

“Why I stayed when others left”

An Appreciative Inquiry of Retention in the Prevention of Mother to Child  
Transmission of HIV in Takoradi Government Hospital, Ghana

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Date: 11<sup>th</sup> February 2019

To Efua Yedua

Your presence in my life and thoughts taught me to believe in the Omnipotence of  
God

and to Onyankopon Daase Amfer Nyame,  
because of you, my lines have fallen in pleasant places.

I have a goodly reward.

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## ABSTRACT

Globally, great strides have been made in developing essential strategies and knowledge necessary to prevent vertical transmission of HIV. Retention in the Prevention of Mother to Child Transmission (PMTCT) programme is essential for the achievement of this aspiration.

The study applied Mixed Method Sequential Explanatory Design to explore the factors that underscored the retention decisions of newly diagnosed HIV positive pregnant women. The study was set in the PMTCT programme in the Takoradi Government Hospital, Ghana, a lower middle income country. PMTCT records were retrospectively reviewed. Subsequently, the Appreciative Inquiry process using the 4Is terminology was applied to unearth the experiences and aspirations of mothers (n=12), midwives and Community health nurses (CHNs) (n=12) engaged in the programme.

Ethical approval was granted by University of Cape Town Faculty of Health Sciences Human Ethics Research Committee and Ghana Health Service Ethics Review Committee.

Retention rate at six weeks postpartum was 67.4%. Retention stories of women enrolled in the PMTCT programme reflected a life-enhancing experience in the face of a life-threatening diagnosis. Four themes were generated: Transitioning to the 'new' woman, Journeying with committed companions, Glimpses of triumph and Tying up the loose ends: A daring new path.

The study highlighted development of hope in a seemingly hopeless situation, supportive network of family, healthcare professionals and religious leaders, and the commitment and companionship of the midwives and CHNs that culminated in the successes of the programme. 'Healthy' HIV-infected mothers and 'exposed' infants who tested negative to HIV at the end of the mother-infant pair's journey in the PMTCT programme was evidence of the diligence of mothers, midwives and CHNs. A collaborative discussion resulted in the development of action plans to improve service delivery, enhance clients' experiences and improve retention.

The study recommends that PMTCT services should be structured to promote hope and empowerment for the clients through shared clients and healthcare professionals'

designed improvement programmes, instituting programmes that promote the emotional health of the health practitioners to sustain the programme, and promptly addressing health system challenges that contribute to disengagement.

Key words: HIV, PMTCT, Retention, Experiences, Appreciative Inquiry

## LIST OF ACRONYMS

3TC	-	Lamivudine
4Ds	-	Discovery, Dream, Design and Deliver or Destiny
4Is	-	Initiate, Inquire, Imagine and Innovate
AI	-	Appreciative Inquiry
AIDS	-	Acquired Immune Deficiency Syndrome
ANC	-	Antenatal care
ART	-	Antiretroviral therapy
ARV	-	Antiretroviral prophylaxis
AZT	-	Zidovudine
CD4	-	Cluster of Differentiation 4
CHN	-	Community Health Nurses
CHPS	-	Community-Based Health Planning and Services
CINAHL	-	Cumulative Index of Nursing and Allied Health Literature
CITC	-	Client Initiated Testing and Counselling
CWC	-	Child Welfare Clinic
DBS	-	Dry Blood Spot
DHIMS2	-	District Health Information Management System 2
DNA	-	Deoxyribonucleic Acid
EFV	-	Efavirenz
EID	-	Early Infant Diagnosis
eMTCT	-	Elimination of Mother-to-Child Transmission of HIV
FANC	-	Focused Antenatal Care
FTC	-	Emtricitabine
GAC	-	Ghana AIDS Commission
GHAPOHA	-	Ghana Ports and Harbours Authority
GHS	-	Ghana Health Service
GHS ERC	-	Ghana Health Service Ethics Review Committee
GSS	-	Ghana Statistical Service
HAART	-	Highly Active Antiretroviral Therapy
HIV	-	Human Immunodeficiency Virus
HRSA HAB	-	Human Resource and Services Administration HIV/AIDS Bureau
HTC	-	HIV Testing and Counselling

IPV	-	Intimate Partner Violence
LTFU	-	Loss to Follow-up
MMR	-	Mixed Method Research
MNCH	-	Maternal, New-born and Child Health
MTCT	-	Mother-to-Child Transmission
NACP	-	National AIDS Control Programme
NVP	-	Nevirapine
PCR	-	Polymerase Chain Reaction
PEPFAR	-	The U.S President's Emergency Plan for AIDS Relief
PICT	-	Provider Initiated Counselling and Testing
PLWHA	-	Persons living with HIV/AIDS
PMTCT	-	Prevention of Mother-to-Child Transmission of HIV
PNC	-	Postnatal care
SdNVP	-	Single dose Nevirapine
SED	-	Sequential Explanatory Design
SPSS	-	Statistical Package for Social Sciences
SSA	-	Sub-Saharan Africa
STM	-	Sekondi-Takoradi Metropolis
TDF	-	Tenofovir
UCT FHS	-	University of Cape Town Faculty of Health Sciences
UNAIDS	-	Joint United Nations Program on AIDS
UNICEF	-	United Nations International Children's Emergency Fund
UNICEF	-	United Nations Children's Fund
WHO	-	World Health Organization

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# **CHAPTER 1 BACKGROUND OF THE STUDY**

## **1.1 INTRODUCTION**

Approximately 17.8 million women and girls were living with Human Immunodeficiency Virus (HIV) globally in 2016 (UNAIDS, 2017). The global estimate for women infected with HIV who became pregnant was 1.4 million in 2016 (World Health Organization, 2017). In 2016, 160 000 children were newly infected with HIV globally and nearly 80% of these new paediatric infections occurred in Sub-Saharan Africa (UNAIDS, 2017). UNAIDS reports that of the number, approximately 120 000 died of Acquired Immune Deficiency Syndrome (AIDS)-related causes globally (UNICEF, 2017). In Sub-Saharan Africa, Marston et al. (2011) reported a pooled survival rate of 75% at five months of children infected with HIV perinatally, but the rate declined to 33% at five years. A study in Nigeria recorded a survival rate of 81% among children aged zero to two years (Ojeniran et al., 2015).

Ghana is among the 22 countries identified by World Health Organization (WHO) as carrying the most substantial burden of HIV and AIDS worldwide and is classified as having a generalized HIV epidemic (Ghana AIDS Commission, 2015). Estimates from the 2015 National AIDS Control Programme (NACP) service data cited in the U.S President's Emergency Plan for AIDS Relief (PEPFAR) country operational plan for 2016, revealed that pregnant women constituted 73% (694 329) of the 955 674 persons who were tested for HIV in Ghana. Of this number, 12 236 (1.8%) pregnant women tested positive to HIV and 7 813 (64%) were linked to health care and placed on treatment (PEPFAR, 2016). The National HIV Prevalence amongst pregnant women attending antenatal clinic was projected to drop to 1.26% by 2020 (Ghana AIDS Commission, 2014a), however, there has been a consecutive upsurge from 1.6% in 2014 to 1.8% and 2.4% in 2015 and 2016 respectively (Ghana AIDS Commission, 2016). The UNAIDS reports that Ghana has approximately 160 000 women and girls in the reproductive age living with HIV (UNAIDS, 2016). The HIV prevalence by age group recorded the highest at 5.6% among the 45-49 year group, followed by 3.5% in the 35-39 year group and the lowest at 0.6% in the 15-19 year

group. In Ghana, HIV prevalence among the young population (15-24 years) was used as a proxy for new infections. The prevalence for HIV infection remained unchanged at 1.1% (Ghana AIDS Commission, 2016) with the incidence of new adult infection of 0.68% in 2017 (Ghana AIDS Commission, 2017). With a fertility rate of 3.77 (Ghana AIDS Commission, 2014b) and an estimated increase to 3.9 in 2019 (Ghana AIDS Commission, 2017), the need to strengthen the Prevention of Mother-to-Child Transmission (PMTCT) programme to identify infected women in the reproductive age, provide treatment and also to curb new infections in exposed children cannot be overemphasized.

An estimated 3 422 new infections, representing 17.9% of all new infections, were estimated to have occurred among children 0-14 years of age, with as many as 2 902, approximately (18.5%) deaths associated with HIV occurring in children, of which 1 316 deaths were in infants between ages 1-4 years (Ghana AIDS Commission, 2017). This is contrary to the situation in high-income countries where maternal and infant deaths linked to HIV as well as incidence of paediatric HIV was virtually zero within the same period (WHO, 2014).

Ghana had a unique opportunity to reduce the HIV prevalence. This is because the national antenatal (ANC) coverage recorded 98%, and 89% attendance for four or more visits in 2017 (Ghana Statistical Service, Ghana Health Service, 2018). However, only 78% of expectant mothers who accessed ANC services were tested for HIV status, counselled and received their results between 2011-2013 (Dako-Gyeke et al., 2016). In 2015, only 30% of the babies exposed to HIV received virological testing by the 2<sup>nd</sup> month of life while only 27% received Antiretroviral (ARV) prophylaxis (UNAIDS, 2016). Consequently, the Mother-to-Child Transmission (MTCT) rate was nine percent after cessation of breastfeeding in 2017 (World Health Organization, 2018).

The global community has made great strides in developing essential strategies and knowledge necessary to reduce new infections and reverse the impact of the HIV epidemic over the years. UNAIDS and WHO developed policy guidelines of effective interventions such as HIV Testing and Counselling (HTC), Prevention of Mother to Child Transmission of HIV (PMTCT) (UNAIDS, 2015; WHO, 2012). Research also established the effectiveness of ARVs to not only treat, but also prevent, new HIV infections (Maltez, Branco, & Valente, 2011). In 2011 UNAIDS

and WHO, together with other development partners, launched the global plan of “Elimination of Mother-To-Child Transmission (eMTCT) of HIV by 2015”. The plan aimed to reduce HIV infection in children born to positive mothers to less than 5% by 2015, as well as ensure that the mothers remained healthy and remained alive (UNAIDS, 2015). Many countries, including Ghana, endorsed the UNAIDS call (Ministry of Health & Publishers, 2010; UNICEF, 2013; WHO, 2010a). Countries incorporated efforts to halt new paediatric HIV infection in their national AIDS programmes that resulted in an increase in coverage of HIV prevention and treatment services to about 80% in the highest burdened countries in 2009 (WHO/ Joint United Nations Programme on HIV/AIDS/UNICEF, 2011).

The Ghana Health Service (GHS) also instituted context-specific strategies to improve the supply side of health service delivery in areas such as service delivery and health planning to strengthen and sustain the gains made in the country’s response to HIV/AIDS. The measures mainly focused on increasing accessibility to, and uptake of quality HTC, PMTCT and ART (Antiretroviral Therapy) services. The approach employed to achieve this goal was the improvement of public health infrastructure, an increased number of trained staff for PMTCT and ART services, strengthening community systems, provision of capacity building and technical support, as well as, improving procurement and supply chain management (Ghana AIDS Commission, 2015; Ghana Health Service, 2014). In spite of these efforts, achieving the less than 5% of new infections through vertical transmission in breastfeeding populations eluded most countries.

At the end of the period, there was a global consensus that most countries could not achieve the agenda by the 2015 milestone. Five countries; Cuba, Thailand, Belarus, Republic of Moldova, and Armenia were validated as having achieved the targets for eMTCT while other countries are yet to be validated (Taylor et al., 2017). Post-2015, the World Health Assembly has set a target for HIV of “Ending the AIDS Epidemic” by 2030 and governments have still maintained their commitments and intensified their actions to achieve this target (UNAIDS, 2014). Evidence from the successes achieved by nations in the fight against HIV over the years shows that when expectant mothers living with HIV have access to timely care and ART, the situation in the 22 HIV burdened countries can be averted (Taylor et al., 2017). Thus,

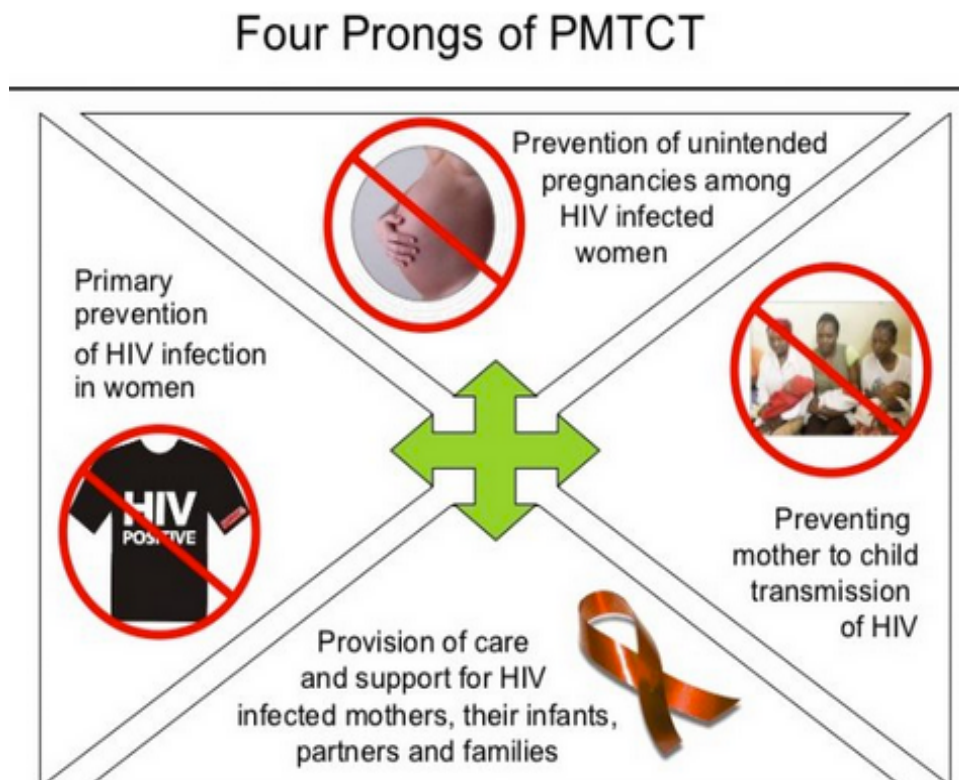
there is a need to virtually eliminate the incidence of paediatric HIV and also to ensure the survival of mothers living with HIV.

