beer (University of KwaZulu-Natal)

Tel: +27312603311

Email: debeej@ukzn.ac.za

Annexure H: Letter of approval from Mchinji District Hospital

Our Ref: MDH/RC/ 13/ 001

All correspondence through the DHO

mcdho@sdp.org

Phone: (01) 242 310 / 906

Fax: (01) 242 442



Ministry of Health

Mchinji District Hospital,

P. O Box 36,

Mchinji.

28th May 2013

TO WHOM IT MAY CONCERN

Dear Sir/ Madam,


RE: MISS ALIKO MMANGA'S RESEARCH

The bearer of this letter requested if she could carry out her research titled "**Exploring the lived experiences of HIV positive women on PMTCT Option B+ Strategy in a selected district hospital in Malawi**" at the Mchinji district hospital.

The district research committee sat down and reviewed her research proposal and has granted her permission to her request considering that her study is in our research area of interest.

Please take note that she will only be allowed to proceed with her research upon production of letters of approval from her university research committee and the research and ethics committee of the Ministry of health, Malawi.

Yours sincerely


S. Julius

For the District Health officer



Annexure I: Sample of in-depth interview with participant.

Transcript for an in-depth interview with Monica

Interviewer: Thank you for accepting to take part in this research, so feel comfortable because whatever we will discuss here will be private and confidential like I already said. So for the sake of this interview you will tell me a fake name that we should use.

Participant: Monica

Interviewer: OK Monica, How are you?

Monica I am fine and you?

Interviewer: I am also fine. How old are you?

Monica: I'm 19 years old

Interviewer: Are you married?

Monica: No, I am not married

Interviewer: Boyfriend?

Monica: Mmmh no... *[Laughs]* no, I don't. He disappeared.

Interviewer: After the pregnancy?

Monica: Yeah, guess he was one of the irresponsible ones. We were together for 8months, he was promising a lot and I thought we could build a family together but when this *[pointing at the belly]* happened he completely changed started acting up and disappeared later. Haven't seen him since.

Interviewer: Is this your first pregnancy

Monica: Yes it is and probably my last *[smiles]*

Interviewer: Why do you say that?

Monica: One is enough, isn't it? *[Laughs]*

Interviewer: *[Laughing]* Ok, so how far did you go with your education?

Monica: I dropped out in Form 2.

Interviewer: Form 2? Why did you drop out of school?

Monica: It was because of lack of financial support. My father died when I was in standard 8 and my mother managed to support me for two years, then later things became tough. I had to drop out of school and help her raise my siblings. It was the only choice.

Interviewer: So who do you stay with at the moment? Who supports you?

Monica: I stay with my mother, we support each other if I may say

Interviewer: When did you know about your HIV status?

Monica: Uum, it was when I came here to start antenatal care almost 6months ago.

Interviewer: Take me through that day, what happened?

Monica: Well I remember I came alone that morning, it was my first time so I was exceptionally early because I didn't know how the clinic operated. The clinic started a bit late because we waited to some time. At the beginning of the clinic we were all placed in one room and we sang songs and then they taught about a lot of issues including HIV and AIDS. Then we were told that for those coming for the first time we will go through to another room while the rest were also directed somewhere else. I really didn't have any expectations for this visit, it was after I went into the room that I realised that we will be tested for HIV.

Interviewer: What happened in that room?

Monica: It was a small group that went through and what happened was that they started by counselling us about HIV again but this time in detail, the advantages and disadvantages and how we would pass the virus to the baby and the issue of Option B+ strategy was brought in saying whoever is found HIV-positive will be put on ARVs for life. That was the very first time it dawned to me that we will be tested for HIV. I did not pay much attention really because I thought it wasn't relevant to me. Then blood samples were collected from each one of us and we were called one by one to receive our results.

Interviewer: You are talking as if you had no choice

Monica: Exactly, there was no choice, none whatsoever, not a chance. It was more like being told than asked.

Interviewer: and what was going through your mind at that moment

Monica: When I was waiting for the results outside that's when I really thought about what just happened. I could see people coming out after receiving their results and I could tell who received bad news [*clears throat*]. A million things run through my mind at one point I thought of just abandoning the queue and go home.

