

**PERCEPTIONS OF BREASTFEEDING MOTHERS ON FACTORS FOR
RETENTION IN HIV CARE AT THYOLO DISTRICT HOSPITAL, MALAWI**

MSc. Midwifery Thesis

By

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Submitted To Faculty Of Midwifery, Neonatal And Reproductive Health Studies, In Partial
Fulfillment Of The Requirement For The Award Of Master Of Science In Midwifery

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June, 2019

Declaration

I, the undersigned hereby declare that this thesis is my own original work which has not been submitted for any other awards at the University of Malawi or any other University, Where other people's work has been used acknowledgement have been made

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Full Legal Name

Signature

Date

Certificate of Approval

The undersigned certify that this thesis represents the student's own work and effort and has been submitted with my approval.

Signature_____ Date_____

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Dedication

I dedicate this thesis to my son Ryan Atusaye Kileta for being an inspiration to my life.

Acknowledgements

I am very grateful to God for seeing me through this process with good health. I could not have done this on my own. I really appreciate.

I am also grateful to my supervisor Dr. Martha Kamanga for being generous with expertise, time, patience and understanding during the development of this thesis. You are amazing!

I would like to thank management of Thyolo District Hospital for allowing me to conduct this research at their institution. I am also grateful to the mentor members for their help in tracing the loss to follow up mothers. My gratitude also goes to all participants of this study for their accepting to take part in this study. May God bless you all!

I am very grateful to KCN and USAID for a scholarship that enabled me to pursue the Masters course. I do not take it for granted. Thank you very much.

I am also thankful to my Husband Brian and son Ryan for the love, support and perseverance during the study period, you are so special. And also to my late mother Mrs. Jessie Jambo for the encouragement and support during the study period. You made such a huge contribution to my life, I wish you were here to witness the results of your hard work. May your soul continue resting in eternal peace.

Abstract

Retention in HIV care is the ability to adhere to critical aspects of care, according to health system standards and as prescribed by a health care provider. People on ART are supposed to continue accessing HIV care for life once they are started on ART. However, it has been revealed that most breastfeeding mothers stop accessing HIV care after the immediate postpartum period. Consequently, this has an effect on the life of the mother and the child who is being breastfed, as it increases risk of HIV reinfection and HIV transmission to the breastfed baby hence associated consequences. The aim of this study was to explore the barriers and facilitators to retention in HIV care among breastfeeding mothers at Thyolo district hospital. The specific objectives were: To describe the facilitators to retention of breastfeeding mothers in HIV care, to identify the hindrances to retention of breastfeeding mothers in HIV care after 6 weeks postpartum and to identify the expectations of breastfeeding mothers regarding retention in HIV care after HIV diagnosis. The study used qualitative data collection and analysis methodology. Data were collected from a purposive sample of 24 breastfeeding mothers through in-depth interviews. The data were analyzed using thematic analysis. This led to emerging the following themes 1) Improved quality of life, 2) Hospital and family support in HIV care, 3) Hindrances to retention in HIV care and 4) Lifetime commitment to therapy. The study found that breastfeeding mothers were motivated to remain in HIV care despite the hindrances they faced. Therefore this study recommends intense counselling of the breastfeeding mothers in the puerperium to promote retention in HIV care. In conclusion, breastfeeding mothers are retained in HIV care during the breastfeeding period with an aim of improving both maternal and child health.

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List of Abbreviations and Acronyms

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral therapy
ARV:	Antiretroviral drugs
COMREC:	College Of Medicine Research and Ethics Committee
DHO:	District Health officer
DNO:	District Nursing Officer
HAART:	Highly Active Antiretroviral Therapy
HIV:	Human Immunodeficiency Virus
HMIS:	Health Management Information System
KCN:	Kamuzu College of Nursing
MDHS:	Malawi Demography Health Survey
PMTCT:	Prevention of Mother to Child Transmission of HIV
UNAIDS:	Joint United Nations Program on HIV/AIDS
WHO:	World Health Organization

Operational Definitions

Retention in care: The ability to adhere to critical aspects of care, according to health system standards and as prescribed by a health care provider

Loss to follow-up: Patients who missed a subsequent follow-up visit and did not return to care for more than 60 days.

Defaulter: Someone who has stopped taking ARVs for at least more than two months from the day of next appointment

Option B plus: A new option for providing anti retro viral drugs to all HIV infected pregnant women beginning in the antenatal clinic setting but also continuing this therapy for all of these women for life (WHO, 2012).

CHAPTER 1

Introduction and Background

Introduction

HIV is one of the top causes of death among childbearing women (UNAIDS 2014). Malawi is among the countries in the world with high HIV prevalence rate of 9.6 % (UNAIDS 2018). HIV prevalence among adult women in the age range of 15 to 64 years in Malawi is high at 12.8% (MOH 2016). In order to meet Prevention of Mother to Child Transmission of HIV (PMTCT) goals, improve maternal survival and reduce HIV transmission to sero-discordant couples, World Health Organization (WHO) introduced a policy of initiating all HIV positive pregnant and breastfeeding women on lifelong ART regardless of CD4 count (option B+) (WHO 2012; Tenthani et al., 2014 & Van Lettow 2010).

Once women are initiated on ART, retention in HIV care is necessary as poor adherence to ART increases HIV disease progression, poses a threat of treatment failure, the potential for development of drug resistance and increased mortality (Ebuy et al 2014; Van Lettow 2010; Clouse et al., 2014). In addition, for breastfeeding women, retention in HIV care also ensures Prevention of Mother to Child Transmission of HIV as continued breastfeeding in the absence of any interventions increases the risk of HIV transmission to 35% (WHO, 2010).

Despite available evidence that mortality is high among women who drop out of ART (Brinkhof et al. 2009; Fox et al. 2010 & Van Lettow 2010), studies done in Malawi and in the sub Saharan Africa have shown that some women enrolled on ART during

pregnancy are not being retained in HIV care after delivery (Tenthani et al 2014; Tweya 2014; Kim et al 2016; Clouse et al 2014; MOH 2012 & Mituku et al., 2016). While women dropping out of HIV care in the postpartum period have increased risk of morbidity and mortality, there is the additional risk of HIV transmission through breastfeeding to exposed infants (WHO, 2010). Therefore more knowledge is needed on what determines retention in HIV care among women initiated on ART during pregnancy. In particular, there is need to understand why a large proportion of women enrolled in the HIV care programme do not return to the hospital after the immediate postpartum period despite the known fact of the risk of HIV transmission to the baby during the breastfeeding period. Therefore, this study aimed at exploring barriers and facilitators to retention in HIV care among breastfeeding women at Thyolo district hospital in Malawi.

Background

Globally, a population of 35.3 million adults and 3.2 million children below the age of 15 years in the year 2012, were estimated to be HIV infected, with Sub Saharan Africa having the largest share (Ebuy, Yebyo & Alemayehu, 2015). The devastating effects of AIDS are one of the worst epidemics that the world has ever faced (AIDS info 2014). Malawi has, 4% of the total number of people infected with HIV in sub Saharan Africa (UNAIDS 2014) and 60% of people infected with HIV in Malawi are women of the childbearing age. Approximately, 1.4 million women who become pregnant are HIV positive. Antenatal attendance of HIV infected women ranges from 5% to 30% (UNAIDS 2010).

In Africa, over 90% of cases of HIV infection in children are through Mother-to-child transmission (MTCT) (WHO 2014). These infections might occur during pregnancy, labour and childbirth or during lactation. With no intervention, rates of MTCT are estimated to be 25-35 percent but with Antiretroviral therapy (ART) and other effective interventions for prevention of mother-to-child transmission (PMTCT), the risk of transmission can be reduced to below 5%, with the transmission rate in high-income countries as low as 1–2% (WHO 2011; WHO 2015). According to Ebuy et al., (2015), the differences in HIV prevalence among developed and developing countries might be due to different treatment strategies, good health systems and accessible information, increased health awareness among women and higher socioeconomic status and educational levels in developed countries compared to limited-resource countries.

PMTCT then is dependent upon provision of a number of services to HIV-positive women including improved antenatal services, provider initiated HIV testing and counselling during pregnancy, use of antiretroviral treatment (ART) for HIV positive pregnant and breastfeeding women, referral to support groups, safe delivery practices, safer infant feeding practices and HIV testing for the child, and continued follow up for the HIV positive mother and exposed infant for the first 18 months of the child's life (Katirayi 2016; WHO 2011 & UNAIDS 2010).

In 2016, Malawi Ministry of Health (MOH) launched a bold initiative called Test and Treat strategy where all people diagnosed with HIV are started on ART for life immediately after HIV diagnosis. This strategy called 90-90-90 targets for epidemic control aims at having 90% of people living with HIV know their HIV status; 90% of people living with HIV being on antiretroviral treatment (ART) and 90% of people on

ART have viral load suppression. Previously, it was only pregnant and lactating women who tested HIV positive that were offered life-long ART, regardless of their CD4 count or clinical staging (option B+) (Van Lettow 2014).

Prior to July 2011, Malawi only offered ART to pregnant women with a CD4 count of below 250 cells per ml or those who presented with other evidence of immunosuppression (Kim et al., 2016). Following the introduction of Option B+ in 2011, HIV positive pregnant and lactating women were initiated on life-long ART, usually the same day of HIV diagnosis, regardless of their CD4 count or clinical staging (Van Lettow 2014 & Katirayi et al., 2016). The introduction of Option B+ led to a dramatical increase of HIV positive pregnant and breastfeeding women initiated on ART, from 17% in 2009 to 79% in 2013 (CDC 2013; Tenthani et al., 2014; Kim et al., 2016 & UNAIDS 2014). Though with such a good uptake of ART in pregnant and breastfeeding women, there have been challenges in terms of retention in HIV care with women enrolled on HIV care during pregnancy being lost to follow up in the months after delivery (Tenthani et al., 2014; Clouse et al., 2013; Kim 2016; Mituku et al., 2016; Katirayi et al., 2016 & Tweya 2014).

According to Tenthani et al. patient loss to follow up varies from 0% to 58% at 6 months after ART initiation (Tenthani et al., 2014). The risk of loss to follow up is five times higher in women who were initiated on ART during pregnancy or breastfeeding unlike the ones who were initiated on ART due to low CD4 count or clinical stage. Similar results were found in Swaziland where women who started ART therapy whilst healthy found it difficult to justify retention in ART care after delivery (Katirayi et al., 2016). This might suggest the perceived need for the drugs, as those who started due to

immunosuppression may feel the need to be on therapy unlike the ones who were initiated on ART whilst healthy (Katirayi et al., 2016). Among women who drop out of ART, the risk of loss to follow up is highest among those who were initiated on day of HIV positive diagnosis, as they might have been started on ART before they were fully prepared and before they dealt with the news of being HIV positive (Kim et al., 2016; Mituku 2016 & Tweya 2014). Non-adherence to ART could be a threat not only to the HIV infected mother, but also to the child that is being breastfed (Mituku et al., 2016). According to WHO, there is a 35% increased risk of transmitting HIV to the child if the mother is breastfeeding and not taking ART (WHO, 2011).

A number of studies have examined potential individual and health facility challenges faced by pregnant and postpartum women as they access PMTCT services (Woelk et al., 2016, Tomori et al., 2014; Kim et al., 2016; Tenthani et al., 2014 & Clouse et al., 2014). The health facility characteristics that may influence retention include both the structural and operational aspects of the facility such as facility capacity (Woelk et al., 2016), difficulties in reaching distant clinics (Tomori et al., 2014), negative treatment by clinic staff (Clouse et al., 2014) and shortage of staff (Tweya 2014 & Kim et al., 2016). However, studies have shown that women become loss to follow- up after the postpartum period but little is known on the causes of this loss to follow-up in breastfeeding women after the immediate postpartum period. Therefore this study aims at exploring the barriers and facilitators to retention in HIV care among breastfeeding mothers at Thyolo district hospital.

Problem Statement

Pregnancy is a time of increased engagement in HIV care for women who are aware of their diagnosis (Clouse et al., 2014). However, this engagement in HIV care does not extend into the postpartum period (MOH 2015 & Tenthani et al., 2014). Retention rate in HIV care decreases in the postpartum period with time periods, which accounts to 78% at 6 months, 71% at 12 months, and 67% at 24 months (Tenthani et al., 2014). Option B+ is a regimen for pregnant women who are HIV positive and are placed on ART for life regardless of CD4 count compared to the previous practice of taking HIV positive women off ART after pregnancy if the CD4 count was over 350cells per ml. According to Health Management Information System data for Thyolo District Hospital, from January 2015 to December 2016, out of the 586 women who were enrolled on ART due to pregnancy or breastfeeding, 90 women defaulted from ART during pregnancy and breastfeeding, representing 15 % of default rate at the facility and 90 exposed children at risk of acquiring HIV through pregnancy and breastfeeding. Therefore, there is a need to study at the facility why women are becoming loss to follow up, putting 180 lives of pregnant and breastfeeding mothers and babies at risk of HIV associated complications. There are few studies in Malawi that have explored barriers and facilitators to retention in HIV care after the immediate postpartum period and the associated risk of HIV transmission to the breastfed babies, hence this study.

Justification of the Study

The knowledge gained from this study will assist in understanding the facilitators and barriers to retention in HIV care, which in turn will help in improving the standard and quality of care provided to breastfeeding mothers who are diagnosed HIV positive

during pregnancy, in labour or breastfeeding and are attending HIV follow up clinic with their children. In the long run this will improve retention of mothers with HIV on ART hence contribute to reduction of child and maternal mortality in Malawi.

Broad Objective

To explore the barriers and facilitators to retention in HIV care among breastfeeding mothers at Thyolo district hospital.

Specific objectives.

1. To describe the facilitators to retention of breastfeeding mothers in HIV care.
2. To identify the hindrances to retention of breastfeeding mothers in HIV care after 6 weeks postpartum.
3. To identify the expectations of breastfeeding mothers regarding retention in HIV care after HIV diagnosis

CHAPTER 2

Literature Review

Introduction

This chapter presents a review of literature related to factors influencing retention in HIV care among breastfeeding mothers. The review was done in line with the study objectives. A literature search was conducted using the following electronic databases: HINARI, Pubmed, Science Direct, EBSCOHOST, Google and Google scholar. Terms such as “ retention”, “breastfeeding mothers”, “facilitators”, “barriers”, “expectations” were entered separately using “ AND” and “OR”. Usage of reference lists of published journal articles retrieved additional articles.

The researcher searched articles from both local and international literature. This was to ensure that all the relevant studies have been picked for the use of the study. The articles that used English language were used in this review as that is the only official language that the researcher knows apart from the Chichewa local language. Literature that was used in this study ranged from 2006 to 2018. Integrative literature review was done to collect and synthesize a number of relevant literature on the topic in an integrated way. This could help the researcher to have a broad understanding of the factors influencing retention in HIV care. It was also done to assess the feasibility of the research topic.