## 1.2 THE PMTCT PROGRAMME

The Prevention of Mother-to-Child Transmission schedules were adopted and continue to be used in most countries as the primary vehicle to achieve the targets set to end MTCT (Mother-to-Child Transmission) of HIV (UNICEF, 2017; WHO, 2010a, 2010b). WHO and their partners outlined a four-pronged approach to reduce vertical transmission:

- Primary prevention of HIV among women of child-bearing age
- Preventing unintended pregnancy among women living with HIV
- Preventing HIV transmission from a woman with HIV to her infant
- Providing appropriate treatment, care and support to mothers with HIV and their children and their families (WHO, 2010b). The four prongs of the PMTCT programme is presented in Figure 1-1 below.

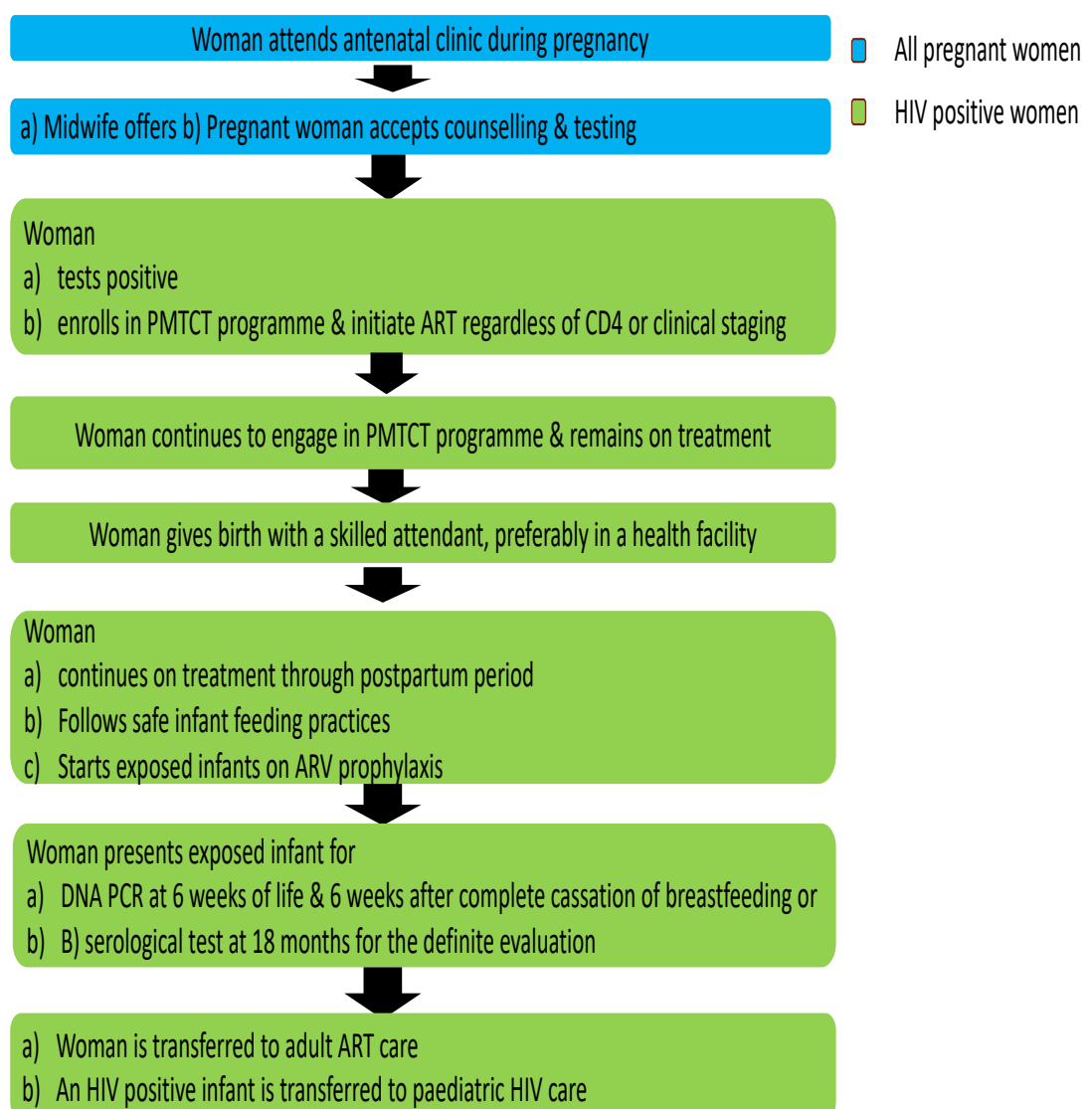
Figure 1-1 Four Prongs of the PMTCT programme



Adapted from Adhikari (2017)

The measures to achieve the objectives outlined under the third prong of PMTCT are organized in a cascade to ensure that the mother-child pair receives the maximum benefit for the programme (Gimbel et al., 2014). The PMTCT cascade involves HIV counselling and testing at ANC, provision of ART or ARV during pregnancy for the women, provision of ARVs for the exposed new-born at birth and during the period of breastfeeding, infant follow-up and testing and finally enrolling the pair into the long-term treatment program (Gimbel et al., 2014). PMTCT Cascade for Option B+ Approach is presented in Figure 1-2 below.

Figure 1- 2 PMTCT Cascade for Option B+ Process



Adapted from Ghana Health Service (2014)

These interventions have proven their effectiveness cost-wise and in the reduction of vertical transmission. Findings of a study reported the effectiveness of PMTCT programme in reducing the rate of peripartum HIV transmission to 2.2% and a cumulative rate of 5.7% at 12 months in West Africa (Tonwe-Gold et al., 2007). Until 2007 HIV testing in PMTCT was client-initiated (De Cock, Marum, & Mbori-Ngacha, 2003). However, in May 2007, WHO recommended provider-initiated testing to all persons accessing ANC in settings with an ANC HIV prevalence of one percent unless they explicitly opted out (WHO, 2007). WHO Programmatic Update recommended three treatment options for PMTCT. Options A and B recommend life-long treatment for those with a Cluster of Differentiation 4 (CD4) count  $\leq 350$  cells/mm<sup>3</sup>. The difference lies in the prophylaxis recommended for expectant mothers who have a CD4 count of  $>350$  cells/mm<sup>3</sup>. The third approach is Option B+ which requires that all expectant mothers who test positive for HIV be started on life-long ART regardless of their CD4 count (WHO, 2010a, 2012).

Many countries including Ghana have integrated PMTCT services into already existing Maternal, New-born and Child Health (MNCH) services such as ANC, Intrapartum and Postnatal care (PNC) (Barker & Mate, 2012). This was targeted for ensuring improved access and uptake of the programme (Ghana Health Service, 2013). As part of the agenda for integration, measurable outputs outlined in 2009 to achieve the eMTCT in Ghana by 2015 included:

- Increase annually the number of expectant mothers who are counselled and tested for HIV from 40%-95%.
- Increase the number of HIV-infected expectant mothers who receive ARVs for PMTCT from 28%-95%.
- Increase the number of HIV exposed infants (HEI) on ARVs for PMTCT from 30%-95% (Ghana AIDS Commission, 2014b).

Key to achieving the eMTCT target is ensuring a surge in the number of expectant mothers and their exposed children who successfully complete the various points of the PMTCT cascade. This could decrease the rate of new infections in children through vertical transmission, reduce HIV-related deaths and ART drug resistance (Barker & Mate, 2012).

### 1.3 OVERVIEW OF THE PMTCT PROGRAMME IN GHANA

The PMTCT programme in Ghana is provided as an integrated delivery of intervention within the Maternal, New-born and Child Health services (MNCH) (Ghana Health Service, 2014). All health facilities in the country that provide MNCH services provide the PMTCT programme. Healthcare staff who provide direct care to the clients who access these services are trained by the Ghana Health Service and National AIDS Control Programme on the provision of care within the PMTCT programme using the national protocols.

The national strategy for the delivery of these interventions is aligned with the four-pronged approach (as explained in 1.2) recommended by WHO. Two main approaches are used for the service delivery: Facility-based care and Outreach/Community-based services. The PMTCT services are provided across various units that includes antenatal care, labour and delivery care, as well as postnatal care up to 18 months (MOH/GHS, 2014).

The policy adopted for testing in the PMTCT programme is Provider-Initiated HIV Testing and Counselling (PITC). However, Client Initiated Testing and Counselling (CITC) is welcomed (Ghana Health Service, 2014; Ministry of Health, 2010). Consequently, HIV Testing and Counselling (HTC) is offered routinely to all pregnant women as part of the initial ANC service and women who initially test negative are encouraged to have the test repeated in the third trimester. Opportunities for HTC are available along the PMTCT cascade for women with undocumented HIV status during labour and postpartum. Serial testing with two rapid serological HIV testing kits (First Response HIV I & II and OraQuick®) are used (Ghana Health Service, 2014). Three adherence counselling sessions are required to be organized for HIV-infected women to ensure they understand and own the decision to adhere to the treatment schedules (MOH/GHS, 2014).

In 2015, the country transitioned from the treatment option B to B+ which culminated in lifelong treatment of all clients enrolled in PMTCT (explained in 2.5.2.1) (MOH/GHS, 2014). Thus, all HIV positive pregnant women and breastfeeding mothers are enrolled on the lifelong treatment of HIV. The preferred ART regimen in Ghana is the triple fixed-dose formulation of Tenofovir, either

Lamivudine or Emtricitabine and Efavirenz (TDF+3TC (or FTC) + EFV.) However, the alternative regimen includes:

- Zidovudine, Lamivudine, and Nevirapine (AZT+3TC+NVP),
- Tenofovir, either Lamivudine or Emtricitabine and Nevirapine (TDF+3TC (or FTC) + NVP)
- Zidovudine, Lamivudine, and Efavirenz (AZT+3TC+EFV) (MOH/GHS, 2014).

In Ghana, vaginal delivery is recommended. However, caesarean section is considered on obstetric grounds rather than solely for PMTCT. ARV treatment is administered during labour and delivery in accordance with the national protocols (MOH/GHS, 2014).

Postnatal care for HIV positive mothers and exposed infants is synchronised and usually occur within 3-7 days after birth and at six weeks postpartum for MNCH/Child Welfare Clinic (CWC) and PMTCT related services. The duration of infant follow-up depends on when HIV infection status is determined and on feeding method. Two infant feeding options are recommended for exposed children: exclusive breastfeeding or exclusive commercial infant formula milk for six months. Complementary feeding for six months follows either of these options. Mixed feeding is strongly discouraged (MOH/GHS, 2014).

All exposed infants receive ARV treatment from birth until six weeks of age when the Early Infant Diagnosis (EID) is done using Dried Blood Spot (DBS) for Deoxyribonucleic Acid Polymerase Chain Reaction (DNA PCR). If the initial HIV DNA PCR is negative at six weeks, the infant is discharged from PMTCT follow-up and referred to continue with the usual CWC programme. For breastfed infants, the test is repeated six weeks after complete cessation of breastfeeding for a definitive evaluation of the infant's HIV status. In places where the DNA PCR machines are unavailable, a serological test to determine the infant's status is done at 18 months or 12 weeks after complete cessation of breastfeeding. A positive serological test at 18 months means the child is positive and receives comprehensive HIV care and ART for life. All these services are free of charge (MOH/GHS, 2014).

## 1.4 RETENTION IN THE PMTCT PROGRAMME

Retention of expectant mothers enrolled into the PMTCT programme is vital to achieve the goal of virtually eliminating new paediatric HIV and keeping the mothers alive and healthy. Infected mothers must remain in care throughout the transmission risk period; pregnancy through to the end of breastfeeding and continue with lifelong treatment to maintain their health. That is necessary to ensure an adequate supply of efficacious ARV drugs to suppress the viral loads, monitoring of CD4 Count, prompt management of opportunistic infection and education on healthy living with HIV.

However, studies have shown that retention has been a significant challenge. In a systematic review and meta-analysis to determine the magnitude of attrition in PMTCT programme globally from 2001-2012, an estimated pooled attrition of 49% of HIV positive mothers was reported between booking at antenatal and delivery. Attrition of infants at three months was 34% while 45% more were lost after HIV testing at the end of the various studies (Kalembo & Zgambo, 2012). Malawi had the lowest rate of attrition of HIV exposed infants in SSA at six weeks, but rate increased to 41% after six months. The review concluded that out of 100 expectant mothers diagnosed with HIV enrolled in PMTCT programme, only 19 infants remained in care after PCR testing during the study period (Sibanda, Weller, Hakim, & Cowan, 2013).

This high rate of attrition is confirmed by another review that focused on loss to follow-up (LTFU) in PMTCT in SSA. The study recorded maternal cumulative attrition rate at 20% during ANC, 70% and nearly 81% at four and six months post-delivery respectively between 1990-2011 (Kalembo & Zgambo, 2012).