Interviewer: What made you think that?

Monica: The truth is, I was not ready. It is not easy I promise you. By that time I had never been tested for HIV, it was my first time and I was scared and yet there was nothing I could have done. There was no time to even get my head straight and prepare myself for a possibility of HIV-positive results.

Interviewer: how much time do you think would have helped you make the decision to get tested.

Monica: I could have made the decision at that time but the only problem is that it came as a surprise.

Interviewer: and how did that make you feel?

Monica: Powerless I guess, I was just weak to my bones. Thinking I would have made the decision myself and yet I couldn't.

Interviewer: Then what happened next

Monica: My name was called and I went in. Since they had already taught us how a positive HIV result would look like I saw it on the table but I convinced myself that it wasn't mine until the counsellor spoke [*She avoided eye contact and became emotional*]. Then she picked the results from the table and showed me, it was a moment of truth.

Interviewer: How did you feel at that moment?

Monica: [*staring blankly*] there is no better word to describe the feeling. It's almost unreal you know, terribly unreal. I thought the nurse was playing a sick joke on me but of course not.

Interviewer: What was the real reason for your worry?

Monica: I was in shock I guess from thinking it can't happen to me then reality struck. The terror came in as a realisation that life will never be the same again. For a moment my mind had a flight of ideas, almost getting me excited but none of it included curing the HIV. I realised there is no cure [*pauses*] felt like reaching a dead end.

Interviewer: and how did that make you feel?

Monica: I was disappointed, I felt like I had disgraced my parents because there is no parent who wants to see their children suffering. Yes my mind went that far.

Interviewer: so after you received your results what happened?

Monica: Then she talked about Option B+ strategy and medications and hospital delivery and preventing transmission and a whole lot. Its was just too much information and the next minute she gives me bottles of medications... ARVs and how I should be taking them, coming for refills and reporting sight effects [*sighs*]... phew it was too much.

Interviewer: so in other words, she was preparing you for Option B+ strategy

Monica: You could say that

Interviewer: You don't sound convinced, do you think the preparation was enough?

Monica: To tell the truth, the first time we were being educated on HIV and Option B+ strategy I had not tested for HIV so I was not paying much attention because I didn't think it was relevant to me. The second time it was right after I received my positive HIV results and honestly I was not listening because there were a lot of things going on in my mind.

Interviewer: How would you have liked the education or the preparation be done in general

Monica: I believe preparation is very important for this strategy but my only problem is that it is not easy to understand the education when you are not in the right state of mind. From testing HIV-positive to lifelong treatment, it is a lot to take in. I wish there was time set aside for education, so that one has time to meditate, understand and make a decision.

Interviewer: what other issues went through your mind then?

Monica: I have seen HIV-positive patients before and that is how I pictured myself in a few weeks ahead, the faces of those sick AIDS patients I saw flashed in my mind [*Pauses*]... it was absolute terror. I was also thinking how I was going to tell my mother and how she would receive the news.

Interviewer: Did you say you came alone to the hospital that day?

Monica: Yes I came alone to the hospital that day, much as it was my first time and my first experience I didn't think it was a big deal. My mum wanted to escort me but I declined, anyway, I didn't realise how much I would need her after the diagnosis, it was so heavy on me. I needed someone to be there to help me through.

Interviewer: Do you think it would have been different if you had someone?

Monica: I believe so, if there was someone with me that time I wouldn't have done what I did, am sure that someone would have talked sense into me.

Interviewer: What happened?

Monica: [*laughing*] I did not take it very well, you can imagine I went to the hospital and I am coming back with these bottles of medications. I did not even want to go home that day to avoid questions and suddenly an idea hit me, it seemed the only option at the point [*Giggles*] so I got rid of the medications along the way and went home like nothing happened.

Interviewer: You mean you threw away the ARVs you were given at the hospital?

Monica: Yes I did, I just found a rubbish pit along the road and yes I threw them in and went home.

Interviewer: How were you feeling on your way home?