Facilitators to Retention in HIV Care

Retention in HIV/ART care is a critical aspect of care once women are initiated on ART (Yehia et al., 2015; Mituku, 2016; Rollins, 2014). The World Health Organization defined retention as “continuous engagement from the time of diagnosis in a package of prevention, treatment, support and care services. It is defined from the moment of initial engagement in care, when a person with HIV is linked successfully to services, to assessment for eligibility, initiation on ART and retention in lifelong ART care (WHO, 2011). Retention in HIV care as described by other authors is the ability to adhere to critical aspects of care, attend regular follow-up appointments, scheduled laboratory tests and other monitoring activities, according to health system standards and as prescribed by a health care provider (Patel et al., 2010).

Retention in care according to Rollins (2014) refers to “both the attendance at health facility and also the continuity of care”. Retention in care is paramount in the HIV care continuum as it ensures successful management of HIV infected individuals (Yehia et al., 2015). And it is also one of the crucial indicators of the success of ART programme (Mituku, 2016). Since it is used as a measure of adherence to ARV intervention and viral load suppression (Rollins, 2014). The same author also described that the effectiveness of antiretroviral therapy is determined by the continuity of care as continuity of care is associated with access to ARVs and its adherence.

Retaining HIV infected patients on treatment has a lot of advantages for both the organization and the recipient of care as it helps in containing health care costs as well as reduces hospital visits and hospitalization respectively (Horstmann et al., 2010). Evidence has shown that women who are retained in HIV care have good health

outcomes (Woelk et al., 2016). Since the drugs reduce the viral load, as a result morbidity and mortality of mothers and children is reduced (Van Lettow, 2010). Studies have shown that effectiveness of ART is directly related to patient adherence since it reduces the risk of mother to child transmission of HIV, which is the primary mode of infection in children (WHO, 2015).

There are several facilitators to retention of women in HIV care which provide an important contextual consideration in the management of HIV women on ART. These factors comprise of individual, structural and operational dynamics (Karutu, 2016). One of the individual characteristics that influence retention in HIV care is the issue of disclosure (Tenthani et al., 2014; Karutu 2016; Kim et al., 2016 & Katirayi et al., 2016). In Kenya, disclosure of the positive HIV status to male partners and family and supportive male partner was a facilitator to retention in HIV care (Karutu, 2016). Similar results were found in Malawi where women reported that male partner support was an important influence in women's decision making regarding uptake of PMTCT services (Kim et al., 2016). In another study on HIV positive pregnant and postpartum women's perspectives about option B+ in Malawi, they found that male partner was an important consideration in women to start or deny ART as women wanted to discuss with their husbands first before they could start therapy (Katirayi et al., 2016). Similar results were also found by Kim et al (2016), where male partner support was identified as an important influence in retention in HIV care, as women's decision to take or not to take ART was based on that. For women who discussed and had supportive partner, they adhered to therapy accordingly (Tenthani et al., 2014).

Literature has also shown that the desire to prevent the transmission of HIV from mother to child was an important facilitator to retention in HIV care (Kim et al., 2014; Clouse et al., 2014; Katirayi et al., 2016; Gugsu et al., 2017 & Ngarina et al., 2013). According to Kim et al., (2014) women expressed that all they wanted was to prevent the transmission of HIV to their children and that was the main influence for them to continue taking ART during pregnancy. For mothers whose primary motivation to remain in therapy was to prevent the transmission of HIV to their children during pregnancy and breastfeeding posed an increased threat to their continued retention in HIV care services once the babies were fully protected from HIV as evidence has shown that there is loss of motivation to continued retention in HIV care once babies are fully protected from HIV (Katirayi et al., 2016; Clouse et al., 2014; Ngarina et al., 2013 & Kim et al., 2013).

In Tanzania women's motivation to remain in therapy decreased once they had protected their children from HIV and successfully weaned them (Ngarina et al., 2013). In another study in South Africa, the results showed that mothers care more about their baby's health than their own since 29.2% of women in the study reported that the whole reason they were committing to ART during pregnancy and the immediate postpartum period was to have an HIV free child. Similarly in Malawi, Katirayi et al., (2016) found that women did not see the need to take ART after giving birth and they asked the health care workers if they were to stop taking ART when they finished breastfeeding and restart ART when they felt ill. Therefore literature has shown that mothers whose primary reason for being retained in HIV care is protection of their children from HIV during pregnancy and breastfeeding are at increased risk of becoming loss to follow up once their babies are successfully protected from HIV.

Acceptance of the HIV positive status and the desire to improve the quality of their (womens) health has also shown to facilitate retention in HIV care. In a study in Kenya, Karutu (2016) found that women who accepted their HIV positive results were well retained in care. And the hope of prolonging their life with ART motivated women to stay in care (Katirayi et al., 2016). In the Global Network of People Living with HIV and International Community of Women Living with HIV/AIDS (2013) women in Malawi reported that they felt healthier and stronger on treatment, felt improvements in their mental health because of their hope for a healthier life, experienced less stigma because people cannot tell they are on treatment, and that they are more encouraged to attend ANC and health centers because there is certainty that treatment is available to them.

Barriers to Retention in HIV Care

Literature has highlighted the importance of retention in HIV care as a crucial element of clinical success for the patient and the program at large. Poor retention in HIV care has been associated with devastating effects for both the mother and the baby (Babatude et al., 2015; Obai, Mubeezi & Makumbi 2017; Kalembo and Zyambo 2012 and Van Lettow 2010). Studies have shown that patients who are not retained in HIV care are generally sicker than those who are retained in HIV care and may therefore experience poorer long-term outcomes (Babatude et al., 2015). There is a threat of development of potent drug resistant HIV strains to the infected individual (Horstmann, Brown, Islam, Buck & Agins 2010) and maternal HIV disease progression (Mituku et al, 2016) which also contributes to high mortality rates in the postpartum period (Van

Lettow et al., 2010). Same author has also shown that mortality rate in both developed and developing countries for such patients is high.

Non-retention also compromises the use of ART by the mother and baby which is important for prevention of HIV transmission during the breastfeeding period. The consequence for this is increased risk of MTCT of HIV (Obai, Mubeezi & Makumbi, 2017). Non retention in HIV care also hinders continuous follow up for the exposed infant, denying him/her the opportunity for early identification and initiation of treatment (Kalembo and Zyambo 2012).

Although clinical attendance of appointments are associated with favourable patient outcomes among individuals with HIV on ART. Studies have shown that a lot of women are becoming loss to follow up months after ART initiation (Tenthani et al 2014; Clouse et al., 2014 & Mituku et al., 2016). In a cohort study in Kenya, where they were understanding the barriers and the facilitators to the retention of HIV positive women along the PMTCT continuum, they found that across the three study sites, only 9%, 10% and 16% of the women were fully retained. In Malawi, 29% of women in option B + are lost to follow up twelve months after ART initiation (Tenthani et al., 2014). And in Ethiopia, 22.6% of women are loss to follow up at 24 months after ART initiation (Mituku et al., 2016). The same author noted that this significantly undermines the success of option B+.

Literature has shown that there are barriers that hinder patients' successful retention in HIV care. These barriers to successful participation in HIV care may occur at the individual, interpersonal, community and the health care facility level (Gourlay et al., 2013). The lifelong commitment in health care services which is influenced by starting

ART during pregnancy necessitates frequent interaction between health systems and HIV infected women (Rollins et al., 2016). However, studies have shown that the interactions between the infected individuals and the health facilities are contributing factors to poor retention in HIV care (Clouse et al., 2014; Tenthani et al., 2014; Katirayi et al., 2016 & Helova et al., 2017). Clouse et al., (2014) conducted a study in South Africa on barriers to retention in option B+ HIV care among postpartum women, they found that 12.5% of the women dropped out of ART due to negative staff treatment.

Literature has shown that same day HIV diagnosis and treatment is a major challenge contributing to early loss to follow up among women (Helova et al., 2017; Tenthani et al., 2014; Chan et al., 2015 & Katirayi et al., 2016). Helova et al., (2017) conducted a qualitative study which aimed at describing the health facility challenges to the provision of Option B+ in western Kenya. The findings revealed that same day ART initiation posed challenges of retention in HIV care as the health care workers expressed that women were not given some time to accept their HIV positive results and disclose their HIV status to their partners and/or family members before ART initiation and this posed a risk of becoming loss to follow up. In another study in Lilongwe, Malawi they found that women found ART that was started during pregnancy as coercive by the health care workers because of the immediacy in starting therapy and this affected adherence (Tenthani et al., 2014).

Additionally, Chan et al., (2015) in their study to evaluate how same day integration of HIV diagnosis and treatment with antenatal care affects retention in Option B+ PMTCT services in Zomba District, Malawi found that same day HIV diagnosis and treatment was associated with reduced retention in HIV care as women felt that they were

not given enough time to adjust to their HIV positive diagnosis before they were initiated on ART and they were initiated on ART on same day due to peer and Health care worker influence. Similarly, Katirayi et al., (2016) reported that one of the main challenges that women faced in accepting the lifelong ART was the practice of initiating them on ART the same day they were diagnosed HIV positive as they felt that the counselling was insufficient for them to understand ART and its lifelong commitment. Therefore this could affect retention in HIV care in the long run.

Counselling has been shown to play an important role during the diagnosis phase to improve retention in HIV care and for it to be effective studies have recommended that counselling must address the psychological, emotional and informational needs of the patients (Gugsa et al., 2017). However, available literature has revealed that in option B+ women receive minimal counselling at ART initiation with major focus on content that focus on the need to start ART and its importance for protecting the baby from HIV and that has affected lifelong commitment to ART (Katirayi et al., 2016; Gugsa et al., 2017 & Helova et al., 2017). In a qualitative study in Malawi, they found that women expressed insufficient counselling time by the Health care workers and that affected client's good decision making as they had a lot of unanswered questions on consequences of missing a pill and what to do on family planning issues and other important topics hence postpartum women did not feel ready to take ART for a lifetime (Katirayi et al., 2016). However, staffing levels have been attributed as a contributing factor to poor counselling and in turn a barrier to retention in HIV care as evidence has shown that in Kenya health care workers did not provide important information on proper medication taking and no follow up on how to take medications because of shortage of staff (Helova et al., 2017).

In another qualitative ethnographic research conducted in Lilongwe, Malawi results showed that women felt that they were not well prepared for ART since the counselling did not focus on important issues that may affect retention in HIV care like transport and food availability, instead it focused on biomedical issues which on its own cannot affect adherence. According to Tomori et al., (2014) in Iringa, Tanzania, he identified access problems like transportation and severe poverty as significant barriers to retention in HIV care despite the available HIV care services. Similarly, Cataldo et al., (2017) in Malawi linked early loss to follow up to lack of means of travel and transportation money. Additionally, Tweya et al., (2014) in his study on understanding factors, outcomes and reasons for loss to follow up among women in Option B+ PMTCT programme in Lilongwe, Malawi he found that lack of money for transport to the clinic was a major reason contributing to loss to follow up.

It has also been documented in literature that weak support system from partners, family and/or designated guardians affect negatively adherence and retention in HIV care (Flax et al., 2017; Gugsu et al.; 2017; Karutu et al., 2015 & Cataldo et al., 2017). Gugsu et al., (2017) in his study to explore factors associated with ART adherence and retention in HIV care under Option B+ strategy in Malawi which used qualitative design found that lack of strong support system impacted negatively on retention in HIV care as some women dropped out of care because of abuse from partners after HIV disclosure. And for the other women who depended on their partners for financial support failed to access HIV care when partner had no money. Similarly, Cataldo et al., (2017) in their study of exploring the experiences of women and health care workers in the content of PMTCT option B+ in Malawi identified male partner support as a critical intervention to promote

retention in HIV care. They found that lack of partner and family involvement was one of the contributing factors to early loss to follow up among women.

Expectations of Breastfeeding Mothers Regarding Retention in HIV Care

Mothers expectations regarding HIV and ART care is critical in management of women in HIV care as it determines their retention in HIV care in the long run. Evidence has shown that women's expectations regarding HIV care and ART are not well addressed during ART initiation and this poses a risk of default (Katirayi et al., 2016; Gugsu et al., 2017 & Helova et al., 2017). In a qualitative study in Lilongwe, Malawi, it was revealed that adequate counselling that addresses every aspect of care in terms of psychological, emotional and informational needs of the patients are the issues that women expect to hear in totality from the health care workers (Gugsu et al., 2017). However, it has been shown that these information is not provided by the health care workers and that leaves the women with a lot of unanswered questions that hinder their retention in HIV care in the long run (Katirayi et al., 2016; Gugsu et al., 2017 & Helova et al., 2017). In a study report by Elizabeth Glaser Pediatric AIDS Foundation (2014) on Acceptability of Lifelong treatment (Option B+) Among HIV Positive Pregnant and Lactating Women in Selected Sites in Malawi they found that the majority of respondents were not able to have adequate information from healthcare workers because they were not given the opportunity to ask questions.

Literature has also shown that womens expectation for protection of their babies from HIV on ART initiation is an important factor that determines their retention in HIV care in the long run as evidence has shown that mothers motivation to remain in HIV care decreases after delivery (Clouse et al., 2014; Katirayi et al., 2016 & Kim et al., 2014).

The desire to prevent the transmission of HIV from mother to child was also an important facilitator to retention in HIV care. Though a lot of women did not like the lifelong commitment of ART. According to a study in South Africa, Clouse et al., (2014) revealed that women expressed that all they wanted was to prevent the transmission of HIV to their children and that was the main influence for them to continue taking ART during pregnancy, but they did not like the idea of being on ART for life. Similar results were also found in Swaziland where women felt that they were not ready to commit their lifetime on ART therapy (Katirayi et al., 2016). Most women felt they were starting ART for the baby than for their own and this affects retention in care in the postpartum period as women asked healthcare workers if they could stop ART after breastfeeding (EGPAF 2014 report).

The timing of ART initiation has also been documented to be a challenge to women's retention in HIV care as option B+ aims at initiating women on ART the same day they have been diagnosed HIV positive. This has been shown in literature that it affects retention in HIV care as women are started on ART before they are fully prepared and ready. This suggests that women have certain expectations that they must meet before being initiated on therapy (Katirayi et al., 2016). In Elizabeth Glaser Pediatric AIDS Foundation (2014) study on Acceptability of Lifelong treatment (Option B+) Among HIV Positive Pregnant and Lactating Women in Selected Sites in Malawi, women reported that initiation of ART on day of HIV diagnosis presented a serious overload of information for them. Similarly, in Swaziland it was found that women found it challenging to learn of their HIV positive status and start ART on the same day (Katirayi et al., 2016).

Additionally, study results in Malawi revealed that women expressed that the immediacy of starting ART left them with little time to process the news of being HIV positive and they had little time to prepare before they could start ART (Kim et al., 2016). According to Tenthani et al., (2014) women who are not well prepared for ART are at highest risk of nonadherence and loss to follow up. Women expected to be given time to discuss with their partners first before they could commit to lifelong therapy (Katirayi et al., 2016).