Ahoua et al. (2010) reported 53% attrition in Uganda among mother-infant pairs who had received either no or incomplete intrapartum ARV prophylaxis. A similar trend in attrition is reported by a study on compliance with recommended follow-up among HIV exposed infants in Ethiopia. LTFU of the mother-infant pair was 31% although the infants had received ARV prophylaxis at birth. The LTFU was attributed to stigma and a negative outcome of an infant's PCR at six weeks (Shargie, Eek, & Abaychew, 2011). While research has recorded a low rate of retention in PMTCT in other parts of SSA, research on this issue in Ghana is limited.

The PEPFAR (2016) reports that “there is currently no data on retention rates and the number of persons who have attained viral suppression in Ghana.”

## **1.5 RATIONALE FOR THE STUDY**

Most women who become pregnant become excited with the news and hope to deliver a healthy baby. An ANC booking visit is mostly to afford the mother the opportunity to confirm the pregnancy and to assess the fetus' state of health (Oluoch et al., 2015). Usually, the pregnant women appear healthy at booking, and most of them willingly accept to undergo the requisite laboratory investigations, including HIV tests, as part of the process required for antenatal care. Thus, an HIV positive result often comes as a shock and some expectant mothers struggle to deal with the diagnosis (Stinson & Myer, 2012) causing many to exit from programme. Coupled with that, challenges such as fear of stigma (Tenthani, Haas, Tweya, Jahn, Oosterhout, et al., 2014), reaction from spouses including blame (Theilgaard, Katzenstein, & Chiduo, 2011), rejection (Otieno, Kohler, Bosire, & Brown, 2010) and fear of being seen at the PMTCT clinic (Chinkonde, Sundby, & Martinson, 2009), transportation cost to access care, as well as frequent hospital visits required for treatment refill (Oyeledun et al., 2014) contribute to low retention in the PMTCT programme.

Likewise, although there is adequate distribution of PMTCT services in the Western region of Ghana, the low retention and non-adherence to ART resulted in an MTCT rate of 12.1% among PMTCT clients with history of ART use, while low knowledge and patronage of EID services has been recorded (Amoh-Addae, 2015).

The GHS has made efforts to improve access to, and provision of quality service delivery. This has been achieved by integrating PMTCT activities into existing MNCH services and providing free MNCH. Structures have also been put in place to train healthcare professionals to support the programme. The health service also collaborates with Ministry of Gender, Children and Social Protection to extend cash grants to poor and vulnerable people including persons living with HIV/AIDS (PLWHA) on the Livelihood Economic Empowerment against Poverty (LEAP) programme to reduce the financial barrier to access (Ghana AIDS Commission, 2014a). In spite of these efforts, some mothers are still lost to follow-up (Ahoua et al., 2010).

The midwives and Community health nurses' (CHN) efforts to provide support through counselling and health education on the availability of medical interventions to prevent MTCT and to embark on activities such as patient tracking to bridge the gap have made an impact (Ambia & Mandala, 2016; Kredo, Bateganya, Pienaar, & Adeniyi, 2012). However, the LTFU has remained high due to factors such as patients declining to be traced or providing an incorrect address making tracing very difficult (Thomson, Cheti, & Reid, 2011). These mothers who are LTFU do not only put themselves at risk of deterioration in health and their unborn babies at risk of infection (Sibanda et al., 2013) but their actions undermine the national efforts to achieve the eMTCT goals. Notwithstanding the challenges and barriers for uptake and access to PMTCT services in Ghana, some expectant mothers remain in programme until they complete the PMTCT cascade. Even though it is uncertain what inspires them, it is believed that there are intrinsic factors that motivate them to remain in programme. This study, therefore, sought to explore those factors that motivate these women to stay in the PMTCT programme and to inform healthcare professionals' efforts to improve retention in the programme.

## **1.6 THE PURPOSE OF THE RESEARCH**

The overarching aim of the study was “to apply the appreciative inquiry process to determine what factors would contribute to the retention of women newly diagnosed HIV positive in pregnancy in the PMTCT programme.”

## **1.7 OBJECTIVES OF THE RESEARCH**

The main objective of the study was to determine the factors that will improve retention of women who are newly diagnosed HIV positive in pregnancy in the PMTCT programme.

The specific objectives are presented in chapter 4 under the various phases of the study (4.3.3.2 and 4.3.4.2).

## **1.8 STUDY SETTING**

Ghana is an emerging lower middle-income country in West Africa with a population estimated in 2010 at 23.4 million, of which 45 percent are in the 15–49 age group. It covers a total land surface area of 238 537 square meters. The country has ten administrative regions (Ghana Statistical Service, 2014).

The Sekondi-Takoradi Metropolis (STM) of the Western region of Ghana was the setting for this study. It is one of the 22 districts of the Western Region and houses the regional capital, Sekondi-Takoradi. STM shares boundaries with Ahanta West District, Mpohor Wassa East, Shama District Assembly and the Gulf of Guinea. The total land area is about 49.78 km<sup>2</sup>. It is the third largest metropolis in the country with a population of 559,548 (Sekondi-Takoradi Metropolitan Assembly, 2014). The metropolis has been divided administratively into four sub-metropolitan areas; Sekondi, Takoradi, Essikadu/Ketan and Effia/Kwesimintim. The Ghana Statistical Service (2014) indicates that about 96.1% of households are in the urban area and 3.9% in rural area.

Figure 1- 3 Map of Ghana showing Sekondi-Takoradi, and detail of the catchment area of Takoradi Government Hospital.



Adapted from Acheampong, Yu, Enomah, Anchang, and Eduful (2018)

The adult literacy rate of the population in STM is 89.5% with the proportion of literate females' lower than that of males. The adult literacy rate is calculated as the percentage of the population aged 15 years and above who can, read and write with understanding, a short simple statement on their everyday life. About 10.9% of the population is unemployed. Of this number, 19.4% perform household duties (Ghana Statistical Service, 2014). For women with little or no education, the main economic activity is commerce (whole sale and retailing of goods and services).

Being a cosmopolitan centre, the socio-cultural disposition of the people in this Sekondi-Takoradi Metropolis has evolved as a result of the influence of education and western culture. In spite of this, the traditional Ghanaian beliefs about marriage, family and childbearing persist as in most parts of Ghana (Hollingsworth, 2013). Ideologies that favour family and marriage still exist. About 47.6% of females between the ages of 25-29 years are married while single families make up 15.3% of the population. The total fertility rate of the metro is 2.8 (Ghana Statistical Service, 2014). According to Oheneba-Sakyi and Takyi (2006), unmarried women of marriageable age are viewed differently from those that are married.

The STM has 36 public health facilities which can be categories according to the level of service delivery provided. The public sector is made up of one Regional hospital, five district hospitals, two health centre, 13 clinics, six maternity homes and nine Community-based Health Planning and Services (CHPS) compounds (District Health Information Management System-DHIMS II<sup>1</sup>). NACP/GHS is the implementing agency for HIV&AIDS/PMTCT service delivery through ANC clinics, regional, district hospitals and health centres (Ghana AIDS Commission, 2015). In 2015, five health facilities provided the full suite of the PMTCT programme; the Effia Nkwanta Regional Hospital, Kwesimintim Polyclinic, Essikado, Ghana Ports and Harbours Authority (GHAPPOHA) and the Takoradi Government Hospital. Of these facilities, the Takoradi Government Hospital was chosen as the setting for this study. The facility was chosen for this study because it is the Metropolitan hospital that serves as the secondary referral point for all the other facilities in its catchment area. It serves the general public and is a referral facility for Community-based Health Planning and Services (CHPS) compounds,

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<sup>1</sup> District Health Information Management System-DHIMS II. Accessed on the 30/01/2019.

health centres and private facilities in the Takoradi sub-district. The facility serves a population of about 46,016 in 2015 and recorded an antenatal clinic attendance of 4 511 within the same period. The facility is endowed with a large number of prescribers and staff trained for the provision of PMTCT services. The characteristics of clients who patronise their services address the general population dynamics. The facility attained the 'Baby-friendly Hospital' status in 2014 (Takoradi Government Hospital, 2015).

The Takoradi hospital was suitable because outcomes of this study would contribute to the efforts of GHS in strengthening quality health service delivery for PMTCT clients. Furthermore, the study would also impact sub-district facilities in its catchment area as the facility supervises and oversees these facilities and outreach programmes within its catchment areas, thus extending the scope of benefit or influence of the study. The map of Ghana showing Takoradi, and detail of the catchment area of Takoradi Government hospital is presented in Figure 1-3 below.

## **1.9 OUTLINE OF THE THESIS**

The study was structured into seven chapters. The study focused on exploring the factors that will improve retention of women who are newly diagnosed HIV positive during pregnancy in the PMTCT programme.

Chapter 1 provides the background and the context of the study. It introduces the study and gives an overview of the PMTCT programme. The problem being researched and the rationale for the study are presented. It further outlines the overarching aim and the objectives which guided the study.

Chapter 2 presents the literature review. It describes the strategies for the literature search and the various definitions and concepts of defining PMTCT. The concept of retention in PMTCT is then explored. Various studies that have been conducted on the factors that influence retention of mothers in the PMTCT programme, as well as, the interventions that have been applied to improve retention in the PMTCT programme are discussed.

Chapter 3 focuses on the theoretical underpinning of the study. The concepts of Appreciative Inquiry, the principles as well as the methods are presented in this chapter.

Chapter 4 provides a detailed description of the methodology and research design employed for the conduct of this study. The research philosophy and paradigm, and the justification for the methodological decisions are presented. The chapter includes the methods of the study. This is presented in two phases. Phase One covers the quantitative methods of the study and presents the method of sampling, data collection and analysis are presented. Phase Two highlights the Appreciative Inquiry process. It further outlines ethical considerations, as well as, the measures to ensure trustworthiness of the study.

In Chapter 5, the findings of the study are presented. There are in two sections. Section A presents the findings of phase one of the study. In Section B, the findings from the data gathered from the Mothers enrolled in the PMTCT programme and the Appreciative inquiry sessions with the health workers will be presented according to the phases of the AI process.

Chapter 6: In this chapter, the findings of the study are discussed in relation to the research objectives and questions. This chapter highlights the new knowledge that will be helpful in improving retention in the PMTCT programme. The strengths and limitations of the study, as well as the researcher's reflexivity report are then presented.

Chapter 7 gives a summary of this thesis as well as recommendations for further actions. The chapter ends with the conclusion of the study.

## **1.10 OPERATIONAL DEFINITIONS**

**Appreciative Inquiry:** The process of conversing, discussion and generativity engaged in by participants to arrive at a desired end.

**Composite stories:** Reconstructed stories of the experiences of the expectant mothers. These are de-identified and generated to serve as catalyst in the appreciative inquiry process

**Hospital shopping:** The phenomenon of pregnant women visiting more than one health facility with the intention of retesting or confirming the HIV positive diagnosis or seeking treatment.

**Nonchalant about HIV:** Women who prior to their pregnancy had not initiated or opted for HIV testing and were ignorant about their status prior to testing in the PMTCT programme.

**Empowered women:** A woman who has accepted her HIV status, is well informed about her condition and has made the meaningful decision to engage in the PMTCT programme continuously. In spite of the perceived or actual challenges associated with accessing PMTCT care, the empowered woman engages in the programme as a partner rather than as a passive recipient

**Retention:** Mothers' remaining in PMTCT care and participating in all care activities from the time of testing and enrolment until six weeks Early infant diagnosis of the exposed infant (Ndaimani, Haruzivishe, Chitsike, & Stray-Pedersen, 2016; Woelk et al., 2016).

**World Health Organisation (WHO) Clinical staging:** A presumptive diagnosis of a client who presents with any of the following clinical signs:

**Stage 1:** Asymptomatic or Persistent general lymphadenopathy

**Stage 2:** Moderately unexplained weight loss (<10% of presumed or measured body weight). Unexplained chronic diarrhoea for longer than a month, recurrent respiratory tract infection, herpes zoster, angular cheilitis, recurrent oral ulcerations, popular pruritic eruptions and fungal nail infections of fingers.

**Stage 3:** in addition to the symptoms presented in stage 2, the client must present with oral candidiasis, oral hairy leukoplakia, pulmonary Tuberculosis (TB) and sever presumed bacteria infection.

**Stage 4:** HIV wasting syndrome, pneumocystis pneumonia, recurrent severe pneumonia, chronic herpes simplex infection, oesophageal candidiasis, extrapulmonary TB, Kaposi's sarcoma, central nervous system toxoplasmosis and HIV encephalopathy (Rosenberg, Pilcher, Busch, & Cohen, 2015; World Health Organization, 2006).

## **1.11 TERMINOLOGIES USED IN PMTCT AND HIV CARE**

Several terms are used in health policy formulation for monitoring and evaluating the HIV and PMTCT programme over the years (MOH/GHS, 2014; WHO, 2014).

Arguments about the appropriateness of words such as compliance, adherence, and

retention have been ongoing (Aronson, 2007). The Oxford dictionary reveals the act of yielding of desire when compliance is defined. Wolfe (2016) argues that compliance connotes an order from the health worker that must be obeyed by the 'patient' or else they suffer some consequence. In her opinion, the use of such terminology in healthcare indicates a paternalistic approach to health activation. The assertion is supported by Aronson (2007) who says that these terms reveal a power play between the health providers and their clients.

Adherence, on the other hand, refers to a collaborative relationship between the partners in the healthcare enterprise and the ability to achieve health outcomes is dependent on an agreement between the parties in the relationship (Cohen, 2009). Aronson avers that adherence is a better terminology that points to the patients' need for tenacity and involvement (Aronson, 2007). Tenacity in the practice of and maintenance of the desired health behaviours is required for adherence to be achieved and this requires active client participation and shared decision making (Cohen, 2009). This terminology somewhat balances the power between the client and the health worker as the onus lies on the client to be committed.