Monica: I will tell you the truth, I was scared to go home to start with. In my mind I knew I had to tell someone, talk to someone... Uum, I did not know who. On my way home I kept thinking who would be the best person to talk to. I had not made the decision when I got home so I stayed for a week before confiding in my best friend of 11 years and later I told my mum.

Interviewer: So apart from your mum and best friend does anyone else know? What motivated you to tell your best friend other than your mum?

Monica: I was single, still am [*Laughing*] I knew my mum would be critical because she was not happy that I got pregnant in the first place, I knew it was only my best friend who would understand you know, and I considered my privacy also. I trusted my best friend to keep my secret better than anyone. Later on I realised that my mum would support me as much if she knew so I told her.

Interviewer: So how was your mother's reaction.

Monica: Even though she pretended to be strong about it I knew that she was hurt and it made we feel sad. But coming back to your question there is no one else who knows I believe but I can never be sure. Our neighbour is very talkative and I feel if she knew my status I would have no peace, she would tell everyone in the village and beyond. I do not want anyone else other than my family to know. If they ever know, it will not be from me.

Interviewer: How do you feel now that your mother knows your HIV status?

Monica: I feel good that I told my mother about my HIV status and participation in PMTCT Option B+ strategy. It gives me an opportunity to discuss with her issues that I wouldn't have if she didn't know my status. I am able to communicate when I have a problem, she takes good care of me. She is also my treatment partner because she reminds me to take medications on daily basis so I never forget

Interviewer: Talking of medications let me take you back to the ARVs you threw away on the first visit. What happened next?

Monica: I spent a month meditating on it until my next antenatal appointment. It all then sunk in, I realised the situation I was in and decided to act in the best interest of my baby. When I went back the next time I was more willing to start the medications, I was convinced I had made the right decision and I have not stopped ever since.

Interviewer: So how has your experience on Option B+ strategy been so far?

Monica: So far, it has been good. I am very happy because I know that my life and that of my child is protected, I get all the care and the advice I need.

Interviewer: do you have any worries or concerns?

Monica: I am worried at the thought that my life will depend on medications for the rest of my life, what kind of life is that? And I always think what would happen if I forgot to take the medication or anything happens?

Interviewer: Do you mean forgetting to take the medication? Or stopping.

Monica: No, I can't stop taking the medication because I want to protect my unborn child. I was told that once I stop, the chances of passing the virus to the baby may be high and I don't want that to happen.

Interviewer: It seems you are more concerned about the baby than anything else. Will you continue the ARVs once the baby is born?

Monica: [hesitation]... It's not like that, but the child is my number one priority at the moment.

Interviewer: I know you told me about the disappeared boyfriend, you knew his HIV status? Where do you think the infection came from?

Monica: We never went for HIV testing, I believe he is the one who infected me. I was young and naive I never thought such things do really happen. Not ever did I thought it necessary to go for testing and am sure wherever he is, he still doesn't know and is busy spreading the virus.

Interviewer: Do you think it would be useful to involve men in PMTCT programme?

Monica: I think so, they would also be tested and know their HIV status and it would be easier for them to support their wives if they had adequate information about PMTCT or HIV in general.

Interviewer: Given the opportunity to change the hands of time what would you change?

Monica: Well I regret getting pregnant, if I knew my HIV status I wouldn't have gotten pregnant in the first place but I knew after getting pregnant and there was no way out.

Interviewer: You wouldn't have gotten pregnant... why do you say that?

Monica: The whole Option B+ strategy is disappointing, we have no say [*sighs*] we are invisible in the system. Everything is laid out, like a play and we are in it.

Interviewer: How does that make you feel?

Monica: It's disappointing and feels hopeless but what can I do?

Interviewer: How do you deal with those feelings?

Monica: There is no way of dealing with such feelings, u just wish u never got pregnant in the first place like I said, otherwise there is no solution.

Interviewer: So what does it mean to you when you think that the ARVs are for the rest of your life?

Monica: Mmh it is difficult my sister, look at me now, just take a good look... [*Pauses*] ... do I look sick? Perfectly healthy, Well is do understand that we need to protect the baby from the infection blah blah blah, I get that but why me? why do I have to take the medication for the rest of my life? I am 19 years old I would want to get married later, Uum, I would surely disclose my HIV status to the future partner but telling him am on lifelong treatment too?