The GNP+ and ICW study found that With option B+ women felt left out by the doctors because the interventions that were being done in option B + were putting the focus largely on the baby, to prevent transmission of HIV with little attention given to womens health needs and this posed a risk of default in between pregnancies especially if they were started on ART for the baby and not for their own health.

Conclusion

The literature has shown that issues regarding HIV and ART adherence and retention in HIV care have been studied in Malawi and the sub Saharan Africa. It has also shown that identifying women with HIV and initiating them on ART is feasible. However, retaining women in HIV care is the most important challenge facing the health care system. Available literature has shown that there is evidence on issues affecting ART adherence and retention in pregnant and postpartum women. However, few studies focused on issues affecting retention in HIV care of postpartum breastfeeding women after the immediate postpartum period. Therefore, literature has identified a gap that needs to be filled by conducting a study that will explore the factors that influence

retention in HIV care among breastfeeding mothers after the immediate postpartum period.

CHAPTER 3

Methodology

Introduction

This chapter explains the method taken to conduct this study, further it describes the study design; place; population; sample size and sampling methods; recruitment criteria; data collection procedure, data management, analysis and trustworthiness. Issues pertaining to ethical considerations and dissemination of research findings have also been elaborated.

Research Design

This was a descriptive qualitative study. Qualitative designs focus on experiences and reality of research participants in which the action takes place (Polit & Beck, 2010). The other designs for qualitative studies are: case study, ethnography, phenomenological and grounded theory (Polit & Beck, 2017; Kumar, 2014; Ritchie, Lewis, Nicholis & Ormston, 2014; Devlin, 2006). While these designs focus on understanding a phenomenon and require intensive study and data collection over an extended period of time, descriptive qualitative studies examine human experience through descriptions that are provided by the people involved, and is aimed at describing what people experience in regard to a certain phenomenon, how they interpret the experience or the meaning that the experiences hold for them (Brink, 2006). Therefore, the design was chosen for this study because it aimed to understand and describe how breastfeeding mothers perceive

factors that influence retention in HIV care. It was also suitable for time and financial resources available for this research.

Study Setting

The study was conducted at Thyolo District Hospital, in the southern region of Malawi at Maternal and Child health department where HIV positive mothers and HIV exposed babies are followed up for 24 months before they are discharged from HIV care clinic or enrolled in ART clinic. This is one of the district hospitals in Malawi offering secondary care. It is also a referral hospital for primary level care facilities within the district. The catchment population for the hospital is 691,915 people. The hospital was chosen because it had an HIV prevalence rate of more than 14%, higher than the national average of around 10%, indicating that there were a lot of people in the district infected with HIV and apart from that there was a significant default rate of pregnant and breastfeeding women. According to Health Management Information System data for Thyolo District Hospital, from January 2015 to December 2016, out of the 586 women who were enrolled on ART while pregnant or breastfeeding, 90 women defaulted from ART during pregnancy and breastfeeding, representing 15% of default rate at the facility and 90 exposed children at risk of acquiring HIV through pregnancy and breastfeeding. Therefore, there was a need to conduct a study at the facility to find out why women were disengaging from HIV care, putting their lives as well as of the exposed child at risk of HIV and AIDS associated complications.

Study Population

The target population in this study were HIV positive breastfeeding mothers. The study focused on HIV positive breastfeeding mothers who were retained in HIV care and

those who were loss to follow up because of the risk of HIV transmission through breastfeeding. These breastfeeding mothers were capable of providing rich information regarding their experience in HIV care.

Sample Size

This study recruited twenty four participants, out of the twenty four participants recruited, twenty women were the ones retained in HIV care and were keeping their appointments dates, indicating that they were adhering to therapy and four participants were loss to follow up women. In qualitative studies samples are based on information needs (Polit & Beck 2010). Nevertheless, the sample should not be too large to avoid repetitions (Mason, 2010). The sample size is said to be adequate when it has reached a saturation point. Therefore, data collection in this study was stopped after reaching data saturation. Data saturation is a situation whereby collection of new data does not provide new insights or information for the issue under investigation (Creswell, 2008).

Sampling Method

Purposive sampling was used to select participants among those who met inclusion criteria. Purposive sampling technique is a form of non-probability sampling (Brink, Walt & Rensburg, 2012). This method was chosen because it allows the researcher to select intentionally who to include in the study on the basis that those selected can present the requisite data (Neergaard et al., 2009). The method was used to target people with rich information about the subject under study. According to Creswell (2013), it is essential that all participants have experience of the phenomenon being studied. Therefore, breastfeeding mothers retained in HIV care and breastfeeding mothers who were loss to follow up were intentionally selected by the researcher as they were

more likely to contribute appropriate data in terms of relevance because they had experience in HIV care.

Inclusion criteria.

Women 18 years and above. HIV positive women after six weeks postpartum, Women taking ART and women who were loss to follow up but were tested for HIV during pregnancy, in labour or breastfeeding and started taking ART in the regimen of Option B+. HIV positive women on ART and women who became loss to follow up but were still breastfeeding their children during the period of data collection were invited to take part in the study. These mothers were invited to take part in the study because they were capable of providing a true reflection of the barriers and facilitators to retention in HIV care based on their experience in the context of same day HIV testing and ART initiation.

Exclusion criteria.

Women below the age of 18 years were excluded from the study because they were minors who could not give consent on their own. HIV positive women in the postpartum period of less than six weeks, were excluded from the study because they had no experience on barriers and facilitators to retention in HIV care after the immediate postpartum period. HIV positive women who were tested for HIV and enrolled on ART before the era of Option B+ were excluded from the study because management of ART before that era was different from the time of Option B+ hence their experience could not give a true reflection on the matter. Option B+ was introduced in Malawi in September 2011 (Van Lettow 2014 & Katirayi et al., 2016). HIV positive women on ART but not

breastfeeding their children were excluded from the study because there was no risk of transmitting HIV through breastfeeding.

Recruitment strategy.

The recruitment of HIV breastfeeding mothers who were still engaged in HIV care was done at the HIV follow up clinic at Maternal and Child Health department at Thyolo District Hospital. The researcher attended education sessions which were done at the department on daily basis and gave information about the study. Women who were interested to participate in the study were asked to approach the researcher. For women who were willing to participate in the study and met the inclusion criteria, they were given thorough information about the study (Appendix 2A and 2B) then enrolled into the study. Consent was sought through written forms (Appendix 3A and 3B) and the women were asked to sign or make a thumb print (for those who could not write) on the consent form as evidence of their willingness to participate in the study. Interviews were conducted in a private room at the hospital when the participants had received the care they had come for on that particular day.

Loss to follow up (LTFU) mothers were followed to their homes for the sake of the study with the help of mentor mothers. Mentor mothers are HIV positive women who serve as peer counselors for PMTCT clients, provide guidance, and support in keeping appointments and promoting antiretroviral adherence and retention in care (Sam - Agudu et al., 2014). Generally, the homes of the LTFU women were some kilometers from the hospital (approximately 3 kilometers), which required travel by motor cycle. Most of the mothers were with their breastfeed babies when they were visited, other home occupants had gone to school and occupation places hence they were not aware of our visit. The

mentor mother made introductions, then the purpose of the visit was shared right in their homes. The mothers were then asked if they would be willing to participate in the study. For the participants who were willing to take part in the study; day, time and place of their convenience was agreed for the interview. However, all the participants preferred that the interviews take place in their homes. Privacy was ensured by excusing the mentor mother to wait outside the house when the interview was in progress.

It was a challenge tracing the LTFU mothers and to have their consent to participate in the study. Travel to their homes also required a paying transportation means (motor cycle) for both the researcher and the mentor mothers who assisted in tracing of the LTFU mothers. Out of the six participants who were approached to take part in the study, four were willing to participate in the study and the other two women refused to take part in the study. One participant expressed that it was her right not to take part in the study, hence was not willing to do so. And the other woman refused to take part in the study based on her religious belief, she made that decision after excusing herself for prayers before she responded to take part or not in the study.

Data Collection Instrument

In this study, interview guide with some probes was used (Appendix 5A & 5B). The interview guide had open ended questions that were formulated according to the study objectives. The main questions were from the objectives namely: factors that enhance retention of breastfeeding mothers in HIV care, factors that hinder breastfeeding mothers from accessing HIV care after six weeks postpartum and expectations of breastfeeding mothers regarding HIV care after childbirth. Use of interview guide with open ended questions was used to stimulate breastfeeding mothers to provide rich

information about their experiences. In addition, literature indicates that an interview guide allow the researcher to have a framework in which open-ended questions are posed to encourage the participants to talk freely about their experiences (Polit & Beck 2010).

Data Collection Process

After obtaining ethical and hospital approval (Appendix 1A, 1B and 6), recruitment of participants was done at the HIV follow up clinic at maternal and child health care department for participants retained in care. For women who were loss to follow up, recruitment was done in their homes. Participants were given brief information about the study after health education sessions. The participants who were willing to participate in the study were given detailed written information about the study (Appendix 2A & 2B) and the consent form to read, understand and sign to indicate their willingness to participate (3A & 3B). For the participants who could not read, the written information was read to them (Appendix 2A & 2B). The participants who could not write, a thumb print was used as a signature. The interviews were conducted in Malawi's local language, Chichewa (Appendix 4A, 4B, 5A& 5B). This language was chosen because it is a language that majority of Malawians understand and are able to share and express themselves freely.

Interview with the participants was conducted in a private room at the hospital in order to maintain confidentiality and anonymity. The interviews lasted approximately 45 minutes to one hour. The in-depth interviews (IDI's) were recorded using audio-digital recorder. That assisted in capturing the experiences of participants in their own words and increased confirmability of the data. It also assisted the interviewer to maintain eye contact during the interview which is an important listening skill in an interview.

Pre- test Interviews

The researcher conducted pre-test interviews with the first two participants at Thyolo District Hospital. It is of importance to conduct a pretest that replicates exactly the processes that will be undertaken in the main study and also to ensure that all members to be involved in the main study take part in the exercise (Hurst et al., 2015). For this reason, the pre-test interviews were conducted at the same site as the one where the main study was conducted. Through the exercise, the researcher ensured that the questions on the interview guide were clear and that they elicited the intended responses. In addition, the researcher confirmed that the digital audio recorder was in good working condition and was user friendly. Through the pre-test experience, the researcher gained confidence and improved on her probing skills during the rest of the interviews.

Data Management

Interviews were recorded on a digital audio recorder then transferred into the researchers password protected Microsoft computer at the end of the interview for back up. Printed copies, field notes and recorder were locked in the drawer of the researcher and were accessible only by the researcher and the research supervisor.

Data Analysis

The researcher analyzed data concurrently with data collection. Interviews were manually transcribed verbatim to prevent distorting the meaning of the given information. Then they were translated to English. To ensure that the meaning of the words spoken by the participants were not changed, back translation to Chichewa was done. All field notes were incorporated in the transcript. The transcriptions were detailed capturing all elements of the interview such as areas stressed by the interviewee, how fast or slow the

interviewee responded to the questions, tone of voice and pauses made before responding to the questions. Emphasis was placed on both verbal and nonverbal utterances. This allowed the researcher to draw meanings from such features and the data was enriched with such features.

To understand the barriers and facilitators to retention in HIV care, data were analysed using thematic analysis as described by Braun and Clarke (2006) in their work on using thematic analysis in psychology. They defined thematic analysis as “A method for identifying, analyzing and reporting patterns within data.” (p. 79) (Braun and Clarke, 2006). The data were analysed in six phase processes namely; getting familiarized with the data, transcription of data, code identification and generation of themes and subthemes, reviewing the themes, defining and naming themes and producing a report.

After transcription, the researcher read and reread the transcripts several times to ensure understanding of the meaning that were coming out from the data. This helped the researcher in immersing oneself in the data and becoming very familiar with it.

Immersion meant repeated reading of the transcripts, reading the transcripts in an active way and searching for meanings and patterns in the data. The entire transcripts were read through before coding. Consideration was given to the words that were spoken by many people (Braun & Clarke, 2006).

Coding was done manually using highlighters. Coding was done for things that were recurrent across the data; interesting, surprising and important to the research question. The same applies to things expressed to be very important by the interviewee or anything that seems to be unique (Ritchie, Lewis, Mcnaughton Nicholls & Ormston,

2014b). The aim was to go beyond the surface meanings of the data and tell an accurate story of what the data meant (corbin & Strauss, 2015).

Once the codes were generated, those that were similar were put together to form categories. The researcher then made decisions about themes that were more important to the research question than others and tables were drawn to organize the identified codes into themes and sub-themes. The themes were then described, showing any connections and differences that exist between them (Braun & Clarke, 2006).

After identification of the themes, they were reviewed. The aim of this was to refine them. The researcher refined the themes to ensure that they were clear and they matched with the data that supported them. The researcher re-read the entire data set to make sure the themes matched the collected data. Thereafter, themes that needed to be combined were combined and those that needed to be separated were separated. The themes were then named and defined.

Then the themes, subthemes and supporting narratives were fully polished in line with the study objectives and wrote in a descriptive report on the factors influencing retention in HIV care among breastfeeding mothers.

Trustworthiness of the Study

Munhall (2007) defined trustworthiness as the degree to which the participants have been fully included in the research process and have had the opportunity to reflect and comment on their story and retold by the narrative researcher. Four criteria for developing trustworthiness of a qualitative study, which include; credibility, dependability, confirmability and transferability were followed (Polit & Beck. 2010).

Credibility.

Credibility refers to confidence in the truth of the data and its interpretations and the congruency of the study findings with reality (Polit & Beck, 2010). The study also needs to enhance the believability of the findings so that it should be credible to the external readers. In order to achieve this, the researcher used probing questions to sought clarifications from participant responses during the interview up to the close of the interview. The researcher also clarified the questions that were asked to the participants during the interview to ensure that they understood them before responding such that they were able to answer truthfully based on the question. Taking of field notes and building a good rapport also assisted in ensuring credibility (Munhall, 2007). Additionally, the transcripts were transcribed verbatim to ensure that the data analysed were the actual words spoken by the participants.

Dependability.

Dependability refers to stability of findings over time and conditions (Polit & Beck, 2010). If the study is to meet dependability, the results need to be consistent. In order to achieve that, the researcher produced a detailed report of all the processes that were undertaken in the study to enable readers of the research report to understand how the study was conducted and enable other researchers to repeat the work and produce similar findings. These processes include; the research methods, detailed collection and analysis of the data.

Transferability.

Transferability describes how the results will be applicable and be meaningful to individuals not involved in the research (Speziale & Carpenter, 2007). In this study,

transferability was ensured by providing sufficient descriptive data in the research report so that anyone who would want to use it can evaluate the applicability of the data to other or similar contexts. The thick description of the phenomenon under investigation was also provided to enable someone interested in using the findings to reach a conclusion

Confirmability.