Retention in care may largely refer to conformity of the patients' behaviour to the recommendations of the health care worker. The definition of retention-in-care (explained under 2.3) by the authorities on HIV/AIDS programme emphasises fact that the patient chooses to continuously engage in the programme and gain the benefits of the programme for themselves and their children.

This study applies Appreciative Inquiry which hinges on collaboration, shared meaning-making and ownership of the outcomes of participants, in this case. The researcher acknowledges that application of the terminologies applied in PMTCT/HIV programme may portray a contradiction. In the light of this, the researcher reframed some of the terms to show the power of the patient to make decisions for themselves, such as 'remained in care', 'continued treatment' etc. Application of the standard terminologies in portions of the write-up were however unavoidable as this would have altered the reporting by researchers and would not have been an accurate reflection of their work.

## **CHAPTER 2 LITERATURE REVIEW**

### **2.1 INTRODUCTION**

This chapter presents a review of current knowledge on retention in the PMTCT programme and is organised around the objectives of the thesis. The literature search strategy is presented under 2.2. The review under 2.3 explores retention in PMTCT. Various definitions of retention in PMTCT care and some concepts related to defining retention in the programme: disengagement and loss to follow up (LTFU) are reviewed.

Subsection 2.4 presents the factors that forms the background to the study; the rate of retention, the point of highest attrition, and maternal socio-demographic and obstetric factors as predictors for retention.

Subsection 2.5 focuses on the factors that inform mothers to remain in the programme. To conclude the review, 2.6 summarises the gaps identified in the literature review and indicates how this thesis contributes to bridging these gaps.

### **2.2 GENERAL APPROACH USED IN LITERATURE SEARCH**

A computer-generated search was carried out using PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and the Cochrane databases. The search terms included: “Retention” OR “Attrition” OR “Lost to follow-up” OR “Disengagement” OR “Engagement” AND “PMTCT” OR “Prevention of Mother to Child Transmission”. The literature search was limited to peer-reviewed journal articles, government papers and monographs published from 2010-2018.

Publications from WHO and UNAIDS that addressed retention and attrition were also included in the review. The search was limited to studies published in the English language or English abstracts for non-English articles. The references that were retrieved were imported into Endnote X6 where duplicates were removed.

Inclusion criteria included:

1. Setting of the study: studies from developing countries, Maternal, Neonatal and Child Health Units (MNCH) and community health units.
2. Study design: Explorative, Descriptive, Intervention studies, Qualitative studies as well as Systematic reviews.
3. Types of participants: HIV positive pregnant women, mother-exposed baby pair.
4. Outcomes: Rate of retention, factors that influence retention, objective measures of outcomes of intervention to improve retention.

A flow chart indicating the results for the search strategy is presented in Table 2-1 below.

Table 2-1 Literature search results

Reviewed studies generated from search	194	
Excluded after title search and abstract filtering		112
Selected	82	
Excluded		39 Reasons for exclusion
		<ul style="list-style-type: none"> <li>• Protocols 3</li> <li>• Duplicates 11</li> <li>• Theoretical descriptions 8</li> <li>• Monographs 18</li> </ul>
Included	43	

Exclusion criteria:

1. Reviews, commentaries and editorials on HIV/AIDS management programmes.
2. Publications on adult ART programme that was not limited to pregnant women and lactating mothers.
3. Publications on policy changes on testing of pregnant women and the modes of delivery was not included.

## 2.3 RETENTION IN PMTCT

As already indicated in 1.1, PMTCT programmes are provided across various MNCH units. The PMTCT cascade describes the programmatic steps that influence HIV transmission rates in HIV-infected pregnant women and mothers (Rollins et al., 2014). The PMTCT cascade has been applied in many research studies as a framework for recording retention in the PMTCT programme (B H Chi, Bolton-Moore, & Holmes, 2013; Church et al., 2017).

The PMTCT cascade also serves as a critical tool for monitoring PMTCT programmes in countries to identify areas of service delivery gaps such as missed opportunities, poor uptake, linkages and LTFU for improvement, expansion of coverage and distribution of resources (Hamilton et al., 2017). This section covers key concepts in monitoring and evaluation (2.3.1) and defining retention for PMTCT care (2.3.2).

### *2.3.1 Key concepts in monitoring and evaluating PMTCT*

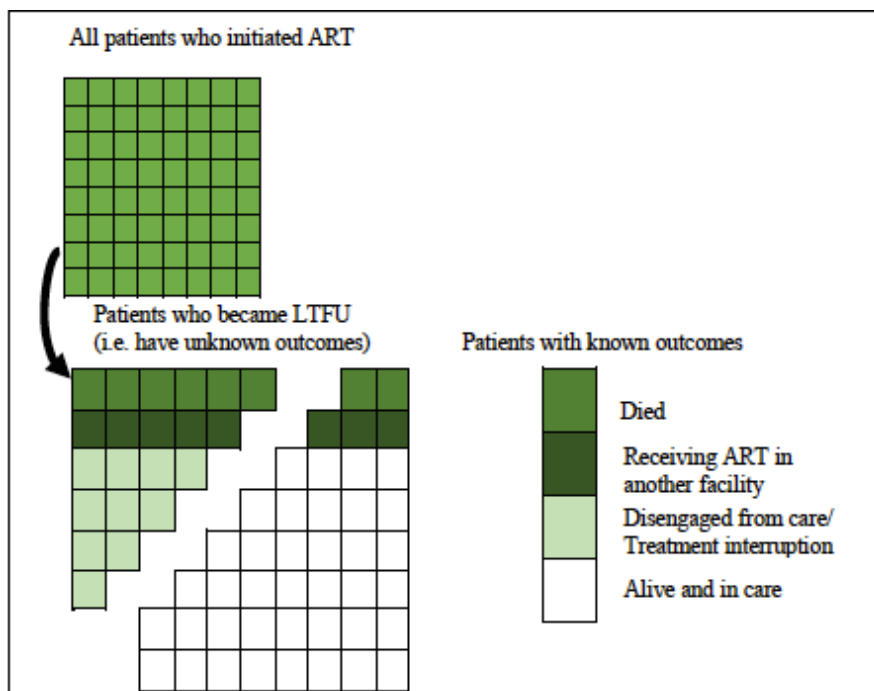
This subsection outlines concepts and defining outcomes of the PMTCT programme. The research and findings for these outcomes will be presented in 2.5. The concepts of disengagement, LTFU and adherence have been researched in studies on HIV and PMTCT. Although they are related, there are differences between them. The World Health Organization (2012) emphasises in its report that there is a distinction between disengagement from care and LTFU.

Disengagement refers to patient-related issues that cause them to cease accessing PMTCT care and usually requires service delivery response for clients to re-engage (WHO, 2012). Studies such as Phillips et al. (2014) and McMahon et al. (2017) have explored aspects of disengagement and revealed service delivery aspects of the programme and patient characteristics that influence disengagement. These characteristics include higher maternal age above 25 years at the time of enrolment in the programme, gestational age at initiation of ART, lower educational level, and lower socioeconomic status contributing to disengagement from the PMTCT programme.

Adherence is the extent to which an individual's behaviour complies with treatment, dietary schedules and or lifestyle recommendations from a health provider. Rollins et al. (2014) point out that the concept of Retention-in-Care is used as a proxy for maternal adherence to ARV therapy and an indication of viral suppression in surveillance and implementation research. The World Health Organization (2012) states that although the concepts may overlap, in evaluating the outcomes of care, it would be incorrect to apply them synonymously.

On the other hand, LTFU refers to patients who previously enrolled in the PMTCT/ART programme for whom the outcomes of care are unknown (World Health Organization, 2012). LTFU refers to gaps in health information systems and knowledge. Clients who are classified as LTFU have three possible outcomes; those with unreported death, those who unofficially self-transfer from one facility to another, and those for whom no reason can be assigned for their non-engagement (Grimsrud, Cornell, Egger, Boule, & Myer, 2013). An illustration of the concepts used in monitoring and evaluating PMTCT is presented in Figure 2-1 below

Figure 2-1 Concepts in monitoring and evaluating PMTCT



Adapted from World Health Organization (2012)

### *2.3.2 Defining Retention-in-Care for PMTCT*

The evolution of HIV management from emergency response to chronic disease management, as well as shifts in policy in the ART treatment options (presented in 1.1) for pregnant women infected with HIV has placed retention-in-care as an important outcome in the PMTCT programme (World Health Organization, 2012). In the wake of this evolution and policy shifts, many studies have been conducted on retention in PMTCT, yet retention-in-care has been defined differently in most of these studies. The variations in defining retention in the PMTCT programme involves the different application of concepts in research including the time periods, classification of clients who are retained, and the constructs used in the measurement of retention such as missed or scheduled visits. Rollins et al., (2014) point to these variations in the definitions or timelines adapted by researchers who purport to study retention in the PMTCT programme either for surveillance or monitoring and evaluation as resulting in outcomes with systematic bias and errors.

The World Health Organization (2012, p. 3) defined retention in ART care as “continuous engagement from the time of diagnosis in a package of prevention, treatment, support and care services.” It proposed that retention-in-care should be measured from the time when the initial engagement in the programme occurs, through when the HIV–infected person is linked to services successfully for assessment on eligibility for ART and retention on lifelong care. In spite of the above definition by WHO, Mugavero et al. (2012) still maintain that there is no particular gold standard for defining or measuring Retention-in-care.

Most studies report mothers’ attendance at the ART clinic at any chosen time period along the PMTCT cascade as an indicator of retention in the PMTCT programme. A study by Oyeledun (2014) to assess the effects of continuous quality improvement intervention on retention-in-care in Northern Nigeria operationalised a mother retained in care to be one who has not missed a previously scheduled visit by more than 30 days and attends the 6-month post-delivery visit. Dionne-Odom et al., (2016) in a study in Haiti measured retention-in-care as a medical visit at least every six months. They argue that the sixth month period is consistent with other published studies in the post-delivery period (Aebi-Popp et al., 2014; Mugavero et al., 2012; Wang et al., 2011). Other researchers also subscribe to measuring retention at a 12-

month period (Hoffman et al., 2017; Mwapasa, Joseph, Tchereni, Jousset, & Gunda, 2017). Even then, there are variations as to the time points. WHO, in an effort to standardize the definition and measurement of retention in PMTCT stated the attendance of an HIV infected woman or mother at the 12-month “after initiating of ART/ARVs, or at any time three months after as retained in care” (World Health Organization, 2012). Rollins et al.(2014) however point out that the time periods proposed by WHO do not consider the ongoing risks that a child who is breastfed after the 12-month period is exposed. Hence, they stated that an HIV-infected mother (and child) attendance at a clinic at 12-months post-delivery is equated with full retention in the PMTCT programme. Woelk et al. (2016) and Tenthani et al. (2014) accordingly measured retention among PMTCT clients in Rwanda and Malawi respectively as extending to the 12 month post-delivery period although other time points such as six weeks, three, six and nine months’ retention were also captured. Variations in the classification of clients retained in the programme are evident in studies by (Dzangare et al., 2016; Woelk et al., 2016). Dzangare et al. (2016) in a study on retention-in-care of HIV-infected pregnant women in Zimbabwe categorized those retained as clients who remained within the facility where care was initiated as well as those who were transferred to other facilities. The researchers, however, reported that they did not follow-up to assess if indeed the clients were still in care or LTFU after the transfer (Dzangare et al., 2016). Other studies such as Woelk et al. (2016) preferred to measure retention as clients retained within the same health facility where treatment was initiated.

Researchers have applied different constructs in measuring retention. Mugavero, Davila, Nevin, and Giordano (2010) aver that measuring retention is complex as it involves multiple visits that are scheduled at different time intervals and over a period. Rollins et al. (2014) argue that to correctly interpret measurement outcomes of implementation research, assessment on retention-in-care must include missed visits or inconsistent attendance and the care received by the mother and child at each visit. They maintain that since the concept of retention-in-care in PMTCT programmes is used as a proxy for adherence and viral suppression, receiving the services designated for those time points are essential indicators for retention. A synthesis of published articles by Mugavero et al. (2010) identified five constructs that have frequently been used to measure retention in care as; missed visits,

appointment adherence, visit constancy, gaps in care and the Human Resource and Services Administration HIV/AIDS Bureau (HRSA HAB) performance measure for retention in HIV care which captures not less than two clients' visits for PMTCT services that are separated by three or more months within a period of 12-months.

In the light of these variations in definition and measurements of retention-in-care of the PMTCT programme, Ndaimani et al. (2016) using a critical appraisal of literature sources proposed a definition of retention in eMTCT care. Retention in eMTCT is “documented regular participation of the pregnant woman, confirmed HIV positive, together with her child or children not yet confirmed as HIV-positive, in all prescribed activities aimed at preventing transmission of HIV from her to the child, and scheduled or unscheduled HIV-related visits, measured during or at the end of care” (Ndaimani et al., 2016; p.13) This definition clearly defines the activities or characteristics associated with retention in the PMTCT programme, but it does not address the critical time points and therefore its use as a proxy indicator for clinical efficacy is not addressed. Mugavero et al. (2012) therefore explained that the selection of a retention measure should be tailored to the context of the study.

Therefore, for this study, retention was measured at six weeks postpartum. This time-point is significant for all infected mothers and their exposed children (as indicated in 1.2), exclusively breastfeeding or otherwise, as it represents the third and final postnatal assessment for mother who thereafter receives ART care and all exposed child undergo DNA PCR test (Ghana Health Service, 2014).