Interviewer: What is your fear?

Monica: He will believe I am that sick that they had to put me on medications forever. No one would want to marry me. Option B+ strategy may just as well be my partner for life.

Interviewer: I sense lack of commitment, will you make it to the end?

Monica: Mmh I don't know for now, will see when I get there *[Both laughing]*.

Interviewer: Ok tell me about your experiences with the hospital do you think you are getting the necessary care?

Monica: Well, they try their best

Interviewer: Explain more...

Monica: Sometimes the nurses and doctors are late in attending to us, we come to the hospital very early but we return late and sometimes they shout at us without showing love and yet a doctor is supposed to be loving to us patients *[Smiles]* I wish they were receiving patients with love so that we could also be coming here with open minds.

Interviewer: Do you think they treat you like that because you are HIV-positive? and how does the attitude make you feel?

Monica: I don't think so, that's how some of them *[referring to health professional]* are, it's not everyone I must say, just a selected few and it's like they are adding on more stresses in my life you know.

Interviewer: and how do you deal with it?

Monica: Its one of those you know, I just convince myself that it is for a short period of time and I will be out of here. I don't let it bother me.

Interviewer: Is there anything else that bothers you when you are receiving care here?

Monica: Sometimes I feel like receiving care on Option B+ strategy is indirectly disclosing my HIV status

Interviewer: Do you feel that your privacy is not taken care of in the hospital?

Monica: No not at all, there is privacy here *[Clears throat]*... Absolutely there is privacy here. But maybe since the counsellors come from the same communities we do... *[Laughs]* we can never be sure, but really, I don't think that is the case. It is just the presence here, feels like someone can see through you. The Mwai clinic that gives ARVs is right behind the antenatal clinic and sometimes you are asked to go there for some reason and you already become conscious. Maybe its paranoia, but it's a real feeling knowing that once people see me here they will speculate.

Interviewer: Have you ever felt like people are talking about you? How do you cope with all that?

Monica: Not directly, but it becomes so real when people are talking about it and you are thinking like Hello I also have it here you know, but once the episode is over and I am home I am in a completely different set of mind. It doesn't bother me much, it's like I have switched off the power button for a while *[makes a face]* it works!

Interviewer: Do people still stigmatise and discriminates HIV-positive people in the community? Or it is just mere talk.

Monica: Umh the stigma is not really there it's more talk, you know women but you know what they say, words are sharper than a double edged saw. Sometimes I feel like the problem is not them but us though. Well I am talking in general because it has never happened to me but I get the feeling that people are talking about me sometimes. I become suspicious and eventually I withdraw myself, so it's not anybody's fault really. It's more like discriminating yourself [*Laughs*].

Interviewer: How far do you stay from the hospital?

Monica: Not far, I walk

Interviewer: Have you ever had run dry of medications because the hospital had drug stock out?

Monica: No it has never happened

Interviewer: Which means ARVs are always in stock when you need them. Do you receive any other support from the hospital or community other than friends and family?

Monica: That is correct. Well, I know there is a support group for HIV people in my community but I am not a member, I am not ready to disclose my HIV status to people who have nothing to do with it. Maybe time will tell. There is also this group here in the hospital, I have forgotten their name but that are also willing to visit me at home.

Interviewer: Have they ever visited you?

Monica: No, I did not accept home visits so I just met them once or twice at their offices

Interviewer: Do you think joining such support groups would help you in any way?

Monica: I really don't know what they do but yeah maybe, I will join someday when I feel comfortable enough to do so.

Interviewer: So what are your plans, how many more children coming?

Monica: Maybe one more [*both laughing*]

Interviewer: Do you have anything else you would like to share with me concerning Option B+ strategy?

Monica: No, nothing I have pretty much said everything [*Smiles*]

Interviewer: Then that brings us to the end of the interview. Do you have any questions?

Monica: Uum, there is no question

Interviewer: Monica thank you so much for your time and I wish you all the best