Confirmability refers to the objectivity of the study findings in terms of accuracy, relevance or meaning. The findings need to reflect the participants' words as they were spoken and recorded during the interview and that would prevent researcher biases (Polit & Beck, 2010). In this study, confirmability was achieved by recording all the words spoken by participants and the researcher during in-depth interview in order to distinguish the participant's data from interviewer's view. The researcher acted as an active listener and facilitator which allowed participants to give detailed information of their experience. To ensure objectivity, the researcher presented the scientific study methods that were followed, presentation of the final study report to the supervisors then internal and external examiners for review before the final report. To ensure accuracy, relevance or meaning, the researcher pre-tested the research instruments such as the in-depth interview questions and the digital audio recorder and improvements were made based on the gaps that were found during the pre-test.

Ethical Considerations

To observe ethics, permission to conduct the study at the facility was sought from Thyolo District Hospital Health Officer (DHO) (Appendix 1). After hospital approval, Research proposal was submitted to College of Medicine Research and Ethics Committee (COMREC) for approval, which approved to carry out the study (Appendix 6). The study

respected rights of the participants by observing (or adhering to requirement for) privacy, anonymity, autonomy, confidentiality, fair treatment and protection from any harm. This was done by giving information about the study before data collection. Participants were asked to sign a written informed consent prior to participation in agreement to their willingness to participate. The consent form (Appendix 3A and 3B) contained information on the purpose, benefits, and risks of the study. Participants were informed of their right to refuse or withdraw from the study at any point and they were assured that they would not face any consequences as a result of that decision.

Participants were duly informed that there was no monetary and other benefits for taking part in the study but that their information would contribute to development of hospital policies and improvements being made at the facility, that would contribute to retention of pregnant and breastfeeding mothers in HIV care in the hospitals. Participants were also assured that their identification would not be known on publication or presentation of the findings. Furthermore, participants were informed that the study did not have any foreseeable physical harm (risks) to the respondents, however in cases of any emotional or psychological harm; participants were informed to forward their complaints and concern to the chairperson, COMREC secretariat at College of Medicine.

Research Dissemination

Dissemination of the results will be done to health care providers through a meeting which will be held at Thyolo District Hospital and during national and international research dissemination conferences. The study will be published in academic journals. Reports of the study will be submitted to COMREC, Thyolo District Hospital and Kamuzu College of Nursing library.

CHAPTER 4

Presentation of Findings

Introduction

This chapter presents findings of a study that aimed at exploring the facilitators and barriers to retention in HIV care among breastfeeding mothers at Thyolo District Hospital. Twenty four breastfeeding mothers were recruited in the study. The first twenty participants were breastfeeding mothers retained in HIV care at Thyolo district hospital, while the other four participants were loss to follow up and were recruited in the study in their homes with the help of the mentor mothers. The findings are presented in two sections. The first part contains demographic characteristics while the second part contains views of the breastfeeding mothers obtained through in-depth interviews using semi- structured interview guide. Data were analyzed using thematic approach and have been presented as themes and subthemes.

Demographic Characteristics of the Participants

The participants' characteristics examined in this study are age, marital status, parity, number of people who lived in the household, level of education and occupation. Summary of the socio-demographic characteristics is presented in table 1.

Table 1: Socio- demographic Characteristics of the Participants

Characteristic	Number (n=24)
Age (Years)	
18-24	7
25-29	6
30-39	11
40-49	0
Marital Status	
Married	17
Single	3
Divorced	4
Widowed	0
Parity	
One	4
Two	7
Three/more	13
Number of people in the household	
1-3 people	6
4-6 people	17
More than 6 people	1
Education Level	
Never been to school	1
Primary	18
Secondary	5
Occupation	
Self employed	4
Employed	6
House wives	10
Farmer	2
Does nothing	2

Categorization of Themes

Four themes emerged from analysis of the transcribed data by looking at common narrations across participants. The themes were: improved quality of life, family and hospital support in HIV care, hindrances to retention in HIV care and lifetime commitment to therapy. The subthemes that had similar meanings were merged together

under their main themes in order to prevent any repetitions in the study findings. The themes and the subthemes have been presented in table 2.

The findings are presented in narrative format with direct quotes from the participants written to illustrate and support the themes and subthemes. Ellipses, which are a series of full stops with spaces in between them (. . .), are used in the direct quotes to indicate the omission of some unnecessary ideas from the narratives. At the end of a directly quoted sentence four dots are used (. . . .); three to indicate the omission and one to indicate a full stop at the end of the sentence. Participant pauses and physical gestures are presented in brackets with the quoted texts. Of importance to note was that participants used the term “doctors” to refer to any health care provider. As such there is no segregation of health care providers in regards to cadres and profession from the participants’ narratives. No names have been used instead the participants have been identified using serial numbers which were assigned to them during the interview.

Table 2: Themes and subthemes

Themes	Sub themes
1. Improved quality of life	Restoration of good health Desire to prolong life Desire to prevent HIV transmission to child
2. Family and hospital support in HIV care	Family involvement in HIV care Quality of care at the hospital
3. Hindrances to retention in HIV care	Personal factors Hospital factors
4. Lifetime commitment to therapy	

Improved Quality of Life

The majority of the participants reported that they were retained in HIV care because they experienced a change in the quality of their lives after ART initiation. Three sub themes emerged from improved quality of life. These were; restoration of good health, desire to prevent HIV transmission to their children and the desire to prolong life.

Restoration of good health.

The in-depth interviews showed that majority of the breastfeeding women were retained in HIV care because of the benefits they gained after taking ART. Women felt that they had regained their health ever since they started taking ART. Some participants had positive feelings towards retention in HIV care because ART gave them the necessary energy to do all kinds of work in a smooth way. One participant said:

... My body was not looking good and I was not feeling energetic. When I sit down I felt weak. But when I came to the hospital and started the drugs (ARVs) I noticed that I had regained my good health (**participant 13, retained in care**).

Another participant said:

... Since I feel I have energy in my body. The way I was before and now I see the difference and that is why I feel that I should continue coming here to get drugs (ARVs) So that my body should not change, it should still be energetic. (**Participant 16, retained in care**).

Some participants also felt that the energetic body they had was as a result of the benefits of ART and they had the desire to continue taking ART with an aim of maintaining the good energy levels they had. The participants compared with the low energy levels they had before ART initiation and they were motivated to be retained in HIV care because of that difference.

One participant said:

...When you are taking the drugs (ARVs) you have energy and with that you have the desire that you should not miss your appointment date at the clinic for drug refill. You are able to differentiate how you were before you were initiated on therapy. The time I was not receiving ARVs, my body was very weak (**Participant 18, retained in care**).

Participants who missed some doses differentiated the energy levels in their body on the day they did not take ARVs. They associated the weakness they felt to the missed dose of ARV which left them with a feeling that the drugs are responsible for the good energy levels they usually experienced whilst on therapy. One participant said

...I have ever tried that when I was pregnant (laughs) when I had a disagreement with my partner I did not take the drugs, I also did not take nsima (Malawi's staple food). But the next morning I woke up very weak then I truly believed that these drugs give energy and they also safeguard the body (**Participant 15, retained in care**).

Desire to prevent HIV transmission to child.

The study showed that some participants were retained in HIV care with an aim of preventing HIV transmission to their children. The participants acknowledged of having the HIV infection but expressed their desire of maintaining the infection to themselves. One participant said ... The child that I am breastfeeding should not be found (HIV) positive even though I have the infection (**participant 17, retained in care**). Another participant commented: ... Like in my case, I take the drugs to protect my child so that he

should not become infected with the infection that I have, that is why I come here (to HIV clinic) every month for drug refill. **(Participant 15, retained in care).**

Another participant demonstrated in her narration that ART was the only way of protecting her child from HIV. She expressed her willingness to participate in HIV care for the sake of protecting her child from HIV. She expressed:

.... I was prepared for this and had no choice because I was pregnant and if I had refused the drugs, then it meant that my child could have acquired the infection (HIV) **(Participant # 10, retained in care).**

One participant reported that she felt she had the responsibility of protecting her children from HIV because if she had failed that, the children would suffer for a long time starting from a tender age. The participant was retained in HIV care for the sake of her children and believed that she had lived on earth for many years and wished the same for her children. She commented:

...What promotes retention in HIV care for a woman who has a child is that she wants to protect the life of the child, that the child should not be infected. So she sees that it is better that I continue taking ARVs because the child is still young, even if I can die today 31 years is enough but the child is only 2 months, so if I infect her and she starts taking medication at two months and if he takes these medications from now to the rest of her life I feel like I am infringing on her rights **(Participant 03, retained in care).**

A few participants expressed the desire to prevent HIV transmission to their children with an aim of saving themselves and the children from the torture that can come as a result of the infection. One participant had this to say:

... It happens that you have been found HIV positive, and you have also infected your child. When he grows up and starts to understand he begins to refuse medications (ARVs) that he does not want to take them. You also feel sorry for the child. May be he starts asking you questions that you cannot answer. Others also happen that they have grown up and are in school, their friends make fun of them **(Participant 2, retained in care)**.

Some women who had an HIV test during pregnancy believed that adherence to PMTCT advice given at the hospital was key to prevention of HIV transmission to their children. They further reported that they would be very proud to have an HIV negative child after they had followed the advice that was given at the hospital and this was something of great value. Some participants commented:

...What promotes my retention in HIV care is that; a lot of children who are born from mothers who had an HIV test whilst pregnant are found HIV negative, they have not been infected with HIV. It is only very few, not all but only a few that are found HIV positive. But when you go by what they tell us at the clinic, you find that a lot of children are found HIV negative **(Participant 8, retained in care)**.

...If they conduct the test again and find that she (referring to her child) is HIV non-reactive, to my part it will be something very valuable because I have not transmitted the virus (HIV) to the child. The problem was mine and it is still mine (**Participant #1 retained in care**).

However, it was revealed in the study that despite the mothers desire to prevent the transmission of HIV to their children, some mothers who dropped out of care were observed breastfeeding their babies. To avoid making the participants uncomfortable and to avoid being judgemental, the researcher did not ask on the reasons why the women were still breastfeeding their babies despite dropping out of care. However, it was noted from the mothers narrations that they believed that they have been healed from HIV hence there was no risk of transmitting HIV to their breastfed babies.

Desire to prolong life.

The desire to prolong their lives was one of the facilitators to retention in HIV care among breastfeeding women. Some participants reported a good understanding of why they take ART. They understood that they were not taking ART for the sake of the child alone but they were well aware that ART is also for their own health and defaulting from ART had serious consequences. Participants narrated that even when they stop breastfeeding they will continue taking ARVs because the drugs are keeping them alive. One participant narrated:

...I am supposed to be getting the care even after breastfeeding because it is protecting my life, because people who stop taking ARVs die unexpectedly. But we are supposed to continue taking the drugs, I must

just accept that I will take the drugs for the rest of my life (**participant #10 retained in care**).

Though the participants had the desire to remain in therapy because it was prolonging their lives, there were also some harmful practices in drug taking that they believed were normal. Some participants felt that it was normal to stop taking the drugs for some time and then resume taking them without any problem. One participant said:

... The end result of stopping taking the drugs is death because a lot of people are dying. In our village we hear that she was taking ARVs and when she stopped taking them she died. Because you can stop taking these drugs for a week and you can be fine, but if you stop taking them for a month when you resume you find that you become sick often, then you can die (**Participant #15 retained in care**).

Some participants found the HIV positive result a challenge but with a desire for a long life they accepted the results and followed the advice that was given at the hospital so that they can prolong their lives. One participant expressed:

.... I accepted it since it has happened because if I had not accepted it and just live my life as it was, I felt that my life would end on the way but I just felt it in my heart that with the situation I should not give up. I should go by what the hospital has told me. I am supposed to follow the advice that I have been given at the hospital. I should follow those advice that is why I followed them up to date, I get the drugs and I will not stop, I will continue getting the drugs (**Participant #11 retained in care**).

Despite the participants' desire to continue taking therapy with an aim of prolonging their lives, there was a practice regarding sexual intercourse that put their lives at risk of HIV related complications. Most women reported having unprotected sexual intercourse with their marriage partners at some point in time in a month. Some participants believed that having less frequent unprotected sexual intercourse eliminated the risk of reinfection. The participants commented:

It happens that you are on ARVs and you use condoms, someday when you want to have unprotected sexual intercourse, you can have it. But it should not be every day, you can find that your body is not healthy because it happens that your blood and that of your partner have mixed. But you can have unprotected sexual intercourse once in a while to ensure a healthy body (**participant #2 retained in care**).

We use condoms the time we want to have sexual intercourse. And also they say that if both of you are a couple you should be using condoms. May be once in a month you should be having plain sexual intercourse (unprotected sexual intercourse) but most of the times you should be using condoms to avoid reinfection (**participant #19 retained in care**).

Family and Hospital Support in HIV Care

Social support from the participant's significant others and the hospital played a role in promoting women's retention in HIV care. The majority of the participants received some form of support from the hospital and family which they felt helped them to be retained in HIV care. Two sub themes emerged from support in HIV care from

family and hospital. These were; family involvement in HIV care and quality of care at the hospital.

Family involvement in HIV care.

Family members and other relatives played a role in promoting the participants retention in HIV care. The participants expressed a positive attitude towards disclosure of HIV positive status to family and relatives. They reported that they received different kinds of support from their family members that contributed to their retention in care. For some, the support was provided by their partners, others their children, close relatives (mother, brother and/or sister) and for others, well-wishers in the community. Findings revealed that the support they received revolved around getting their medications at the clinic when they could not manage to do so, encouraging them to go for their appointment at the clinic and exempting them from some kind of work on appointment days. Participant number 12 (retained in care) said:

... When it is my appointment date, . . . I tell my mother that my appointment date is tomorrow so she tells me that I should miss the farm session of that day so that I could go early to the clinic with my child to get the drugs. . . . She also encourages me that I should not stop taking the drugs.

Other participants narrated:

... My mother supports me, sometime back when I was sick, I was giving her my health passport so that she could come to get my

medications. Sure, so I feel that she supports me. (*Participant # 01 retained in care*).

... My relatives take a big role that if I am seriously sick and fail to come here to take my medications, they can come and get them (ARVs and Cotrimoxazole Preventive therapy) for me (**participant # 6 retained in care**).

Some participants also reported that they disclosed their HIV status to their children who reminded them on daily basis to take their medications. Some participants narrated:

... I told my children that “my kids, what I can tell you as of now is that I have been found with this problem (referring to HIV infection). But you should not be worried with this problem, we will be living just like we used to. And also if I forget (to take my medications: ARVs and Cotrimoxazole preventive therapy) you have the freedom to tell me that mother you have not taken your medications today, there is no problem. Since then, December up to date (June), my children have been reminding me or they go themselves to take the medications and say mother here are your medications.” (**Participant # 3 retained in care**).