## **2.4 FACTORS THAT FORMS THE BACKGROUND TO THE STUDY**

Following the diagnosis of HIV of any pregnant woman, initiation of treatment and subsequent retention in the PMTCT programme is necessary to ensure that plasma viral load is maintained at undetectable levels so that the risk of MTCT is reduced or eliminated (Fox, Larson, & Rosen, 2012) and the mothers maintain their health. It is encouraging to see that many research studies have been conducted in the area of retention of PMTCT in the past few years.

The studies discussed in this section are closely aligned with main objectives of section A of this study that sought to

1. determine the retention patterns and rate in the PMTCT programme.
2. investigate the socio-demographic and obstetric characteristics of expectant mothers who remained in the programme until six weeks postpartum for the DNA PCR for their exposed children.
3. identify the lowest retention (highest attrition) points along the PMTCT cascade.

Literature in this section is reviewed under the following subheadings: Rate of retention (2.4.1), and points along the PMTCT cascade where disengagement occurs (2.4.2).

### ***2.4.1 The rate of retention***

Various rates of retention have been reported across studies in sub-Saharan Africa (Atanga et al., 2017; Dionne-Odom et al., 2016; Etoori et al., 2018). A prospective cohort study in Cameroon reported high rate of retention in the PMTCT programme at 88% and 81% at six months and twelve months post-delivery follow-up respectively following a retention enhancement process (Atanga et al., 2017). On the contrary, maternal retention at 12 months post-delivery follow-up in Rwanda was low (58%) (Dionne-Odom et al., 2016). The retention rate of exposed infants at 12 months postpartum within the same facility was however high (81%) based on the analytical sample of 348. The maternal retention rates in Southern Swaziland at 24 months was 52.9%. The infants' retention was 53.6% within the same period (Etoori et al., 2018). In a similar study in Ghana, the levels of engagement were classified as optimal follow-up, suboptimal follow-up and LTFU. The study findings indicated an overall optimal follow-up (66%) in the post-delivery period. In all, follow-up of 16% of mothers was suboptimal whilst 18% were LTFU. The difference in the time point the retention rates were recorded may have accounted for the variation in retention across the studies.

The initial high retention rate and subsequent decline in engagement in the PMTCT programme is not limited to Sub-Saharan Africa. In Haiti, high rates of retention, 80% at delivery was recorded for pregnant women but at 12-months post-delivery follow-up, the retention rate declined to 67%, further declined to 59% at 24 months

and reportedly plateaued after 36 months of engagement in the programme (Dionne-Odom et al., 2016).

Several of the studies reporting on the rate of retention in PMTCT are retrospective studies. Thus, the homogeneity in the designs of the various studies included in this review underscores the fact that similar limitations, such as small sample size that affected the power of the study to determine any associations, were common to most of the studies. The quality of the routinely collected patient records that were extracted and analysed to determine the trends also presented a bias of the findings for most of the studies. This presented a challenge for the generalisation of the trends of retention across various settings. There was also a lack of consistency in the definition of retention and the time points of the PMTCT cascade at which the retention was recorded (as presented in 2.3) that were being implemented in the various studies.

In spite of these limitations, these studies reveal some key trends of retention in the PMTCT programme. Several of the studies reported on retention in the post-delivery period. Table 2-2 presents the timelines for reporting PMTCT retention rates of studies included in this study. Generally, although the rates of retention were initially high in the postpartum period, these declined over time. The trend of decline in maternal retention in the PMTCT programme especially in the postpartum period points to challenges with achieving the programmatic outcomes of PMTCT.

Table 2-2 Timelines reviewed in studies reporting on PMTCT retention rates

Authors	Setting	Antenatal period	Labour	Postpartum period			
				6 weeks	6 months	12 months	24 months
Atanga et al. (2017)	Cameroon				✓	✓	
Dionne-Odom et al. (2016)	Haiti		✓			✓	✓
Etoori et al. (2018)							✓
Woelk et al. (2016)	Rwanda	✓	✓	✓	✓	✓	✓
Reece et al. (2016)					✓	✓	

### *2.4.2 Highest point of LTFU on the PMTCT cascade*

WHO/ Joint United Nations Programme on HIV/AIDS/UNICEF(2011) purport that expectant women disengage from care or are LTFU at all the points along the continuum of HIV care. They however assert that the highest point of the HIV care cascade where LTFU occur was the point of testing and enrolment unto treatment in the antenatal period where about 80% of patients diagnosed with HIV will be LTFU. This is supported by findings from a mix method prospective study by Ferguson et al. (2014) in Kenya which recruited 100 HIV positive pregnant women. Findings from the study revealed that the highest point of attrition was between initial diagnosis and registration for care at an HIV clinic accounting for 47% of the total LTFU. It is important to note however that attrition at various points of the PMTCT cascade were also significantly high as 45% LTFU was recorded between receiving the CD4 count results and actually initiating ART whilst 18% were LTFU around the time of delivery and the postnatal period. Dionne-Odom et al. (2016) also found the highest rate of disengagement from the facility (33%) occurred within the first 30 days of registration at ANC in Haiti. Disengagement from the programme after delivery and six months post-delivery period were relatively lower.

This is in contrast with findings of a qualitative study by Stinson & Myer (2012) to explore the barriers to initiating ART during pregnancy in South Africa. Participants included 28 HIV positive women (who were either pregnant or in the early postpartum period and were either eligible for ART or were already initiated) and 21 PMTCT service providers. The health providers identified the postnatal period as the point in the PMTCT cascade where the highest LTFU occurred. The clients explained that, the messaging of the counselling and the education expectant mothers who test positive to HIV receive before treatment is mainly about protecting your unborn child from vertical transmission and so the women tend to think that there is no need to continue with treatment after the child is born. This they purport contributes to the high LTFU in the postnatal period of the PMTCT cascade.

This is supported by findings of a two-year retrospective cohort study conducted by Phillips et al. (2014) involving 358 pregnant women who had initiated ART in pregnancy in south Africa. The outcome of the study was to determine the frequency of disengagement and also investigate factors that were predictors for disengagement

of ART care. Of the number who were eligible for the study, 49% had either disengaged or missed an appointment by six months of initiation of care of ART. The highest rate of disengagement (36%) was recorded in the postnatal period with the incidence recorded as twice compared to the ANC period ( $p=0.0004$ ). The risk for disengagement in the postnatal period was also recorded as increased to almost 4 times that of the ANC period (aHR: 3.93 CI 1.25, 12.31).

Clouse et al. (2013) in a retrospective study sought to determine the rate of LTFU in women who were diagnosed with HIV during pregnancy. The study findings revealed that LTFU occurred in both the antenatal and postnatal period recording a cumulative LTFU rate of 57.5% (95% CI: 51.6–63.3%). It further detected that the most LTFU occurred in the postpartum period (47.9% (95% CI: 41.2–54.6%)) within 6 months as compared to the 20.7% that was recorded in the antepartum period. Needless to say, however, the rate of LTFU in both periods were alarming and needed urgent attention. Ineligibility for ART initiation during the AN period was also associated with LTFU postpartum as only 22.6% of participants who were ineligible for treatment were retained in care till the point when they had a repeat of CD4 count test done postnatally.

## **2.5 FACTORS THAT INFLUENCE RETENTION IN THE PMTCT PROGRAMME**

The factors that contribute to HIV-infected women's decision to continuously engage in the PMTCT programme after enrolment are multi-causal (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Landon Myer & Phillips, 2017). Several studies have categorised these factors underscoring disengagement in PMTCT programme using different frameworks. The basic framework for reviewing literature on disengagement has been to categorise these factors under 'barriers and facilitators' (Anígilájé, Ageda, & Nweke, 2016; Gourlay et al., 2014; Gourlay et al., 2013; Kim et al., 2016; Panditrao, Darak, Jori, Kulkarni, & Kulkarni, 2015; Tomori et al., 2014).

On the other hand, Myer & Phillips (2017) developed a framework on the fundamental drivers of disengagement from the PMTCT programme. This review applied the framework by Myer & Phillips (2017) to organise this sub-section. This framework was chosen as it presented the fundamental drivers that contributed to retention or disengagement in the PMTCT programme and allowed for a more

detailed review of the factors unlike the other framework that broadly categorised the contributing factors under barriers and facilitators. The framework categorised the fundamental drivers influencing disengagement from the programme under structural, social and economic conditions (2.5.1); health systems and services (2.5.2); individual level factors (2.5.3); and bio-medical considerations (2.5.4). The body of studies selected for this review were mostly conducted in high prevalence and low-income countries in Sub-Saharan Africa. For ease of reference, the studies that were selected for this review are discussed below.

### ***2.5.1 Structural, social and economic conditions***

The drivers of disengagement that relate to the structural, social and economic situations of the women include poverty, mobility, gender inequalities, food insecurities that indirectly influence retention (Myer & Phillips, 2017). Hiarlathie, Grede, de Pee, & Bloem (2014) identify economic and social factors as the most common barrier to retention emanating from the demand side of service delivery.

The most cited socioeconomic barrier to accessing PMTCT service was transportation to access PMTCT care (Clouse et al., 2014; Hiarlathie et al., 2014; Iroezi et al., 2013; Kim et al., 2016; Peng, Wang, Xu, & Wang, 2017; Yang, Zhou, & Eemu, 2013). Mobility of the clients in relation to the distance from the location of the health facility where PMTCT services are rendered in relation to the residence of the clients was identified as influencing retention (Iroezi et al., 2013). Risk factors associated with disengagement included the transfer of PMTCT services to another health facility and moving residence (Dionne-Odom et al., 2016). Lack of money for transportation has also been cited as a reason for disengagement from the PMTCT programme (Atanga et al., 2017; Iroezi et al., 2013).

Food security is another socio economic determinant of retention in PMTCT care. Food insecurity is a critical determinant of retention and adherence of HIV-infected pregnant women and their exposed children in the PMTCT programme (Young, Wheeler, McCoy, & Weiser, 2014). Fear of food insecurity associated with the risk of poor or no crop has been cited as a reason for non-disclosure of HIV status and disengagement from the PMTCT programme (Iroezi et al., 2013). This fear of food insecurity is attributed to fear of losing agricultural support as a result of the stigma associated with HIV. The provision of food for infected women and exposed

children improves retention and acts as a barrier to disengagement especially of the exposed infants (Phelps et al., 2013).

Gender roles and dynamics of relationships are social factors that influence the women's decisions to disclose their status to their partners (Bhatia et al., 2017) and this affects their decision to remain in the PMTCT programme. Gender autonomy as a social factor influences a woman's choice to remain in the PMTCT programme or otherwise. Yourkavitch and colleagues found that in Malawi and Uganda, gender-related factors such as decision-making autonomy, family responsibilities, spousal/partner influence, fear of disclosure and stigma underscore the infected women's decision to remain in the PMTCT programme (Yourkavitch et al., 2018). Flax et al. (2017) also reported that the socio-cultural norms that confers respect for married women and those with children as well as, the duty to defer decision-making and choice to men in Uganda affected the women's decision to disclose their status and this inadvertently affected retention in the PMTCT programme. In Malawi, partners of women who tested positive were blamed or abandoned for not requesting permission to take the test (Njunga & Blystad, 2010). Consequently, women were prevented from enrolling or remaining in PMTCT programme in Uganda (Nakigozi et al., 2013) and Zimbabwe (Skovdal, Campbell, Nyamukapa, & Gregson, 2011).

The decision to remain in the programme is affected by financial implications of programme such as transport cost and food. The control of family finances by the partners or even other older members such as the mothers-in-law sometimes affects the woman's economic status resulting in lack of financial access. Gender-based violence has been associated with disengagement from the programme (Donahue, Dube, Dow, Umar, & Van Rie, 2012).

Issues with transportation and access to PMTCT services, food insecurity and gender inequalities affecting women points to the power imbalances that are underscored by poverty and cultural influences. However, they represent only a section of the multimodal factors that influence retention.

### ***2.5.2 Health systems and services***

The health system and service delivery factors that influence disengagement are associated with the issues of access to the programme, the quality of services rendered in the programme and the models of care employed (Myer & Phillips,

2017). This sub-section reviews literature on the programmatic changes that have occurred in the PMTCT programme since its inception in the 1990s and how these have influenced retention in the programme. These changes have occurred in the policy and service delivery approaches of the programme including HIV testing and counselling, treatment modalities, intrapartum care (modes of delivery) and modes of service delivery. This subsection reviews literature on two main programmatic changes, treatment modalities in PMTCT (2.5.2.1) and models of service delivery (2.5.2.2), and how they have impacted retention in the PMTCT programme. A review on the changes in testing of pregnant women and the modes of delivery was not included, as they were noted to influence uptake of services but not necessarily retention in the programme, which is the focus of the review.

### **2.5.2.1 Treatment policy changes: Impact on retention**

Retention in the PMTCT programme is influenced by the HIV-infected mothers' knowledge and perception that the treatments are efficacious in protecting their babies from vertical transmission, as well as maintaining the mothers' health (Elwell, 2016; McLean et al., 2017). There is still a lot to be learnt about how retention-in-care has been impacted by the changes in treatment policy in the PMTCT programme over the years.

The efficacy of the antiretroviral treatment regimen has contributed greatly to the success of the PMTCT programme outcomes including retention over the years (UNICEF, 2012). The path towards the success story of the PMTCT programme in sub-Saharan Africa has been longer and meandering compared to the developed countries mainly as a result of infrastructural limitations, high disease burden, and lack of funding to roll out highly efficacious treatments (Chi, Stringer, & Moodley, 2013). Hence, the treatment regimen for the PMTCT programme has also undergone various changes over the years.

In the early nineties when PMTCT was initiated, monotherapy zidovudine and later nevirapine (NVP) were administered peripartum (Guay et al., 1999). However, to assuage the cost of treatment, prevent emerging drug resistance to the monotherapy, and to improve coverage to breastfeeding populations, treatment options rapidly changed to more efficacious and effective regimens over the years (Chi et al., 2012). In 2010, WHO recommended guidelines on ART based on the public health

approach for treating pregnant women and preventing HIV infection in infants (WHO, 2010). This guideline called for early triaging of HIV-positive pregnant women to determine those who met the clinical staging (3 or 4) or immunologic criteria for lifelong treatment ( $CD4 < 350 \text{ cells/mm}^3$ ) for early initiation of ART. For those who did not require ART for their own health, WHO recommended treatment with antiretroviral prophylaxis (ARVs) and offered two approaches; Option A and B treatment regimen.

In option A, mothers who did not meet the criteria for lifelong ART for their own health, initiated ART on Zidovudine (AZT) monotherapy antenatally from 14 weeks gestation, took a single dose of Nevirapine (NVP) and completed with a week-long 'tail' of combination therapy of zidovudine -lamivudine (AZT-3TC). Nevirapine was administered to the exposed infant daily from birth until complete cessation of breastfeeding (WHO, 2010).

In the option B regimen, the women who were not eligible for lifelong treatment received a three-drug combination prophylaxis during pregnancy and continued till complete cessation of breastfeeding. In this approach, the exposed infants were prescribed NVP or AZT daily for the first six weeks of life (WHO, 2010). In both options A and B, there was interruption in treatment after a period on ARVs until the women became pregnant again or required lifelong treatment for their own health (Chi et al., 2013).

The option B approach set the stage for transitioning to universal access to ART in pregnancy in 2011. The strategy was referred to as option B+ and implemented by the government of Malawi (Schouten et al., 2011). It required that all pregnant women who tested positive to HIV in the PMTCT programme enrol on lifelong ART. This option therefore eliminated the triaging processes based on clinical staging and immunological status required for treatment in option A and B, as well as any interruption in ART (Chi et al., 2013).

In spite of the potential of the treatment options to reduce vertical transmission, retention of mothers in the PMTCT programme and adherence to the treatment regimen is critical for achieving the programme outcomes. Studies have reported various rates of retention of mothers in the PMTCT programme where the various

treatment options were implemented (Atanga et al., 2017; Dionne-Odom et al., 2016; Ferguson et al., 2012; Rosen & Fox, 2011).

There is evidence of missed opportunities for PMTCT services and high attrition of women during the antenatal period in the option A and B approach which required a longer period of waiting from the time of testing positive to initiating treatment as a result of the triaging process required by these options. Rosen and Fox (2011) highlighted the low retention of mothers in the option B PMTCT programme. In their systematic analysis of 28 studies from seven countries, a median proportion of 59% of the women who accepted to be tested returned for their CD4 results within 2-3 months of testing HIV positive. Across studies, 44% of patients enrolled in the programme while only 14-84% of eligible patients initiated treatment across all the studies. Similarly, Ferguson et al. (2012) reported a low rate of registration (17.2%) in the programme and only 4% of women who were eligible for Highly Active Antiretroviral Therapy (HAART) after testing positive in pregnancy, initiated treatment within a period of six months in Kenya.

UNICEF (2012) recommended the option B+ treatment regimen and was optimistic that it could positively improve uptake and retention of women and their infants in the PMTCT programme. The authors averred that this treatment option conveyed a clearer public health message to the clients that ART was lifelong and cleared any potential misconception about the need for continuous engagement in the programme that the option B presented.

The assertion that retention in the option B+ programme is high has been confirmed by studies in lower income countries such as Cameroon, Swaziland, Rwanda and Haiti (Atanga et al., 2017; Dionne-Odom et al., 2016; Woelk et al., 2016). In Cameroon, retention rates in PMTCT care was 88% and 81% at six months and 12 months respectively. Although the rates were high, there was a decline in retention at 12 months post-delivery.

The relatively high retention rate in the option B+ programme has been associated with the same day testing of HIV and initiation of treatment which eliminates waiting time before initiation of treatment (Orne-Gliemann et al., 2017). Although, Helova et al. (2017) agree to the high acceptability of option B+ treatment approach among PMTCT clients, they argue that option B+ specific factors such as initiation of treatment on the same day of testing is a barrier for retention among women of

western Kenya. Lipira et al. (2018) reported that the risk of attrition of women who were initiated on ART under option B+ was 36% (95% CI 1.15-1.62) high at any given time. The risk for attrition under option B+ is linked to the assertion that initiation of ART for life on the same day the HIV positive diagnosis is made is a daunting decision for expectant mothers (Stinson & Myer, 2012). This they felt was because the mothers did not get enough time to assimilate the new information that will affect the unborn baby, the mother's health as well as her future for the rest of her life. In this regard, this argument might explain why there is still disengagement from the programme especially in the postpartum period. In spite of these contrary arguments about that same day ART initiation in option B+ and how it affects retention, Myer, Zulliger, Bekker, and Abrams (2012) reported that in South Africa, health systems strategies to delay initiation of clients on ART until three sessions of counselling does not promote retention. The study reported that a median delay between the time when mothers test HIV positive and the initiation of ART was 21 days (IQR, 14-29 days). There was no statistically significant effect of delaying initiation on ART for up to 35 days on retention in PMTCT (RR: 0.89, 95% CI, 0.72-1.03) after they had adjusted for women's age and gestational age at screening. These dissenting views about the various treatment options and how they influence retention points to the fact that the factors affecting retention in PMTCT are varied and cut across various time points along the PMTCT cascade.

### **2.5.2.2 Models of service delivery: implications on retention**

Retention in PMTCT programme has been linked to the models of service delivery that are adopted in the health care facility. Several models of care such as integrated and segregated approaches, facility-based and community based programme, as well as physician-led, nurse-led and lay worker involvement have been employed as service delivery strategies globally (Ivers et al., 2011; Kredo et al., 2012; Lipira et al., 2018; Suthar et al., 2013).

The integration of PMTCT programme within MNCH clinics has yielded mixed outcomes on retention of women enrolled in the PMTCT programme. Lipira et al. (2018) report that provision of PMTCT services within the MNCH clinics results in improved retention in the programme (22% risk of attrition; 95% CI 0.64-0.96) than when women were referred to other clinics for services such as HIV testing and

refilling of ART. Similarly, a cluster-randomised study in Nigeria found integration of care to improve mother-infant pair retention in the PMTCT programme.

Mother-infant pairs were more likely to remain in care at 6 weeks (125/150 [83%] vs 15/170 [9%]) and 12 weeks (112/150 [75%] vs 11/168 [7%] pairs postpartum (Aliyu et al., 2016).

Contrary evidence on the effects of integration on retention was reported by Washington et al. (2015) in a randomised trial in 12 Kenyan government health facilities. The study sought to determine the feasibility, value and effectiveness of integrating the PMTCT programme, particularly in settings with low resourced facilities. The retention across the PMTCT cascade and the utilisation of services were suboptimal recording 51.1% (313/611) and 28% (256/611) at six and 12 months respectively in spite of the convenience the integrated service delivery provided to the pregnant women while uptake of early infant diagnosis at six weeks remained low in both arms of the study (25%; 43/568 and 18%; 106/594 OR 1.57, 95% CI 0.61 - 4.07). Similarly, in a systematic review, one eligible study that reported on the effects of integrated PMTCT service retention found no statistical differences in the intervention (87.8%) and control (91.3%) arms of the study at both individual and cluster levels (Suthar et al., 2013). In a systematic review, Geldsetzer (2016) attributed the inconsistency of study findings on the effect of integrated care on PMTCT retention on low quality of the studies, heterogeneity of study designs and outcome measures.

Other studies have discussed the effects of the physician-led, as well as the nurse-led models of care on retention. Ivers et al. (2011) found that in the wake of shortage of health staff in Haiti, nurses provided 10% of tasks related to triaging of patients, counselling and testing, initiation on ART and tasks associated with new-born care in the PMTCT programme. They reported a loss to follow up rate of less than 5% at 24 months and increased staff satisfaction in the nurse-led model of service delivery. Comparing the effects of doctor-led against nurse-led ART care, Kredo et al. (2012) found that nurse-led care decreased the rate of loss to follow up in the programme at one year of treatment initiation relative risk of 0.73 (95% CI 0.55 to 0.97) as compared to the doctor-led care relative risk 1.27 (95% CI 0.92 to 1.77). This is an absolutely critical finding and begs the question ‘what are the nurses doing that enhances retention?’

These findings suggest that the factors that affecting PMTCT utilization and retention, although influenced by global policy on service delivery, go beyond policy development and implementation. A focus on the clients' perception and experiences in the PMTCT programme and its influence on their decision to remain in the programme may be insightful.

### ***2.5.3 Individual level factors***

The individual levels drivers of disengagement relate to factors such as disclosure of status by the women, availability of social support, the mental states of the infected women as well as the psychology of pregnancy and motherhood (Myer & Phillips, 2017). The clients' experiences while engaging in the PMTCT programme can also contribute to their decision to remain in programme. This sub-section is presented as follows: spousal and family support (2.5.3.1), psychology of pregnancy and motherhood (2.5.3.2) and patient experiences in the programme (2.5.3.3).

#### **2.5.3.1 Spousal and family support**

Thomson et al. (2018) found that the decision to continuously engage in the PMTCT programme by mothers who test positive to HIV in pregnancy triggers a continuous process of risk-benefit analysis that could positively or negatively influence retention. This decision to remain in the programme was weighed against the desire to preserve their relationships with their male partners, meet the expectations of their communities on womanhood while following the treatment recommendations of the health systems. A retrospective study in Malawi found that involvement of male partners in the PMTCT programme significantly improved hospital delivery (AOR = 25.9, 95%CI: 10.6–63.6, P,0.001), and completion of follow-up in the programme (AOR = 16.8, 95% CI: 8.5–33.4, P,0.001) (Kalembo, Zgambo, Mulaga, Yukai, & Ahmed, 2013). Brusamento et al. (2012) however did not find any association between male partner involvement and retention in a systematic review. In the eligible study, written letters/invitations were given to the participants to be delivered to their partners to encourage male partner involvement in PMTCT. After the study period, only 16% of the women in the intervention group were retained and completed the full complement of the services in the PMTCT programme.

Thomson et al. (2018) found that in the face of stigmatization of persons living with HIV, community and male partner support and implementation of community-based

approaches to PMTCT services delivery enhance retention. Spousal and family support is only possible when participants disclose their status. Disclosure of HIV status was identified as a facilitator for retention in Nigeria (Sarko et al., 2017). Analysis of records of HIV positive women from a clinical trial found that 86.5% (OR 3.17, 95% CI 1.39-7.23) of participants in the intervention arm had fully disclosed their HIV status to their partners. After adjusting for confounders, Sarko et al. (2017) reported that the participants with full disclosure were more likely to deliver at the health facility (OR 2.73, 95% CI 1.11-6.72) but the trends of early postpartum retention in the programme at 6 and 12 weeks (OR 2.72 95% CI 0.79-9.41) and 2.46, 95% CI 0.70-8.63, respectively) were not significant. The small sample size for the comparison group (those who did not disclose) reduced the power of the study and therefore decreased the power to detect any effects of disclosure on retention. The possibility of the occurrence of social desirability bias occurred as the disclosure was self-reported and not confirmed by the researchers.

Negative disclosure experiences have been linked to increasing disengagement in the programme. Participants in the study by Buregyeya et al. (2017) cited fear of abandonment and domestic abuse by their husbands and HIV related stigma as the reasons why they disengaged from the PMTCT programme.

### **2.5.3.2 Impact of pregnancy and motherhood**

The review of literature found that pregnancy and breastfeeding had an impact on retention at the various phases of the PMTCT programme and that being pregnant at the time of testing HIV positive and enrolling in the PMTCT was a risk factor for disengagement. Phillips et al. (2014) indicated that in Cape Town, South Africa, being newly diagnosed with HIV during the current pregnancy and having a later gestational age (median 28 weeks IQR: 21-32) posed a 57% and 4% increased risk of disengagement respectively by six months postpartum ART care. These findings are plausible although the use of routine medical records has its limitations. These findings were corroborated by Tweya et al. (2014) who reported that women pregnant at the time of PMTCT initiation disengaged from the programme when compared to those who enrolled during the breastfeeding period (RR 0.63, 95% CI: 0.49-0.82;  $p < 0.001$ ) in Lilongwe, Malawi. Tenthani et al (2014) found that women who initiated ART while pregnant under option B+ were five times more likely to

disengage from the programme (adjusted OR 5.0, 95% CI 4.2-6.1), while breastfeeding mothers were twice as likely to miss their first appointment following the initiation of treatment (adjusted OR 2.2, 95% CI 1.8-2.8;  $p < 0.001$ ).

Both factors may be related to the shock of being informed of the new diagnosis which may result in an inability to assimilate much information during the post-test counselling. Stinson and Myer (2012) aver that the initiation of ART for life on the same day the HIV positive diagnosis is made may be a daunting decision for the expectant mother. The expectant mothers do not get enough time to assimilate the new information that will affect the unborn baby, her health and her future for the rest of her life. This is further supported by Kgwete (2008) who stated that most women have to deal with the shock of being HIV positive and the feeling of betrayal by their partners and may therefore be unprepared to make a lifelong decision to initiate ART. This may therefore result in the LTFU.