... My child is ten years old. She asks me that mother, are you not going to take your medications today? She reminds me. . . . Yes, I disclosed my status to her, she was asking me that “mother what are these drugs that you take every day?” I explained to her that I was found with this

problem (HIV positive). So when she notices that I have not taken my medications that day, she asks me that you have forgotten to take your medications. Yes, she reminds me (**Participant # 4 retained in care**).

Though some participants disclosed their HIV status to their children and received their support, some participants narrated that they received their children's support despite their non-disclosure. One participant expressed that she did not disclose her status to her child because she felt that he was still young (nine years old) hence cannot understand the meaning of HIV. However, she pointed out that the child supported her in drug taking. She had this to say:

... If I have taken the drugs in his absence he ask me that “mother have you taken your drugs?” so if I have taken in his absence I tell him that “yes I have taken”. If I have forgotten he is the one who reminds me to take the drugs. . . . I have never explained to him the function of the drugs. But he knows that I take the drugs every day. . . . I cannot explain to him why I take the drugs every day because he is still young. He cannot understand the meaning of HIV (**Participant # 7 retained in care**).

The majority of the participants expressed that their partners were the key people who provided them with the necessary support for them to be retained in therapy. They reminded them to take their drugs and also to go to the clinic on their appointment dates. One participant commented: ... Since my partner is close (laughs) he reminds me to take the drugs every day (**Participant # 15 retained in care**). Another participant said ... I am supposed to take the drugs every night when the time is 8 o'clock and also if I have

forgotten my husband reminds me that I should take the drugs **(Participant # 6 retained in care)**.

... They give us a date that on this particular date you should come to the hospital. When it is the date I remember and also my husband reminds me that I am supposed to come to the hospital to get the drugs. . . .

(Participant # 10 retained in care).

Though a lot of partners were supportive, one participant expressed that her partner was not willing to go by the advice that was given at the hospital. One of the packages of HIV care is consistent protective sexual intercourse, however, the participant reported that her partner refused to use condoms. She said:

... We do not have sexual intercourse frequently, may be twice in a week or once in a week and the days go by, what else can we do? Because he (her partner) refuses to use condoms **(Participant #15 retained in care)**.

Though the majority of the participants felt that the support they received from family was essential for them to remain in care, some participants felt that the support that people could provide would be useless if they have not accepted their results and take an active role in their care. Participant # 5 (retained in care) expressed:

... People surrounding you can encourage you but if you yourself do not take the drugs when it is time, will their encouragement be useful? It needs the owner to accept it first, when you accept it then people supporting you will just be reminding you to take your medications. And if you say you forgot, you will then take the drugs. But first it requires

you as the owner to accept it. . . . The ones to encourage you cannot really matter if you as the owner you are not serious with it.

Another participant said:

... I cannot say my partner or my relatives take part (in my care concerning HIV) there is nothing that they do, but I just know that you are a custodian of your life. You keep it yourself. So I know that if I can consider their support that means I will put my life on danger **(Participant # 20 retained in care).**

There were also some participants who felt that support from family was not necessary because everyone is responsible for her life. She expressed:

.... So even if my mother was aware of my (HIV) status, what would she do? Everyone is responsible for her life, period. And there is nothing she can do to make me access the HIV care, I stay here in my house and she also stays at her home **(Participant #21 LTFU).**

Quality of care at hospital.

The study findings revealed that some women who were attending the HIV follow up clinic with their children were impressed with the health care that was given at the hospital and with that they had no excuse for missing their appointment days. One participant said:

... on my part, the time that I can come here it all goes well and I do not see any problem that can make one to stop getting the drugs, the doctors assist us well. I come here, get my drugs and they assist us well. It is just

our different personalities, but personally I do not see any hindrance of failing to get drugs or to face any problem here, no **(Participant # 5 retained in care)**.

Another participant expressed:

... The reception is good and also when we enter the consultation room they ask us to explain any problems and if there is no problem you say there is none. But if you experience any problem you explain that I am experiencing this problem and they also assist you with that problem. So that is what motivates me that I should go to the hospital. I feel this problem I should go to the hospital and explain they will assist me **(Participant #9 retained in care)**.

The support that was provided by the health care workers and mentor mothers provided some encouragement to women. The women were very happy with the support and felt that it assisted them to be retained in HIV care. One participant who was retained in HIV care because of the encouragement she got at the clinic expressed:

... In terms of the hospital, I can say the advice that they give us at the hospital encourages me. They encourage us that if you have been found (HIV) positive, that is not the end of your life. It is what encourages me to be in care **(Participant # 8 retained in care)**.

Results also revealed that some participants felt that being a breastfeeding woman gave them all the reasons to be retained in HIV care because the hospital utilizes every

opportunity with the woman to ensure that she has access to the required health care.

Participant #7 retained in care narrated:

... It is a difficult thing for a breastfeeding woman to stop taking drugs, but may be to somebody who has no child. Who is not breastfeeding can stop taking the drugs. But for a breastfeeding woman it is a difficult thing because it happens that you have come with your child like this to under five clinic, that you want her weight to be checked so if you were not vaccinated with Tetanus Toxoid Vaccine (TTV) it means that they are supposed to vaccinate you. Whether you want or not they will still vaccinate you. The time you have the child is an easy time for you everything is possible, you are available to the health care workers (laughs).

The study results showed that some women gave antenatal care priority over drug refill. One participant felt that the antenatal attendance helps women to be retained in HIV care since they access HIV care when they come for their routine antenatal checkups. However, it was demonstrated in the participant's narration that the hospital provided support in terms of integration of clinics (antenatal and HIV clinics). She had this to say:

... The time that you are pregnant is like you are coming for two things; you are coming for antenatal clinic and sometimes the dates are close to each other. So at the HIV follow up clinic they were encouraging us that if the dates are close to each other you can make one date that you will go to antenatal clinic and also you will go for drug refill. Or else if it is

the date for drug refill it means you will go and get the drugs then attend antenatal clinic. So during that time you cannot do otherwise because of the antenatal clinic but when the child is born like this (pointing her child), you are also done with the antenatal clinic. You cannot have time to be going there for drug refill (**Participant # 8 retained in care**).

On hospital facilitators to retention in HIV care at the HIV follow up for pregnant women and children, some participants expressed satisfaction with the place where HIV follow up clinic was done. One of the participants said:

... Ever since I started taking the drugs, the hospital has never given me a reason to stop taking the drugs. Everything is confidential, it is between you and the doctor. They do not dispense the drugs in public, everybody has her own turn in the consultation room and it is a good room. You enter that room and close the door and have your consultation with the doctor (**Participant #9 retained in care**).

The study results revealed that some women were satisfied with the counselling they received on ART initiation as they stated that it prepared them well for the experience that they might face while on therapy and that promoted their retention in HIV care. She expressed:

.... The drugs gives you problems when you are just starting them. You tend to have bad dreams. But once your body is used to them it does not become a problem.... You have dreams where you see yourself dead, you see yourself shouting for help in the dreams but nobody can hear you, sometimes you feel dizzy but you want to go outside to

urinate and you do not see the door. You walk while leaning on the walls, you feel very dizzy and you can even fall down just like a drunkard. It ever happened to me (laughs)... Since they explained to me at the hospital that I can experience different things that some people dream death and some people experience severe headache when they start taking the drugs but some people do not experience anything. Some have severe headache and they say that when you experience severe headache that is worse than having such dreams (**Participant # 18 retained in care**).

Although some women expressed their satisfaction with the HIV care that was being provided at the facility, some participants expressed their dissatisfaction with the counselling that was provided at the facility expressing that it only focused on drugs and left aside other important components of retention in HIV care. She expressed:

. . . I feel the ones who give counselling are tired with their work. Previously there was special counselling for people who are on therapy that they should not be having sexual intercourse too often, they are supposed to be eating good food. But to be frank with you, I heard that counselling from a friend. I was not given that counselling at the hospital. They just told me that when you experience these problems you should come back. You should be taking the drugs and the child should be breastfed for a year and eight months. You should be taking the drugs and come back on such a date. But they did not tell me a lot of things (**Participant #15 retained in care**).

Another woman expressed that despite receiving counselling during pregnancy at the hospital, she felt that intense counselling was necessary after

delivery to promote retention in HIV care as women tend to lose the motivation to remain in HIV care after delivery. She expressed:

... I think when the woman has given birth she should also be given enough counselling more than she received (during pregnancy) that she should not stop taking the drugs... I feel in order to prevent the loss of motivation, may be when you have just delivered because when you are pregnant as I have already said that if you have gone in the morning, they make you sing some songs on issues of pregnancy so the loss in motivation comes after delivery. Therefore, after delivery there should be special counselling, encouraging us to remain in HIV care, to continue taking the drugs (**Participant #8 retained in care**).

Hindrances to Retention in HIV Care

The hindrances to retention in HIV care that the participants faced were either hospital related or personal factors depending on the cause of the barrier. From the results of this study, it has been shown that out of the four women that defaulted from care, three were lost to follow up because of personal factors. One participant mentioned hospital factors as the main reason for her loss to follow up. Some participants who were retained in HIV care mentioned a number of hospital factors as risk factors for their loss to follow up in the future.

Hospital factors.

Some participants expressed their dissatisfaction with HIV care that was provided at the facility and felt that this could be a hindrance to their continued access to HIV care

in the future. Mainly there were issues of long waiting hours, long distance to clinic, rude health care workers and lack of privacy.

Long waiting time.

Participants who experienced long waiting time shared their experiences as follows:

... I would love to be treated timely. It happens that I have come early in the morning around 6:30 am, but you find that they start giving us drugs at 9 or 10 am. Sometimes I come here before I have done household chores just because I want to be assisted on time. May be the child did not eat porridge because I came to the hospital (**participant # 2 retained in care**).

... The way we are assisted others feel that it is better I just leave and go to another hospital. Because the care we get here is somehow difficult, the difficult part is that a person can come early so that she can also go back home early. But the way they do their work it makes others lose their motivation because of the way they do their work, it draws them back. We arrive here around 6 am but until past 8 or to 9 am the doctors have not yet started their work concerning the drugs. So for a person to start accessing the care, you find that you leave this place around past 12 or 1 o'clock it means you will arrive home late as I have said on my part that I stay far away from here (**Participant #3 retained in care**).

One participant felt that the long waiting time at the facility was also as a result of staff members giving priority to some clients who report late. She commented:

... There are others who come late but just because they say they are staff members, they tell them to go in and yet the ones who came in the morning are just waiting (**Participant #2 retained in care**).

Other participants understood the reason for the long waiting hours and were calm with that. One client expressed that:

... It depends on how many people are dispensing the drugs. When there is one person, you find that he comes out to do some things then go back to continue giving us the drugs. So it happens that we take long or we are being served fast. But when there are two people dispensing the drugs, at least they serve us in good time (**Participant # 12 retained in care**).

Long distance to clinic.

The issue of long distance to the clinic was also mentioned as a hindrance to retention in HIV care. Participants raised issues of challenges in finding money for transport and the long walking distance as contributing factors to their loss to follow up as follows:

... It happened that I travelled to Mozambique, when I came back I was struggling to find money for transport to come for drug refill, you know money is a problem here in the village. That is the reason I missed my appointment days for six months (**participant # 22 retained in care**).

... In my case, I find it difficult in terms of transportation like from where I come from and this child is growing up and I tend to become tired whilst in transit. I wish that when my child stops breastfeeding, I

should get my file and be receiving the drugs at the nearest health facility in my area (**Participant #13 retained in care**).

Rude health care workers.

Participant who was treated by rude health care worker expressed that this could make her think twice before going for her next appointment. She said:

.... Sometimes it happens that we are troubled in our minds because the doctor was rude to us. When you tell her to review you early, she says she has a patient and they are rude. They say “I also have some work to do at home”. It happens that the doctor is being rude and you find that you are disappointed. You think about it when coming again that if I meet her again will she not speak the same unkind words or do the same thing (**Participant # 2 retained in care**).

Personal factors.

Other participants faced personal problems which hindered their retention in HIV care. Participants reported abusive partners, influence from religious gatherings, shy and lack of motivation.

Religious influence.

The study results have shown that religious influence is one of the contributing factors to poor retention in HIV care. Out of the four participants who dropped out of care, two of them expressed that they became loss to follow up because of religious belief. The Participant who stopped taking ART because of religious influence had this to say:

... My pastor has prayed for me, he has told me that I will never suffer from any disease, I have been healed from the disease that I had and I have no reason for going to the hospital to continue getting the drugs **(Participant # 21 LTFU)**.

Another participant said

Ever since I started going for the prayers, I no longer take the drugs because I believe that I have been healed from my sickness. I cannot take those drugs anymore because it will be like I do not trust the power of the prayers **(Participant 23 LTFU)**.

Another participant who witnessed the influence of religion on continued ART taking had this to share:

... Like there are others in certain churches they are telling people that I have prayed for you, you are healed you should stop taking drugs, like I have ever seen this where I stay somebody has been discharged from the hospital just a day before yesterday when she went to a certain church where they told her that I have prayed for you, stop taking drugs. Indeed she stopped and when she stopped she became very sick and she came here (at the hospital), with the grace of God she is now fine. When they restarted her on drugs she has been healed. A lot of them are due to the influence of the pastors they are telling them that I have prayed for you, you should stop taking the drugs you have been healed in the name of Jesus but they are laying with an aim that you should be saying that I am

healed. . . . This is happening in a lot of churches (**Participant # 9 retained in care**).

When the participants were asked on continued breastfeeding in the state of dropping ART. It was revealed that all participants who dropped out of ART for whatever reason they had, they continued to breastfeed their children. They narrated:

I still breastfeed my baby because I know that I was healed and there is no way I can put my child on danger. I know I am healed (**Participant 21 LTFU**).

Unsupportive partners.

Unsupportive partners have also emerged as a hindrance to retention in HIV care. One of the participants narrated:

...I saw a certain woman in the clinic and when they asked her for how long she has stayed at home without drug refill she said that I am now separated with the partner who was against me taking the drugs so I have found a new partner who is also taking ARVs so he has given me a go ahead to be accessing the care (**Participant #20 retained in care**).

Another participant expressed that having a new partner could hinder retention in HIV care as women were not willing to disclose their status for fear of losing their partners. She expressed:

... Sometimes it happens that they (referring to other women) have found a new partner and they are afraid that the new partner will know that they take ARVs so they stop taking the drugs because they have got

married to a new partner so he should not know that she gets ARVs
(Participant # 10 retained in care).

Some unsupportive partners could also hinder participation in some activities which are essential for women accessing HIV care. One component of preventing reinfection with HIV is consistent protected sexual intercourse, but it was reported in this study that some partners refused to use condoms.

...Like in my case when they asked me if they should give me condoms I refused. I refused because I do not have sexual intercourse frequently may be twice or once in a week. My partner also refuses to use condoms
(Participant #15 retained in care).

Despite majority of the participants in this study expressing that they received partner support, some participants expressed that the main reasons their colleagues dropped out of care were unsupportive partners and abuse in the homes as a result of positive HIV result. They expressed:

.... When she (referring to another women) come to the hospital and receive the drugs and go home, she finds that the partner is telling her not to take the drugs in his house. Sometimes it happens that the woman has been diagnosed (HIV) positive, has gone home and when explaining to the partner, instead of him accepting the news, he starts beating the wife. And he tells her to go and tell her doctor that she should be taking the drugs right there at the hospital not at his home. That is when the wife stops taking the medications **(Participant #2 retained in care).**

Feeling ashamed and afraid.

The study has shown that some participants became loss to follow up due to fear of the community members. Women expressed that they were shy when people from their community see them at the ART clinic and that was one of the reasons some participants became loss to follow up. She expressed:

... In my case the news that I take ARVs was spread at my community because of some people from my village who saw me at the clinic, because of that I was shy to continue coming here for drug refill **(Participant #24 LTFU)**.

Another participant commented

... Some women are shy to come to the hospital to get ARVs, they say they are afraid that people will make fun of them that they are on ART **(participant #14 retained in care)**.

Though some participants were still in care, they felt that the issue of privacy especially at the adult ART clinic, which they will be discharged to after breastfeeding was a concern. She expressed:

... I could have loved if adult ART clinic was done in a private place. Because where it is done every person who passes by see you and they know that such a person gets ARVs. You even find that the ones who are shy cover themselves with a wrapper so that when relatives are passing by they should not see them **(participant # 20 retained in care)**.

Loss of motivation.

Some participants expressed that there is loss of motivation in drug taking along the way. The participants felt that pregnancy gave them an opportunity to be retained in HIV care but after childbirth, there is decreased motivation to retention in care. She expressed:

... Most of the times it is the loss in motivation that women stop accessing HIV care. I was diagnosed HIV positive whilst pregnant now that I have given birth, I can stop going to the clinic (**Participant # 8 retained in care**).

Other participants reported that some women lose the motivation to continue taking ARVs because they develop side effects whilst on therapy. She commented:

... Some women stop taking medications (ARVs) because they develop rashes while on therapy. For some they become sick so that is the reason why people lose the motivation of continued therapy (**Participant #1 retained in care**).

Other participants also felt that the hospital should improve on counselling that is given to mothers post-delivery because it is a time that they usually lose their motivation to remain in therapy. She expressed:

. . . Inorder to prevent loss of motivation, I think that after delivery there should be special counselling, encouraging us to continue on therapy, so that we should not stop taking the drugs. Since when you are pregnant, as I have already said that if you have gone in the morning, they make you

sing some songs on issues of pregnancy but the loss of motivation comes after delivery. So after delivery they should intensify the counselling
(Participant #8 retained in care).

Lifetime Commitment to Therapy

Participants expectations regarding HIV care after childbirth was assessed in order to ascertain their expectations regarding the duration of therapy and the outcome of HIV test on the wellbeing of the baby. The results of this study showed that most of the participants were well aware that ART is a lifetime commitment and they were prepared for lifetime commitment to therapy. Participants expressed knowledge on how the drugs work that it was not a cure for HIV but to lessen symptoms of the infection. Two participants expressed:

... When you have been found HIV positive, you will take the drugs for the rest of your life. It does not mean that when they have found you positive and given you drugs that you are healed, no. you are not healed, it is just to protect you (Participant #2 retained in care).

...I will take these drugs for the rest of my life, the only limit is death. Once I die it is when I will stop taking them that is how I will be separated from the drugs period. But there is no such thing like I will leave ARVs because if I stop taking them I will add other problems.

(Participant 4 retained in care).

Women showed the enthusiasm to remain in therapy even after breastfeeding because ART is a lifetime commitment. One participant said:

... I am prepared to take the drugs for a lifetime. Even after the child has stopped breastfeeding, I will continue taking these drugs for the rest of my life (**Participant # 16 retained in care**).

Another participant said

...I am supposed to be accessing HIV care even after breastfeeding because it is protecting my life. People who stop taking ARVs die unexpectedly. But we are supposed to continue taking the drugs, I must just accept that I will take the drugs for the rest of my life (**Participant #10 retained in care**).

The study also revealed that most participants were aware of the effects of defaulting from ART. The participants reported that the end result of stopping the drugs is unexpected death or a syndrome of diseases. One participant said

...The danger of stopping ART is that once you stop taking the drugs it means you should just know that death is close because with this infection when you stop taking drugs, you suffer from a syndrome of diseases, you suffer from abdominal pains, malaria that is what I hear. Like where I come from there was a relative, she stopped taking drugs and the end result was death. So I feel that it is a risk to stop taking these drugs (**Participant # 11 retained in care**).

CHAPTER 5

Discussion

Introduction

This chapter presents a discussion of findings of the study which aimed at exploring the facilitators and barriers to retention in HIV care among breastfeeding mothers at Thyolo District Hospital. The study results show that breastfeeding mothers were retained in HIV care because of the benefits of ART on their lives, children and the family. Breastfeeding mothers were also supported by their family members and the health care providers which enabled them to remain in HIV care. However, the desire of breastfeeding mothers to remain in therapy was hindered by some personal and hospital factors. Despite the participants hindrances to retention in HIV care, majority of the mothers were well aware that ART is a lifetime commitment and expressed their desire to remain in therapy for life. Therefore, the discussion is based on four main themes that emerged from data analysis. These were: improved quality of life, family and hospital support in HIV care, hindrances to retention in HIV care and lifetime commitment to therapy. Finally, recommendations, conclusion and limitations of the study are presented.

Improved Quality of Life

Restoration of good health.

The findings of this study show that the immediate benefits of ART on the quality of life improved retention in HIV care among breastfeeding mothers. The breastfeeding mothers reported that restoration of good health and increase in strength were some of the

important facilitators to retention in HIV care because it enabled them to perform all kinds of household work. Breastfeeding mothers felt that ART was responsible for the good health they had that enabled them to do all kinds of household work. Similarly in Zimbabwe, Chadambuka et al. documented that women reported strengthened health as a benefit of ART because it allowed them to take care of their families and do all their daily household chores (Chadambuka et al., 2017). Thus improved quality of life for breastfeeding mothers improved uptake of HIV care and promoted retention in HIV care. In a qualitative study done in Lilongwe Malawi, results showed that women were accepting the treatment easily because they perceived that ART would improve their health since they believed that the ill health was as a result of the HIV infection (Kim, et. al., 2016). In a related study in the same city Lilongwe Malawi, Gugsu et al., found that the motivating factor for women to remain in treatment was the improved health and feeling better after starting ART, as women compared their health before and after ART initiation Gugsu et al., 2017). This could be true for majority of breastfeeding mothers in this study as they reported the immediate benefits of ART as restoration of their health after ART initiation which improved the quality of their lives.

Desire to prolong life.

The study findings showed that the desire of breastfeeding mothers to prolong their lives was one of the important facilitators to retention in HIV care. The breastfeeding mothers reported that they were retained in HIV care with an aim of prolonging their lives so that they could take care of their children. This implies that breastfeeding mothers could be aware that ART improves the quality of life as the drugs improve the immune system of an individual and helps one to live long. The findings are

in line with available literature that women found hope of prolonging their lives with ART and achieved their desire of raising their children themselves (Katirayi et al., 2016 and Elwell, 2016). However, the study findings show that there were some misconceptions in taking of ART. This was evidenced by some participants who reported that they had interruptions in taking ART on certain days of the month with a thought that such practice was normal. Consequently, this practice could put breastfeeding mothers at risk of ART and HIV associated morbidity and mortality because literature shows that the effectiveness of ART is dependent on continued adherence to ART (Rollins, 2014). The interruptions in ART has serious consequences for the mother, child and the population at large, because it leads to development of drug resistant strains of HIV in the mother that cause disease progression which is difficult to treat especially in resource limited settings (Bhardwaj et al., 2015 and Ngarina et al., 2013). This practice also contributes to the immediate impact of increased risk of HIV transmission to the child because continued breastfeeding in the absence of any intervention increases the risk of HIV transmission to 15 to 45% (WHO, 2010) and such practice also affect the population at large by promoting development of viral resistance (Bhardwaj et al., 2015).

The interruption in ART taking has also been reported in earlier studies, but the reasons for interrupted ART taking reported in previous studies were different from the reasons reported in this current study. In the previous studies, side effects and forgetting to take drugs were the commonly mentioned reasons for drug interruption in Lilongwe, Malawi, (Gugsa et al., 2017) While in this study, the main reason for breastfeeding mothers to interrupt ART taking during breastfeeding period was the feeling that skipping drugs in certain days of the month had no effect on their lives. In another study in

Tanzania, ART interruption was reported by women who had stopped breastfeeding because they felt that the risk of transmitting HIV to their children was eliminated (Ngarina et al., 2016).

Desire to prevent HIV transmission to child.

Most mothers had a strong desire for an HIV negative child. Mothers expressed their readiness to do everything possible to have an HIV negative child. This finding is concurrent with other studies done in sub Saharan Africa that showed that mothers gave priority to the protection of their children from HIV above everything else. In a study in South Africa, Clouse et al., found that mothers cared more about their children above their own health as they were keeping their appointment days during pregnancy and adhering to therapy with an aim of protecting their children from HIV (Clouse et al., 2014). In a related study in Zimbabwe, the investigators found that mothers were committed in taking ART in order to protect their children from the drug burden (Chadambuka et al., 2017). Additionally in Tanzania, mothers were bearing the side effects of ART during breastfeeding because they wanted to protect their children from HIV and could not stop taking the drugs despite the severity of the effects (Ngarina et al., 2013).

The mothers desire to protect their children from HIV during pregnancy and breastfeeding was a good initiative and it should be commended as they contributed to the elimination of HIV epidemic to future generation. However, it could also be a threat to continued retention in HIV care once the child is fully protected from HIV because loss of motivation to continue therapy when the risk of HIV transmission is gone has been reported in this current study and earlier studies (Clouse et al., 2014; Ngarina et al.,

2013). Even though this study revealed that mothers were committed and motivated to continue therapy because they wanted to protect their children from HIV, their continued commitment to therapy after breastfeeding was questionable as breastfeeding mothers expressed that their main motivation to remain in therapy was to protect their children from HIV hence the risk of loss of motivation to continued retention in HIV care. This is consistent with studies in South Africa and Tanzania by Clouse et al., (2014) and Ngarina et al., (2013) respectively that showed that there was loss of motivation to continued retention in HIV care once mothers felt that their children had been protected from HIV.

Family and Hospital Support in HIV Care

Family involvement in HIV care.

In this study, majority of breastfeeding mothers reported that they disclosed their HIV positive sero status to their male partners and in return they were supported in HIV and ART related services which promoted their retention in HIV care. The support was in form of encouragement to go for their HIV clinic appointments, provision of transport money to the HIV clinic and also reminding the women to take their drugs on daily basis. The findings above imply that partner support in HIV related care services is one of the most critical factors influencing retention in HIV care, as it leads to improved utilization of HIV care services and retention in care. This concurs with the findings of Gugsu et al., (2017) who found that in central region of Malawi, partners aided women's retention and adherence in ART by motivating them to take the prescribed ARVs, reminding them to take their drugs on daily basis, allaying treatment related fears and assisting them financially to be retained in care

Additionally, several studies reported that partner support produced desirable outcomes in retention in HIV care (Hodgson et al., 2014; Dunlap et al., 2014; Busza et al., 2012, Kalembo et al 2013; Aluisio et al., 2016; Gugsu et al., 2017 and Flax et al., 2017). In a systematic review in sub Saharan Africa, investigators found that women who had their male partners involved in their treatment had improved ART initiation, adherence and retention (Hodgson et al., 2014). Additionally other studies found that male partner involvement in HIV care statistically increased the probability of women accepting HIV testing, initiate treatment and be retained in HIV care and decrease the risk of infant death due to vertical transmission of HIV (Dunlap et al., (2014), Busza et al., (2012), Kalembo et al., (2013) and Aluisio et al., (2016). On the other hand, Gugsu et al., (2017) in Lilongwe, Malawi found that more than half of the women who were loss to follow up were the ones who were not supported by their partners and families to cope with their diagnosis and assist in treatment despite their disclosure to them. This implies the power of partner support in retention in HIV care.

Despite the study findings that show that majority of the breastfeeding mothers received support from their partners, some mothers frequently reported incidents of domestic violence and lack of partner support as reasons for loss to follow up of other breastfeeding mothers. It could be true that the violence that women reported could relate to their own life experiences because issues of domestic violence are difficult to discuss hence people tend to get emotional distance from traumatic events so they feel safer to discuss such issues in other people's circles. Literature shows that much abuse remains hidden and requires active efforts to make it possible for women to express their experiences and seek help (Spangaro, Zwi, Poulos and Man 2010). According to Malawi

demographic health survey of 2015/2016, the percentage of married women who have ever experienced emotional, physical or sexual violence committed by their current or most recent partner was 30% for Thyolo which is higher than the national average. Additionally, Thyolo district accounted for 21-22% of women who have experienced violence in the past twelve months (MDHS 2015), and women with HIV usually were more vulnerable to violence than HIV negative women. Therefore, this suggests that women interviewed in this study could have experienced domestic violence.

Findings of this study further showed that the support of other family members was critical to women's successful participation in HIV care. Participants expressed that their children and some close relatives provided them with some support necessary to be retained in HIV care. The participants expressed that their children reminded them to take their drugs on daily basis and their close relations reminded them to go for their appointment days and asked them periodically if they were still taking drugs. Disclosure to more than one person is critical in people on ART because it ensures available help in times of need (Flax et al., 2017). The findings are consistent with earlier studies that showed the importance of family involvement and support in HIV care (Foster et al., 2010 and Yehia et al., 2015). In a study in Uganda, the investigators found that multiple family members were important for adherence among all women initiating ART treatment because they reminded the women to take their drugs (Foster et al., 2010). Similarly Yehia et al., (2016) found that family members motivated participants to attend clinic appointments and assisted in food availability and transport costs.

Quality care at the hospital.

The findings of this study further found that the support that was provided by the health care providers and mentor mothers (mothers to mothers) was a source of encouragement to women. The results indicate that women were very happy with the support they received at the HIV care clinic and felt that it assisted them to be retained in HIV care. The participants received support from mentor mothers in form of encouragement, follow ups and advice during their drug refill appointments. This is concurrent with results of a study which was conducted by Shroufi et al., in Bulawayo, Zimbabwe which found that Mentor mother support led to improved retention and adherence in HIV care because of the increased credible first-hand experience the women got from the mentor mothers (Shroufi et al., 2013). Similarly in Lilongwe Malawi, Kim et al., found that the support through treatment support, encouragements and home visits that the community health workers made helped women to be retained in HIV care (Kim et al., 2016).