### **2.5.3.3 Patient experiences in the PMTCT programme: implications for retention**

Retention in the PMTCT programme is dependent on the infected women's commitment to remain in the programme, in spite of any challenges that they may encounter. Clients experiences are increasingly being identified as an important indicator in provision of quality health care and patient engagement in healthcare in general (Department of Health, 2008; Gleeson et al., 2016). Jason, Niederhauser, Marshburn, and LaVela (2014) in a synthesis of published studies, identified emotional and physical lived experience, personal interactions, spanning across a continuum, the organization or culture, and importance of patient involvement as persistently running through literature when patient experiences are discussed.

The provider-patient interaction has been found to influence the clients' decisions to remain or disengage from the PMTCT programme or disengage. Negative staff attitudes towards HIV-infected clients engaged in the PMTCT programme have been cited as a barrier for retention (Clouse et al., 2014; Gourlay et al., 2013). Gourlay et al. (2014) in a study to understand how patient-provider interactions influenced utilisation of PMTCT found that anticipated or experienced negative staff attitudes such as discrimination, disrespect, scolding especially during delivery, omission of pre-HIV counselling and unclear communication often resulted in missed subsequent

appointments or disengagement. Gourlay et al. (2014) also reported that concerns with confidentiality also affected the development of trust in the patient-provider interaction, thus clients often experienced anxiety when they had to establish new relationships with health workers as a result of referrals after they had gained the trust of the initial provider. This they found affected retention in the programme. Similarly, a trusting provider-patient relationship was positively associated with adherence to ARVs and consequently retention in HIV care. High trust in the primary care provider was significantly associated with adherence and consequently retention than low trust (AOR<sup>2</sup>, 2.67; 95% CI, 1.24 to 5.67; p= 0.01). Hence, low trust in primary care providers potentially resulted in disengagement from care and low acceptance of health provider's advice. Enhancing patient provider trust can improve clients' engagement in the PMTCT programme.

On the other hand, although research on the positive experiences of clients engaged in the PMTCT programme is infrequently one, studies on facilitators of retention in the PMTCT programme provided insights on the effects of positive patient-provider relationships on retention. Positive patient-provider interactions have enhanced uptake and retention in the PMTCT programme. In a qualitative study, Gugsu et al. (2017) found that re-engagement of clients who defaulted occurred as a result of the encouragement from the health professionals. Positive interactions with health professionals (Aluwani, 2012), assistance with disclosure of HIV status as facilitators for retention in the PMTCT programme in a systematic review (Gourlay et al., 2013).

Patients' experiences in the programme are also influenced by the organisation of service delivery in the facility and the health care environment. Inconvenient operating times for clients have been identified as constraints in the PMTCT programme in Western Kenya (Helova et al., 2017) and South Africa (Nkomo & Goga, 2015) and these affect patients' experiences and consequently retention in the programme. Long waiting times to access PMTCT services have also been identified as a barrier to retention in the programme. Hospital visits to access PMTCT care that took over 2 hours (OR 2.3, 95% CI 1.1 ± 4.7) were identified as a deterrent for returning for subsequent care thereby causing missed visits and disengagement (Naburi et al., 2016).

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<sup>2</sup> Adjusted odds ratio

### 2.5.3.4 Maternal socio-demographic characteristics

Maternal age was associated with retention and LTFU in the PMTCT programme in several studies. Tweya et al. (2014) in a retrospective study in Malawi to determine the factors, reason and outcomes of LTFU in Option B+ PMTCT programme, found that women of a higher maternal age (above 25 years) at initiation of ART were more likely to remain in the programme (RR 1.29 95% CI 1.09-1.52) than younger women (aged 13-24 years). This finding is corroborated by a case-control study in Malawi that reported the odds of remaining in the PMTCT programme were higher among women who were >25 years (OR 2.44; 95% CI 1.24-4.81) (Hoffman et al., 2017). Dzangare et al (2016) on the other hand reported from a study in Zimbabwe that women 19 years or older were more likely to remain in the programme than those within the ages of 15-19 years. Hence, the older the mother the greater the likelihood of retention.

Other socio-demographic characteristics such as the educational and marital status of the mother also affects the decision to remain in the PMTCT programme. The level of education attained by the mother at the time of enrolment into the PMTCT programme and initiation on ART was also found to be associated with retention. In Maharashtra, India, women enrolled in the PMTCT programme with education less than graduate level was associated with disengagement antenatally (RR 6.32; 95% CI 1.84-29.68), and after delivery (RR 1.82 95% CI 0.48-1.40) (Panditrao, Darak, Kulkarni, Kulkarni, & Parchure, 2011). In North-eastern Ethiopia, Mitiku, Arefayne, Mesfin, & Gizaw (2016) also found that higher number of women who were LTFU from the PMTCT programme had no education or primary education, 17 (31.5%) and 23 (42.6%) respectively.

Several studies reported that knowledge of the partners' HIV status informed the woman's decision to remain in the programme (Hoffman et al., 2017; Panditrao et al., 2011). Awareness of a partner's HIV status was associated with retention in PMTCT in Malawi (OR 4.07, 95% CI 1.51-10.94,  $p = 0.02$ ). Panditrao et al. (2011) reported that the women were likely to be LTFU when they were unaware of their partners' HIV status (RR7.40; 95% CI 1.84-29.68). In Haiti however, the clients' marital status was not related with retention or disengagement (Dionne-Odom et al., 2016).

The clients' religious and cultural affiliations play a significant role in hindering and facilitating uptake and retention in HIV services (Tomori et al., 2014). Cultural beliefs influence the women's perception of causes of HIV infection. Among the Tonga people of Zimbabwe, HIV infection was believed to be caused by witchcraft spells and ancestral anger (Bourdillon & Pilosof, 1993). Ncube (2016) attributed HIV infection to evil spirits or powers that is believed to be caused by a member of the family.

Religion plays a strong social force in Africa, and religion and traditions have a substantial impact on the health-seeking behaviour of people (Campbell, Skovdal, & Gibbs, 2011). Tomori et al. (2014) found that faith healing was recommended by religious leaders over biomedical care as the first option for treating HIV and AIDS in Tanzania. The religious leaders attributed the 'low' reports of faith healing of HIV to a lack of true faith by their members. This theology perpetuated by religious leaders hinders uptake and retention in the PMTCT programme. Campbell et al. (2011) state that faith organisations can contribute to enhancing acceptance of biomedical care for HIV and AIDS by creating the social atmosphere that challenges religious and cultural ideologies and practices that promote HIV stigmatisation.

#### ***2.5.4 Bio-medical considerations***

The drivers of engagement and disengagement based on bio-medical considerations include physiological changes of pregnancy and postpartum, and HIV and ART related concerns that include side effects of ART (Myer & Phillips, 2017). The positive effects of ART on maternal and exposed infants' health has been linked to retention in the PMTCT programme (Theilgaard et al., 2011). Elwell (2016) in Malawi reported that improved survival of patients on treatment in recent years and the need to remain healthy to care for their children contributed to the enhanced retention in the programme. On the other hand, the side effects of the ARVs were the main reasons why mothers who had initially initiated ART did not adhere to the treatment. Some women who re-engaged in the programme revealed that encouragement of the CHW or others, resolution of the side effects and other barriers, a decline in health and a change in partner contributed to their decision to continuously engage in the programme (Kim et al., 2016).

Retention in the programme therefore becomes a product of the importance PMTCT clients assign to the programme (mainly associated with the benefits to mother and child) which is weighed against the patients' experiences of the service delivery and the interpretations they assign to those experiences.

## **2.6 STRATEGIZING TO IMPROVE RETENTION**

In the bid to improve outcomes of women and infants enrolled in the PMTCT programme, many interventions to improve retention have been implemented globally (Clouse et al., 2017; Kebaya, Nduati, Wamalwa, Kariuki, & Bashir, 2014; Mwapasa et al., 2017; Yotebieng et al., 2016).

A foremost consideration of the success of any intervention is its acceptability to the beneficiary. Some interventional studies to improve retention in the PMTCT programme have been planned and implemented without explicitly involving the main stakeholders such as the clients and the experienced health care providers who provide daily services in their deliberations and planning (Clouse et al., 2017; UNICEF, 2012). This may have resulted in the minimal or no effects of some of the interventions on retention in spite of their novelty. In some instances, some studies reported undesirable implications experienced by participants that were avoidable. This is evidenced in a three-arm interventional study in Malawi that involved integrated mother-infant pair (MIP) PMTCT programme and Mother-infant pair plus SMS service in the intervention arms matched with routine ANC/PMTCT services (Mwapasa et al., 2017). The study found no effects on maternal retention and reported sixty-nine percent of the participants were not retained. At 12 months, maternal postpartum retention was similar in all arms of the study; routine care (22.2%), MIP arm (19.3%) and MIP+SIM arm (24.9%). Additionally, unexpected social implications which included suspicions of infidelity by some husbands and a husband's consideration of divorce were reported. This unexpected outcome was attributed to the husbands finding out about their wives being tracked by community volunteers and being requested to report at the health facility without their knowledge. These incidents if not managed effectively could impact retention and participation in future studies.

Involvement of stakeholders in the planning of interventional studies could also be cost effective as their inputs may guide the planning and implementation of the

intervention, hence eliminating the cost associated with implementing interventions that would not be accepted or improve retention in routine care. A study in South Africa on the acceptability of financial incentives to improve retention in PMTCT services emphasises this assertion. Mothers who participated in the study asserted that although financial incentives were welcome, they would prefer health education, counselling, home visits and better services to encourage retention (Clouse et al., 2017).

Peer to peer mentorship has been explored as a strategy to enhance retention and re-engagement in the PMTCT programme in several countries. In Eastern South Africa, Hamilton, le Roux, Young, & Södergård (2018) explored the effects on mentor mother (MM) on uptake of, and retention in PMTCT services. She found that they filled the gap between the patients and the health workers by serving as a source of educational resource for the other infected mothers. This resulted an increase in social support, promoted exclusive breastfeeding and encouraged early testing.

This is consistent with findings by Sam-Agudu et al. (2017) where exposure to MM support was statistically significant in retention in the programme (AOR, 5.9; CI 95%; 3.0-116) and a better odds of viral suppression at 6-month postpartum (AOR=4.9; CI 95%; 2.6-9.2) than those who did not utilise the service. They however suggested that a more structured peer support system could yield better results. Similarly, Fan-Osuala et al. (2018) also recorded a greater likelihood of retention (AOR=6.6, 95% CI 3.4 to 13.1 when women in rural Nigeria enrol in the MM programme. They further determined that women engaged in MM programme had a higher propensity of retention up to 12 months postpartum as compared to women who did not enrol in similar programmes. Recommendations from the two studies in rural Nigeria indicated a need for a more structured MM programme essential for improved retention.

Another strategy that has been positively associated with improved uptake and retention in the PMTCT programme is community engagement and mobilisation. In a study in four African countries, Cote d' Ivoire, Uganda, Democratic Republic of Congo and Malawi, Besada et al. (2018) found that the community cadre who engaged in PMTCT activities were mostly volunteers. They were found to operate solely in the community and provided services such as household mapping of pregnant and lactating mothers, adherence and retention support, and they assisted

with linkages to health care services. Evidence supports Community Health Workers (CHWs) effectiveness in delivering various preventive, promotional and curative health services by improving access to care while supporting the empowerment of communities (Millington, 2018).

Consequently, there were limited studies that had high effect sizes. Planning and implementing context specific interventions that would make great gains in the retention of mothers in the routine PMTCT programme must involve stakeholders at all the stages.

## **2.7 GAPS IN LITERATURE ON RETENTION**

Several studies have been conducted on retention of women in PMTCT programme. However, the literature reviewed for this study reveals gaps in the information on retention in the programme.

Most studies that sought to study retention in PMTCT rather reported on disengagement and loss to follow-up. There is also limited literature available on research conducted in West Africa and particularly Ghana.

Numerous studies reported on the effectiveness of integrating PMTCT/MNCH services on improving retention of HIV-infected women. However, there is limited information on the mechanisms in place in the health facility to ensure smooth transitions across the various units and services. This study therefore addresses this shortfall by assessing the mothers' experiences during accessing PMTCT care and transitioning across the PMTCT care continuum.

Most interventional studies that have sought to improve retention in the PMTCT programme have focused on the experiences and expectations of the clients (demand factors). Information on the aspirations of midwives and nurses in enhancing service delivery in the programme to improve retention has however been lacking. This study assesses the aspirations of the midwives in improving health service to enhance clients' experiences and retention.

Several studies have reported on the attitudes of nurses and other health professionals providing services in the PMTCT programme and its impact on retention. Most studies have focused on the effects of negative attitudes on retention. The study assesses patients' positive nursing and midwifery care experiences and how these

attitudes influenced their perception about nursing and midwifery care in the PMTCT programme and how these experiences impacted their decision to remain in the programme.

Most interventional studies implemented to improve retention in the PMTCT programme have been developed by researchers outside of the health service and rolled out in the facilities of studies. Most of these studies have reported limited or no effects. This study presents information on collaborative strategies of clients, midwives and CHNs on developing context specific action plans to enhance service delivery and client's retention in the programme.

## **CHAPTER 3 THEORETICAL UNDERPINNINGS**

### **OF THE STUDY**

#### **3.1 INTRODUCTION**

This chapter presents the theoretical perspectives applied in the design of this study. It details the underlying theoretical assumptions that guided the research process and methods. A review of the Interaction Model of Client Health Behaviour (IMCHB) is presented under 3.2. This is followed by a brief history of the Appreciative Inquiry approach is presented under 3.3. The framework of the AI process (3.4), Principles underlying AI (3.5) and Method of AI (3.6) are then presented. A subsection on the generative power of the AI process is discussed under 3.7. A subsection on Appreciative Inquiry as a theoretical framework and methodology is then presented under 3.8. The chapter concludes justification of the integration of AI and IMCHB (3.9).