Additionally, the findings of this study found that the health care workers were supporting women to be retained in HIV care by integrating the antenatal clinic and HIV clinic services. Participants in this study reported that at the HIV follow up clinic, they were encouraging them to have one date of appointment in a month, that is if the dates for antenatal clinic and HIV clinic were close to each other they made it one date so that the mothers would attend antenatal clinic and also go for HIV care appointment and vice versa.

Evidence has shown that integrated HIV and antenatal clinics promotes retention in HIV care as it eliminates challenges of frequent need for hospital visits (Helova et al.,

2017; Iroezi et al. 2013; Govindasamy et al. 2014; WHO 2014). In a qualitative study in western Kenya, investigators found that different clinic dates created challenges of distance, time and costs that created additional barrier for women accessing care (Helova et al., 2017). However, other investigators found that integrated antenatal clinics and/or infant testing increased the probability of ART initiation and retention in HIV care (Aloezi et al., 2013; Govindasamy 2014; and WHO 2014). Therefore, it could be implied that the integration of the antenatal clinic and HIV clinic in this study was promoting retention of breastfeeding mothers in care because they had no issues of frequent visits to the hospital hence eliminating the barrier of transport costs and time.

Another element of quality care that was revealed in the findings is the way risk factors for loss to follow up were handled at the HIV care clinic. In this study, participants reported side effects like strange night mares during the first days on ART which they were told at the HIV care clinic when starting ART. The regimen that pregnant women in Malawi are taking is 5A which contains Efavirez and one of the known side effects of Efavirez is vivid dreams or night mares especially in the first months of treatment which eventually resolves within a month or two. In earlier studies, strange night mares have been reported to be the cause for interrupted ART taking and it took the initiative of the clients to go to the hospital to ask about their experience (Gugsa et al., 2017). However, this was a different experience in this study as participants were well aware that they might experience this and they continued to take the drugs with the hope that one day the side effect will resolve.

Hindrances to Retention in HIV Care

Hospital factors.

Participants reported of receiving inadequate information at the clinic. The counselling that was provided at the facility mainly focused on issues directly related to ART like drug adherence and keeping appointment days. The participants' complained that the information they got lacked other important information like safe sex and different food groups. Another participant in the current study recommended intense counselling on importance of retention in HIV care after delivery as there might be reduced motivation to continue therapy after the first postpartum checkups. This suggests that the information that is given to clients at the HIV clinic might be inadequate and this might affect engagement in HIV care in the long run. Earlier studies in Malawi demonstrated similar findings that counselling was not given enough time by health care providers so good decision making of clients was hindered (Katirayi et al., 2016).

Additionally, majority of the participants reported in this study that they did not had enough time with the health care workers which resulted to unanswered questions to most of the questions they had like consequences of missing a pill. In Lilongwe Malawi, investigators found that majority of women who became loss to follow up were the ones who received little counselling at ART initiation with content that majorly focused on the need for initiation of ART and its advantages on protecting the baby (Gugsa., 2017). Therefore this suggests that with counselling that does not focus on the mother holistically, women tend to drop out of care.

Long waiting time was also mentioned as a possible risk of loss to follow up for participants in this current study. The findings showed that women were going to the

clinic early with the hope of being assisted on time and going back home early. However, it was reported that they took long to be assisted due to staff shortages, staff attitude and some hospital staff members given priority over them despite their coming early. Therefore such issues implies that retention in HIV care would be affected in the long run as the quality of care is compromised and some women may lack patience and understanding under such circumstances. In Kenya, investigators found that staff shortages negatively affected the quality of services given to women on ART and that had an impact on adherence and retention in HIV care (Helova et al., 2017).

The findings of this study also found that negative treatment by health care workers was reported as a threat for continued retention in HIV care because some participants reported that they were treated by rude health care workers. This could suggest that if such practices continue at the facility, some mothers on ART programs may disengage from care as earlier studies have demonstrated that negative staff treatment was a barrier to continued access to HIV care (Flax et al., 2017; Clouse et al., 2014). Investigators in their study of factors influencing postnatal option B+ participation and breastfeeding duration among HIV positive women in Lilongwe, Malawi found that negative treatment by health care providers was a barrier to engagement in care (Flax et al., 2017). Similarly, in South Africa Clouse et al., (2014) found that negative staff treatment was a barrier to PMTCT participation.

Personal Factors.

The study findings showed that some participants had personal factors which hindered their retention in HIV care. One of the commonly mentioned personal hindrance to retention in HIV care that was reported in this study was religious influence.

Participants reported of dropping out of ART because they have been healed from HIV through prayers. Unlike in the previous studies in Lilongwe, Malawi that found that religious belief was insignificant factor for contributing to loss to follow up among women on ART (Kim et al., 2016), this study has produced conflicting results as it found that religious belief was the main contributing factor to loss to follow up among some breastfeeding mothers. Women were so rooted in the religious belief and stopped accessing HIV care in the belief that they have been healed from HIV.

It was heartbreaking to find out that although women were not accessing HIV care in the belief that they have been healed from HIV, they continued to breastfeed their babies which put them on increased risk of HIV transmission to the exposed baby. Studies have found that women who drop out of care continue to breastfeed their babies based on different factors. A study in Lilongwe, Malawi investigators found that women continued to breastfeed their babies despite their disengagement in PMTCT because they had no alternative. Though they were aware that they were putting their children at risk of HIV transmission, they could not help the situation because they also had problems of food insecurity in their homes and had no ability to feed their babies on formula (Flax et al., 2017). Additionally, it was mentioned in the same study that despite food insecurity and poverty playing a role, issues of cultural norms also influence the decision of mothers on breastfeeding as Malawi culture expects women to breastfeed for at least 24 months. So this implies that the risk of children acquiring HIV from mothers who drop out of care will continue to rise as evidence shows that there is an increased risk of HIV transmission to babies who are continually breastfeed without any intervention (WHO, 2010).

Additionally, some participants in this study reported that they had witnessed women who dropped out of ART due to religious influence facing severe consequences like serious sickness and sudden death. This suggests that the women who witnessed such consequences in the colleagues might continue being engaged in HIV care in fear of facing the same consequences. The known effects of disengagement in HIV care are increased risk of HIV transmission to the exposed infant through breastfeeding (Obai, Mubeezi & Makumbi 2017), hindrance to continuous follow up for the exposed infant, denying him/her the opportunity for early identification and initiation of treatment (Kalembo and Zyambo 2012) and increased mortality and morbidity for the mother due to HIV related complications (Van Lettow 2010). However, studies in Lilongwe, Malawi have shown that awareness of some women on the consequences of stopping ART was a motivating factor to remain in treatment (Gugsa et al., 2017).

Lifetime commitment to therapy.

The study findings revealed that mothers were well aware that ART is a lifetime commitment and they shared their intention of remaining connected to HIV care for life despite stopping breastfeeding at the recommended time. This is contrary to findings from other studies which found that women were not ready for lifetime commitment to therapy ((Kim et al., 2014; Katirayi et al., 2016; Kieffer et al., 2014; Gugsa et al., 2017 & Helova et al., 2017). For instance in Swaziland, Katirayi et al., found that women were afraid of lifetime commitment to therapy and discussed the use of other drugs to help in improving their immunity rather than to commit to therapy for life (Katirayi et al., 2016). Similarly, in Lilongwe, Malawi, Kim et al., found that women were concerned with the lifetime commitment to therapy despite their desire to prevent HIV transmission to child

and wished they could stop ART after breastfeeding and restart when they felt ill (Kim et al., 2014). The commitment to take ART for life regardless of their good health state was a concern for most mothers in a study in central region of Malawi (Katirayi et al., 2016).

Additionally, findings of this study revealed that the reasons mothers were ready for lifetime commitment to therapy was the fear of facing the consequences of defaulting from ART like frequent illnesses and sudden death, effects they had seen in the community members who dropped out of ART. The participants expressed that they would not want to face those consequences and that was another reason for their retention in HIV care apart from the desire to prevent HIV transmission to their children. This concurs with the findings of Gugsu et al in Lilongwe, Malawi who found that the awareness of some women on the consequences of stopping ART was a motivating factor to remain in treatment (Gugsu et al., 2017). However, the difference in the results on readiness for lifetime commitment to therapy reported in the study and the previous studies could be explained in part by the time period people have been exposed to ART and the negative effects they have seen in people who dropped out of ART. Earlier studies done in Lilongwe, Malawi showed that women who started ART a year later after option B + was introduced were more likely to remain in care than the ones who were initiated on ART the same year option B+ was introduced (Tweya, 2014). This implies the impact of time on acceptability of lifetime commitment to therapy and this could be true for the breastfeeding mothers in this study.

Despite the readiness of the majority of participants for lifetime commitment to therapy, the findings also showed that there were some sentiments few women expressed that were questionable as far as their continued retention in HIV care after breastfeeding

was concerned. For example, some mothers expressed that as long as you are a breastfeeding mother, you cannot stop taking ART because the hospital utilizes every opportunity it comes in contact with a breastfeeding mother to ensure that she accesses all the necessary health care. This therefore implies a possible threat of becoming loss to follow up after breastfeeding since the women will not have frequent visits to the hospital.

Additionally, this sentiments reveals that mothers care more about their children's wellbeing than their own health as they can be in care the time they are breastfeeding their child with an aim of preventing HIV transmission and might stop accessing HIV care after breastfeeding. Similarly, in Kenya investigators found that health care providers perceived that postpartum women may drop out of care once the child was found to be HIV negative at 18 months (Helova et al., (2017). That finding is also concurrent with study in South Africa who found that the main reason women are retained in HIV care was to protect the child from HIV and nothing else hence the risk of loss to follow up after protecting their child from HIV (Clouse et al., 2014).

Recommendations

Based on the study findings. The following recommendations have been made in terms of Nursing and Midwifery practice and Research.

Nursing and Midwifery Practice

The study showed that breastfeeding mothers had interruptions in ART taking because of lack of knowledge on the impact of such practices. Therefore, there is need for women to have more intensive adherence education augmented by an increased frequency of follow up visits to increase women's understanding of and engagement in

the ART program. Evidence has shown that non adherence to ART is associated with severe consequences for the mother, child and the population at large. However, with counselling and home visits, there is improved engagement in HIV care programs.

There is a need for assessment of domestic violence for breastfeeding mothers assessing HIV care clinic. The current study suggested that there might be domestic violence secondary to disclosure of positive HIV status to partners, but women were not so free to talk about it. However, previous studies have also shown that a lot of abuse remains hidden and there is a need for active efforts to help women to express their experiences and seek help (Spangaro, Zwi, Poulos and Man 2010).

The study revealed that few women were worried of their privacy after the breastfeeding period as the area where the clinic is conducted is a way for other patients in the hospital, they therefore expressed that such lack of privacy could be a threat to their continued retention in HIV care. Therefore, there is need to provide enough privacy at the adult ART clinic to prevent involuntary disclosure of HIV status. Evidence has shown that a mother who feels that there is no enough privacy may decide to stop accessing HIV care in the long run (Wachira et al., 2012) which might increase the risk of morbidity (Van Lettow 2010). Conducting ART clinics at a separate private place within the hospital premises might help in solving issues of involuntary HIV disclosure.

Research

The study identified the gaps that need to be addressed through further studies as follows:

A similar study can be conducted at a secondary and tertiary levels of care to explore the factors influencing retention in HIV care among breastfeeding mothers from the perspective of Health care providers

There is a need of a study to assess the magnitude of domestic violence in breastfeeding mothers with HIV following disclosure of HIV status to partners. This is because responses that women gave in this study suggested that there might be domestic violence as a result of positive HIV result and issues of HIV sero discordance in couples.

There is a need for a study to assess the magnitude and predictors of loss to follow up after breastfeeding period in women on option B+, as the findings of this study suggested that some mothers can become loss to follow up when their child has been fully protected from HIV.

Limitations of the Study

The study did not explore Health Care Providers perspective on the matter as their perception on factors influencing retention in HIV care could have enriched the findings, this might have a bearing on the findings.

Tracing of the loss to follow up mothers was a challenge as most of them stayed in distant places which required the mentor mothers to be free in order to provide company. There were also some challenges in terms of how many women to recruit in the study as some refused to take part in the study. This affected the number of the loss to follow up mothers recruited in the study as only four LTFU women accepted to take part in the study against six women who were approached to take part in the study.

Conclusion

This study has highlighted some factors influencing retention in HIV care from the perspective of breastfeeding mothers at Thyolo District Hospital. Findings revealed that the main facilitators to retention in HIV care among breastfeeding mothers were; improved quality of life as a result of access to HIV care and support that family and hospital provided to the breastfeeding mothers. However, there were some hindrances to retention in HIV care that mothers reported in this study which were both personal and hospital related. Despite the hindrances to retention in HIV care, the study has revealed that mothers were ready for lifetime commitment to therapy. Though some women were perceived to be at increased risk of loss to follow up after breastfeeding despite their expression that they were ready for life time commitment to therapy.

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APPENDICES

Appendix 1A: Letter to the District Health Officer (DHO)

University of Malawi
Kamuzu College of Nursing
Post Office Box 415,
Blantyre
28th March, 2017

The District Health Officer
Thyolo District Hospital
Post Office Box 21
Blantyre
Dear Sir

REQUEST TO CONDUCT A RESEARCH STUDY AT THYOLO DISTRICT HOSPITAL

I write to seek permission to carry out a research study at Thyolo District Hospital, maternal and child health department. I am a student currently pursuing a Master of Science Degree in Midwifery at the above mentioned institution. In partial fulfillment for the degree, I am supposed to carry out a research study related to Midwifery practice. The title of the research project is **“Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district Hospital.”** The knowledge gained will assist in improving standard and quality of care provided to patients at the facility.

Looking forward to hearing from you soon.

Yours Faithfully

ANGELLA JAMBO (Ms)

Appendix 1B: Approval letter from District Health Office

Telephone: + 265 1 473 411
Facsimile: + 265 1 473 409

All Communications should be
addressed to:

The District Health Officer:



In reply please quote NoTDH/
Ministry of Health,
Thyolo District Hospital,
P.O. Box 21,
Thyolo.
Malawi
Central Africa

5th April, 2017

The chairperson,
College of Medicine Research and Ethics Committee,
Malawi College of Medicine,
Private Bag 360,
Blantyre.
Dear Sir/Madam,

LETTER OF SUPPORT TO CONDUCT A STUDY AT THYOLO DISTRICT HOSPITAL

This letter serves as support for a study titled “**Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo District Hospital**”.

Retention in HIV care among women after the postpartum period is a challenge at Thyolo district Hospital. The barriers and facilitators to retention in HIV care among breastfeeding women have not yet been comprehensively studied so as to evidence for development of suitable policies that will enhance retention of breastfeeding women in HIV/ART care.

Yours Sincerely,

A handwritten signature in black ink, appearing to be 'Dr Michael Murowa'.

Dr Michael Murowa
DISTRICT HEALTH OFFICER



Appendix 2A: Participants' Information Letter– English version

Dear participants

My name is Angella Jambo and I am currently registered as a student at University of Malawi, Kamuzu College of Nursing for Master of Science degree in Midwifery. I am conducting a research project on “**Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district Hospital.**” and I write this letter to ask you to participate in the study mentioned above.

The aim of the study is to explore the barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district hospital.

Participation in the study is entirely voluntary. You may choose to participate or withdraw from the study at any time, which will not have any effects on the services that you are receiving from the health care providers in this hospital. There are no major risks associated with the study but some participants may feel uncomfortable to answer some questions in which case they will be reminded that they have a right not to answer all questions or to withdraw from the study at any time.

I appreciate that you will derive no benefit from participating in the study. However, exploring the barriers and facilitators to retention in HIV care among breastfeeding women will assist in improving the standard and quality of care given to ART patients at the facility. No reports in this study will identify you in any way and results of the study will be given to you should you so wish. Should you agree to participate, I will ask you to sign a consent form or put a finger print on the space provided to indicate that you have accepted to be interviewed. It is anticipated that the interview will take 45 minutes to one

hour of your time. The interview will be conducted at a time that is most suitable and convenient to you in a quiet environment to avoid any disturbances.

The study has been approved by College of Medicine Research and Ethics Committee (COMREC) and Thyolo district hospital.

Should you require any further information regarding the study or your rights as study participant you are free to contact me on the following number: 0881 551 246 or the chairperson, COMREC Secretariat, P/Bag 360, Chichiri, Blantyre 3 or you may call on 01989766.

Thank you for taking time to read this information letter.

Appendix 2B: Participants Information Letter – Chichewa Version

Kalata yofotooza za kafukufuku wa zolepheretsa amayi oyamwitsa kupitiliza kulandira chithandizo cha HIV patadutsa masabata asanu ndi imodzi kuchokera tsiku lomwe anachira kuchipatala chachikulu ku Thyolo.

Wokondedwa otenga mbali

Ndine Angella Jambo, wophunzira zaunamwino kusukulu yaukachenjede ya Malawi ku Kamuzu Koleji, amene ndikuphunzira za uzamba ndipo ndikupanga kafukufuku wokhuza zolepheretsa amayi oyamwitsa kupitiliza kulandira chithandizo cha HIV patadutsa masabata asanu ndi imodzi kuchokera tsiku lomwe anachira kuchipatala chachikulu ku Thyolo.

Ndalemba kalatayi ndi cholinga chofuna kukupemphani kuti mutengepo mbali polowa nawo mukafukufukuyu. Cholinga cha kafukufukuyu ndi kusathula maganizo amayi oyamwitsa pa chithandizo cha HIV kuchokera pa masabata asanu ndi imodzi kuchokera tsiku lomwe anachira. Izi zizathandiza ogwira ntchito kuchipatala kugwira bwino ntchito yawo ndi amayi omwe akulandira chithandizo cha HIV. Dziwani kuti simukukakamizidwa kutengapo mbali komanso muli ndiufulu ngati mukufuna kusiya nthawi imene mungafune popanda vuto lina lililonse ndipo muli omasuka kufunsa mafunso alionse okhudza kafukufukuyu. Mukuyeneranso kudziwa kuti mayankho anu adzasungidwa mwachinsisi ndipo sizizadziwika kuti anayankha mafunsowa ndindani chifukwa mayina anu sadzayikidwa pamapepala a mafunso m'malo mwake tizagwiritsa ntchito manambala.

Dziwaninso kuti pali chiopsezo chochepa chokhudzana ndi kafukufukuyu. Motero otenga mbali ena atha kukhala omangika mu kuyankha mafunso ena, zoterezi zikachitika ndidzakukumbutsani kuti muli ndi ufulu osayankha mafunso ena komanso osiya kafukufukuyu nthawi ina iliyonse. Ngati mwavomereza kutengapo mbali pakafukufukuyi muzapemphedwa kusayina fomu kapena kusindikiza chala chanu ndiponso kuyankhapo mafunso kwanthawi yosachepera mphindi 45 kapena ola limodzi.

Ngati pangakhale mafunso kapena nkhwana ina ili yonse yokhudzana ndikafukufukuyu khalani omasuka ndikubweretsa madandaulo anu kwa wapampando, COMREC P/Bag 360, Chichiri, Blantyre 3 kapena muyimbire telefoni pa nambala iyi 01989766.

Appendix 3A: Participants Consent Form– English Version

Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district Hospital

1. I confirm that I have read and understand the participant information sheet dated [Insert date] explaining the above study and I have had the opportunity to ask questions about the research.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the reports that result from the research.

4. I am aware that the interview will be audio recorded

5. I agree to take part in the above research

Name of Participant _____ Signature _____ Date _____

Participants thumbprint (for those who cannot write) _____ Date _____

Witness name _____ Signature _____ Date _____

Name of researcher _____ Signature _____ Date _____

Date to be written in the presence of the participant

Appendix 3B: Participants Consent Form – Chichewa Version

Zolepheretsa amayi oyamwitsa kupitiliza kulandira chithandizo cha HIV patadutsa masabata asanu ndi imodzi kuchokera tsiku lomwe anachira kuchipatala chachikulu ku Thyolo.

1. Ndikubvomeleza kuti ndawelenga ndipo ndamvetsa nkhani zomwe ziri mu chikalata chomwe chikufotokozerana otengapo mbali Tsiku la[lambani tsiku] kufotokoza za kafukufuku amaene wa tchulidwa pamwambapa ndipo ndinapatsidwa mwayi ofunsa mafunso okhuzana ndi kafukufukuyu.
2. Ndamvetsa kuti kutenganawo mbali ndikosakakamiza ndipo kuti ndiri ndi ufulu kusiya osapitiliza kutengapo mbali ngakhale osapereka chifukwa chosiyila ndipo sindizakumana ndizophinja chifukwa chosiyira pa njira kutengapo mbali pa kafukufukuyi. Kuwonjezera apa, ngati sindikufuna kuyankha funso kapena mafunso ena ndili ndi ufulu kusayankha.
3. Ndamvetsa kuti mayankho anga azasungidwa mwachinsinsi. Ndikupereka chilorezo kwa amene akupanga kafukufukuyi kumva mayankho anga amene sazawonetsa kuti ndayankha ndine. Ndamvetsa kuti dzina langa silizawoneka pena paliponse pankhani zonkhuzana ndi kafukufukuyi ndipo dzina langa silizawoneka kapena kutchulidwa muzotsatira zomwe zilembedwe zokhudzana ndikafukufukuyi.
4. Ndikudziwa kuti zokambirana zathu zijambulidwa ndi chojambulira mawu
5. Ndikuvomera kutengapo mbali pa kafukufukuyi.

Dzina la otenga mbali_____Sayini_____Tsiku lo
sayina_____

Chidindo cha chala cha otenga

mbali_____Tsiku_____

Dzina la mboni_____Sayini_____Tsiku lo

sayina_____

Dzina la mwini kafukufuku_____Sayini_____Tsiku lo

sayina_____

Zofunika kusayina ndi kuyika tsiku lo sayina otenga mbali pa kafukufuku ali pompo.

Appendix 4A: Demographic Data – English Version

Question guide for a study on barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district hospital.

SECTION A: DEMOGRAPHIC DATA

Interview Number*:

ID Number of Participant*:

Date of Interview*:

Please answer the questions below and circle as appropriate

Please answer the questions below and circle as appropriate

1	What is your age?	25-29 Years	40-49 Years
		18-24 Years	30-39 Years

2	What is your marital status	
	Married Living with partner	
	Single	Divorced

3	This is my..... baby	
	First	Second

4	How many people including yourself live in the house hold
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	1-3 People	More than 6 People
	4-6 People	

5	What is your level of education?		
	Never attended school	Secondary School	Diploma
	Primary school	Bachelor and above	

6	Occupation:

7	When did you had an HIV test?	pregnancy	In labour	After
	delivery			

Appendix 4B: Demographic Data - Chichewa Version

Interview Number* :

ID Number of Participant* :

Date of Interview* :

Chonde yankhani mafunso ali m'munsimu ndi kuzunguliza ansala mwadongosolo

1	Muli ndi zaka zingati?
	Zaka 18-24 Zaka 25-29 Zaka 30-39 Zaka 40-49

2	Muli pa banja?
	Okwatiwa ndipo akukhalira limodzi ndi okondedwa wawo
	Osakwatiwa Osiyidwa ukwati Amuna
	anamwalira

3	Uyu ndi mwana wa nambala.....
	oyamba wachiwiri wachitatu/kupyola

4	Munyumba mwanu mumankhalamo anthu angati kuwonjezera inuyo?
	Anthu 1-3 Anthu 4-6 Kupitilira anthu 6

5	Maphunzilo munafika nawo pati?
	Sindinapite kusukulu Sekondale sukulu Diploma
	Pulayimale sukulu Digili kapena kupyolere

6	Mumapanga chani kuti mupeze zosowa zanu:
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7	Munayezetsa liti kachilombo ka HIV? muli oyembekezera muli kuchilowero
	mutachira kale

Appendix 5A: Interview Schedule – English version

Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo district hospital.

Checklist

Document the date and venue; tape recording (by permission)

Confirm that consent has been given (can withdraw at any time)

Reassure participant regarding anonymity

Assure participant that they can decline any question

Explain that any question can be reworded if it is not clear to participant

Questions

1. How can the transmission of HIV from mother to child be prevented?
2. What are your expectations regarding HIV care during pregnancy, breastfeeding and thereafter?

PROBE

How do you understand the activities that happen in HIV care?

What plans of HIV management did you made from HIV diagnosis to now?

3. What factors help to promote the retention of women in HIV care during the postnatal period and afterwards?

PROBE

What are the things that help breastfeeding women to continue taking ART?

How do you participate in your care, from home to the health facility?

What activities are done at the ART/HIV care follow up clinic?

4. What factors hinder breastfeeding women to retention in HIV care?

PROBE

What are the things that can make women to stop accessing ART care /HIV follow up clinic?

5. What do you think would help encourage breastfeeding women to be retained in HIV care?

PROBE

What support from homes and hospitals do breastfeeding women require to ensure PMTCT services are utilized?

As a hospital they would like to ensure that the services that are provided in terms of HIV care are utilized. How would you love to be handled/ treated at the facility?

6. Do you have any other suggestions/ anything else you would like to add regarding this issue?

THANKS FOR YOUR PARTICIPATION!

Appendix 5B: Interview Schedule – Chichewa version

Zolepheretsa amayi oyamwitsa kupitiliza kulandira chithandizo cha HIV patadutsa masabata asanu ndi imodzi kuchokera tsiku lomwe anachira kuchipatala chachikulu ku Thyolo.

GAWO LACHIWIRI: MAFUSO AKUYA AMAYI OYAMWITSA

Onesetsani kuti izi zapangidwa

Lembani tsiku ndi malo; kujambula mawu (ndi chilorezo)

Tsimikizani kuti chikalata chosonyeza kuti chilorezo chaperekedwa cha sayinidwa.

Atsimikizireni otengapo mbali zonkhuza chinsinsi chosa yikapo dzina la otengapo mbali

Atsimikizireni otengapo mbali kuti akhoza osayankha mafunso ena

Alongosolereni kuti funso liri lonse litha kufunsidwanso ndicholinga kuti otengapo mbali athe kumvetsa funso.

Mafunso

1. Kodi kupatsirana kachiroombo koyambitsa matenda a Edzi kuchokera kwa amayi kupita kwa mwana tingakupewe bwanji?
2. Kodi chiyembekezo chanu ndichotani molingana ndi chithandizo chomwe chimaperekedwa kwa amayi oyembekezera komanso oyamwitsa omwe ali ndi kachilombo koyambitsa Edzi?

Mafunso othandiza kupeza zambiri

Kodi mumamvesetsa bwanji muzochitika zomwe zimapangidwa muchithandizo chomwe chimaperekedwa kwa anthu omwe ali ndi kachilombo koyambitsa matenda a Edzi?

Kodi inu munali ndi ndondomeko zotani zokhuza chithandizo chokhudzana ndi kachilombo ka HIV kuchokera nthawi imene munapezeka kuti muli ndi kachilombo koyambitsa matenda a Edzi kufikila pano?

3. Kodi ndi zinthu ziti zomwe zimapititsa patsogolo kupitiliza kwa amayi kulandira chithandizo chopewa Edzi panthawi imene ali oyembekezera, atachira komonso kupyora apo?

Mafunso othandiza kupeza zambiri

Kodi ndi zinthu ziti zomwe zimapangitsa amayi oyamwitsa kuti apitilize kulandira thandizo la anthu omwe apezeka ndi kachilombo koyambitsa Edzi?

Kodi mumatenga nawo mbali muchithandizo chanu munjira ziti? Kuchokera kunyumba kufika kuchipatala.

Kodi kuchipatala komwe mumalandira thandizo la anthu omwe apezeka ndi kachilombo koyambitsa Edzi kumachitika zinthu zotani?

4. Kodi ndi zinthu ziti zomwe zimaletsa amayi oyamwitsa kupitiliza kulandira thandizo lomwe limaperekedwa kwa amayi omwe anapezeka ndi kachilombo koyambitsa Edzi?

Funso lothandiza kupeza zambiri

Kodi ndi zinthu ziti zomwe zimapangitsa kuti amayi oyamwitsa asiye kulandira thandizo lomwe limaperekedwa kwa anthu omwe anapezeka ndi kachilombo koyambitsa Edzi?

5. Kodi mukuganiza kuti ndi zinthu ziti zomwe zingathandize kuti amayi oyamwitsa asamasiye kulandira thandizo lomwe limaperekedwa kwa amayi omwe anapezeka ndi kachilombo koyambitsa Edzi?

Mafunso othandiza kupeza zambiri

Kodi ndi thandizo lotani kuchokera kunyumba komanso kuchipatala Lomwe amayi oyamwitsa amayenera kulandira kuti azilandira thandizo lopewa kupatsirana kachilombo koyambitsa Edzi kuchokera kwa mayi kupita kwa mwana?

Monga chipatala ndi chokhumba chawo kuonesetsa kuti thandizo Lomwe limaperekedwa kwa amayi omwe ali ndi kachilombo koyambitsa Edzi likugwiritsidwa ntchito. Kodi inu mungakonde kuti adzikuthandizani motani pachipatala pano?

6. Muli ndi maganizo ena owonjezera/ china chili chonse mukufuna kuwonjezera zokhuzana nkhaniyi?

ZIKOMO POTENGA NAWO GAWO PA KAFUKUFU

Appendix 6: Certificate of Ethics Approval



**CERTIFICATE OF ETHICS
APPROVAL**

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.04/17/2169 - Barriers and facilitators to retention in HIV care among breastfeeding women after six weeks postpartum at Thyolo District Hospital version 2 dated May 2017 by Angella Jambo

On 31-May-17

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page


Dr. YB. Mlombe - Chairperson (COMREC)

Approved by College of Medicine 31 MAY 2017 (COMREC) Research and Ethics Committee	02-Jun-17
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