#### **3.2 THE INTERACTION MODEL OF CLIENT HEALTH BEHAVIOUR (IMCHB)**

Conceptual framework refers to “the system of concepts, assumptions, expectations, beliefs, and theories that supports and informs research” (Robson, 2011). The Interaction Model of Client Health Behaviour (IMCHB) is useful in exploring the factors that underscore clients’ decisions to continuously engage with a health system and to comply with guidance for health maintenance. As a framework, IMCHB suggests that a “client’s health outcome is influenced by an interaction between numerous antecedent health-protective and risk-taking behaviour of the client and the health provider’s behaviour” (Cox, 2003). These antecedents include the client’s affective, cognitive, environmental, motivational, physical and social antecedents to health behaviour (Cox, 1986). The role of the health provider is paramount in shaping the health outcomes of clients, which can be either positively and negatively (Tang, Soong, & Lim, 2013).

The main concepts of the Interaction Model of Client Health Behaviour model are;

- Client singularity,
- Client-professional interaction and
- Health outcomes (Cox, 1982, 1986, 2003).

The first concept, Client singularity refers to the unique and holistic aspects of the client including the demographic characteristics, health experiences, environmental resources and social influences (Carter & Kulbok, 1995). These elements can be categorised into two: the background variables and the dynamic variables (Tang et al., 2013).

The background variables refer to the client's demographic characteristics including the age, religion, health history, marital status and sex among others. These according to the authors are factors that define the uniqueness of each client at any given point in time and in different contexts they find themselves (Carter & Kulbok, 1995). These elements of the clients' singularity remain stable over a period of time and greatly influence the client's decision in health related issues and are therefore pivotal to other concepts in the model (Kinder, 2016; Tang et al., 2013).

The dynamic factors of client singularity include variables such as the client's motivation, cognitive appraisal and affective response. The cognitive appraisal refers to the client's perceived health state that is influenced by knowledge, beliefs and attitudes towards the specific health state in question. Affective responses on the other hand are those variables that occur as a result of emotions and invariably influence a client's decision on health. These emotions may either hinder or promote health. Emotions such as denial, fear, sadness and anger are strong indicators of a client's behaviour in a health situation or towards a health intervention. Carter and Kulbok (1995) explain that the client's motivation represents the feelings of capability a client has in relation to managing a disease, treatment or expected modification in health behaviour. It could be intrinsic and extrinsic. The intrinsic factor refers to the client's self-determination in health judgment and behaviour and the perceived competence in health matters whilst the extrinsic motivation is not self-determined. The dynamic singularity factors are easily modifiable and should be the focus of health interventions.

The second concept in the model; client-professional interaction refers to the therapeutic content and processes of interaction that occurs between the client and the health provider (Cox, 2003). It includes variables such as affective support of the health provider, provision of health information, decisional control and professional competencies of the health provider (Graham, 2015; Hickman Jr, Clochesy, & Alaamri, 2016). The response of the health provider to the emotional needs of a client in a given context will influence the extent of trust and invariably the commitment of a client to an intervention (Graham, 2015). The Reproductive and Child Health Services has adapted the Focused antenatal policy (Ghana Health Service, 2013). This implies that the client continues to interact with the health worker (midwife) who attended to her at booking and also tested her for HIV. The relationship is expected to last throughout pregnancy and postnatal and even enrol her in the PMTCT programme (MOH/GHS, 2014). She may invariably be the most trusted person to the client. The interaction should include the timing, content and method of delivering an information in a given context, as well as the providing the necessary support to ensure client participates in making decision concerning health care (Carter & Kulbok, 1995). This will help in the designing of a health intervention to suit the client's singularity.

The clients' health outcome is the third concept in this model (Carter & Kulbok, 1995; Cox, 1982). It refers to the behaviour or the behaviour-related outcome that occurs as a result of the client-professional interaction. It covers variables including adherence to the treatment regimen, utilization of healthcare facilities and services, clinical health status indicators, severity of the health problems and clients' satisfaction with healthcare (Kinder, 2016; Morris & Kanji, 2016). In this instance the study seeks to improve retention of women who test positive in pregnancy in the PMTCT programme. The retention involves utilisation of the health facility and adherence to the treatment regime throughout the cascade of the PMTCT programme by both the mother and exposed child.

The model infers that the positive interaction between the concepts is essential because the relationship is reciprocal and a change in one element affects all the outcomes (Carter & Kulbok, 1995). The hypothesis underlying this model is; the prospect of a positive health behaviour in a client increases as the intervention or provider interaction is tailored to the unique attributes of each patient (i.e. singularity) (Carter & Kulbok, 1995; Cox, 1986, 2003). This is because the singularity remains relatively

constant and the intervention can therefore yield positive health outcomes. This, the authors postulate that the reciprocity of the effects of each element on the other is felt as the subtle but persistent feedback effect from the intervention and the client-professional interaction is exerted on the element of client singularity.

The model provides a guide for the selection and inclusion of the patients characteristics that could be the basis for the determination of variables suitable for research (Carter & Kulbok, 1995).

This model is useful in this study as the researcher seeks to appreciatively inquire about those client singularity variables and the aspects of Client-professional interaction within the PMTCT programme that yields the positive health outcome of retention in the PMTCT programme. It also seeks to identify these variables so as to form the basis for discussions among the health workers towards the design of interventions to improve retention among women diagnosed with HIV during pregnancy.

Empirical support for the IMCHB as a viable health behaviour change model is evidenced by the various studies that have been conducted on health seeking behaviour and change over the years. Analysis has been conducted for the concepts underscoring the model such as singularity (Ademe, Aga, & Gela, 2019; Vagenas et al., 2016), health worker-client interactions (Kinder, 2016; Poost-Foroosh, Jennings, & Cheesman, 2015).

The model has been applied to the study of healthcare compliance (Morris & Kanji, 2016; Temerak, Winklhofer, & Hibbert, 2018), and identifying factors associated with medication use (Shade et al., 2017).

## **3.2 HISTORY OF APPRECIATIVE INQUIRY AS A RESEARCH METHOD**

The theoretical perspective selected for this study was based on the Appreciative Inquiry (AI) theory. Appreciative Inquiry emerged in 1980 from a doctoral study of change by David L. Cooperrider at Case Western Reserve University, Cleveland, Ohio, USA. His study focused on a group of medical health professionals at the Cleveland clinic and sought to understand physician leadership (Cooperrider, Whitney, & Stavros, 2003). The theoretical framework for Cooperrider's doctoral

study was social constructionist (Cooperrider, Barrett, & Srivastva, 1995) and his goal was to develop participatory management using grounded theory. His experience at the clinic during the study led his supervisor to propose that they focus on the positive image and successes as they found consensus and innovation running through the participants' discourses. They proposed Appreciative Inquiry as a different method for studying organisations. The underlining assumptions for the analysis were centred on future possibilities (Cooperrider et al., 2003).

### **3.4 FRAMEWORK OF APPRECIATIVE INQUIRY**

AI is a systematic and comprehensive process of inquiry that employs whole systems involvement in the search for the best of an organisation and the people who work in it when it is functioning at its best (Cooperrider & Whitney, 2007). The objective of the AI process is to discover, gain understanding, and stimulate transformation and innovation in the processes and practices of an organisation (Coghlan, Preskill, & Catsambas, 2003; Cooperrider & Whitney, 2001).

The AI practice is founded on four guiding propositions (Cooperrider & Srivastava, 1987).

- Every Inquiry must begin with appreciation,
- The Inquiry must be applicable and lead to the generation of new knowledge or theory that can be validated through the activities of persons in the organization.
- The Inquiry must be collaborative
- The Inquiry must be provocative and capable of initiating and sustaining change

The theoretical perspective of AI is based on the assumption that every organisation has something that works for it. Thus, although there may be shortfalls, AI seeks to stimulate a new and constructive trend of conversation that will re-focus attention away from those problems towards a hopeful and energising future (Ludema, Cooperrider, & Barrett, 2006). The focus of AI is to affirm the strengths and the factors that give credence to the successes of an organisation, with the intention of building on it to improve the organisation. The positive core of an organisation represents every best experience or highpoint, achievements or values in an organisation that sustains its growth (Cooperrider & Whitney, 2007). Through AI,

the experiences of stakeholders in an organisation are highlighted with the hope of generating a set of core values or practices that lead to the development of a vision for the organisation and the design of strategies to achieve the vision (Bushe, 2007). It creates the opportunity for inquiry that will result in effective, collaborative, and sustainable social systems.

Other assumptions that guide AI include the fact that people have the confidence to make a journey into the future (the unknown) when they bring along aspects of their past (the known). Thus, Hammond (2013) averred that if people ought to carry a part of their past into the future, it ought to be the best of the past.

### **3.5 PRINCIPLES UNDERLYING APPRECIATIVE INQUIRY**

Five foundational principles were enacted to guide the philosophy and methodology of AI (Cooperrider & Whitney, 2001). Over time other AI consultants and practitioners added three additional principles resulting in eight principles (Watkins, Mohr, & Kelly, 2001). These are Constructionism (3.5.1), Poetic (3.5.2), Simultaneity (3.5.3), Anticipatory (3.5.4) Positive (3.5.5), the other principles (3.5.6); Wholeness (3.5.6.1), Enactment (3.5.6.2) and Free-choice (3.5.6.3) (Kessler, 2013).

#### ***3.5.1 The Constructionist Principle***

AI is grounded in the theory of social constructivism. Social constructivism states that a social system creates its own reality. This paradigm is underscored by the assumption that people construct multiple realities. Thus, people seek to study the implications of these constructions on their lives and their interaction with others (Coghlan et al., 2003). The constructionist principle underscores the fact that the reality of our world is created through social discourse and social knowledge (Bukashe, 2015). The principle states that there are various lenses through which social reality and truths are viewed, hence continuous collaboration shapes and constructs our reality of the world we live in (Cooperrider & Whitney, 2011). Bukashe (2015) states that AI is a practical daily philosophy and a way of “being in the world” that guides researchers’ work with families, communities and organisations. She avers that the worldview of AI uses knowledge and language to create the world we know and understand. The power of language creates the present and the future (Gergen, Gergen, & Barrett, 2004). Thus, although there may be facts

supporting the existence of problems in a group or organisation, the thoughts and conversations of the people who interact must be focused on what they want to achieve, such as the good experiences, successes, hopes and aspirations.

### ***3.5.2 The Poetic Principle***

The poetic principle makes room for people to tell their stories the way they see them and creates the opportunity to build on those positive experiences for the future. The use of stories as a tool of inquiry in AI helps in the identification of successes, positive experiences and the common connections between individuals in the same situation (Abma, 2003). The notion of inner dialogue is fundamental to the concept of poetry in AI as it contributes to the change process. The inner dialogue is voiced through the stories that are told (Bushe, 2001).

### ***3.5.3 The Principle of Simultaneity***

The principle establishes that inquiry and change occur simultaneously. The AI process has been proposed as an intervention that discovers the best of what is, by focusing on and amplifying the processes and the people who support the best of what persists in an organisation (Bushe, 1995). Consequently, all forms of inquiry should be seen as an intervention (Bushe, 2001). Asking positive questions helps to construct positive images that serve as the basis for building the desired future. The process of inquiry is based on positive questioning. This approach directs participants to focus on the positive experiences and incidents of strength that invariably will enable them to envisage positive aspirations and hope (Coghlan et al., 2003). Thus, the process of inquiry not only enables the collection of data, but also sets in motion an intervention.

### ***3.5.4 The Anticipatory principle***

The anticipatory principle states that things done in the present are guided by the vision carved for the future (Coghlan et al., 2003). This underscores the need to develop the shared imagination that can drive change in the members of the group. If all members in a group have positive image and aspiration, there is a sense of ownership that consequently drives and maintains the momentum for change.

### ***3.5.5 The Positive principle***

AI highlights the use of positive feelings for building and supporting the drive for change (Cooperrider & Whitney, 2001). The focus on the positive can support generativity and change, as the more positive the questions used to guide a group, the more lasting and effective the change effort (Bushe & Coetzer, 1995). This does not however imply that AI requires an unflinching focus on the positive. It gives room for expressing what may not be working in an organisation (Bushe, 2007).

Appreciative inquiry is a theoretical perspective that embodies the art and practice of asking unconditional positive questions that have the potential to strengthen an organisation's capacity to name, envisage, and increase its positive potential (Cooperrider et al., 2003). Ludema and Fry (2008) explained AI is a source of hope that acts as a catalyst for positive transformation in an organisation. The positive focus of the discourse that the inquiry employs provides the constructivist power that is necessary to reshape the organisation.

### ***3.5.6 Other principles of Appreciative Inquiry***

Several authors have included other principles to the list of principles underscoring AI. These principles although added later are largely adopted by the AI community (Watkins et al., 2001; Whitney & Trosten-Bloom, 2010). Whitney & Trosten-Bloom (2003) included the principles of Enactment (3.4.6.1), Free choice (3.4.6.2), and wholeness (3.4.6.3).

#### ***3.5.6.1 The principle of wholeness***

Wholeness refers to the collective engagement of stakeholders in the change process (Bukashe, 2015). AI sees the whole organisation as a complete system where individuals come together to determine the primary core and vision that has positive effects on the future of the organisation (Fifolt & Lander, 2013). Thus, Whitney (2003) explains that involving all the stakeholders in the process at the same time stimulates creativity and energy that enhances the capacity for change. The principle points to the effectiveness of the AI process to garner widespread understanding and generating momentum (Bushe, 2010). Involving all stakeholders promotes trust because all members who engage in the process share the responsibility for the process and the outcome (Whitney, 2003).

### 3.5.6.2 The principle of enactment

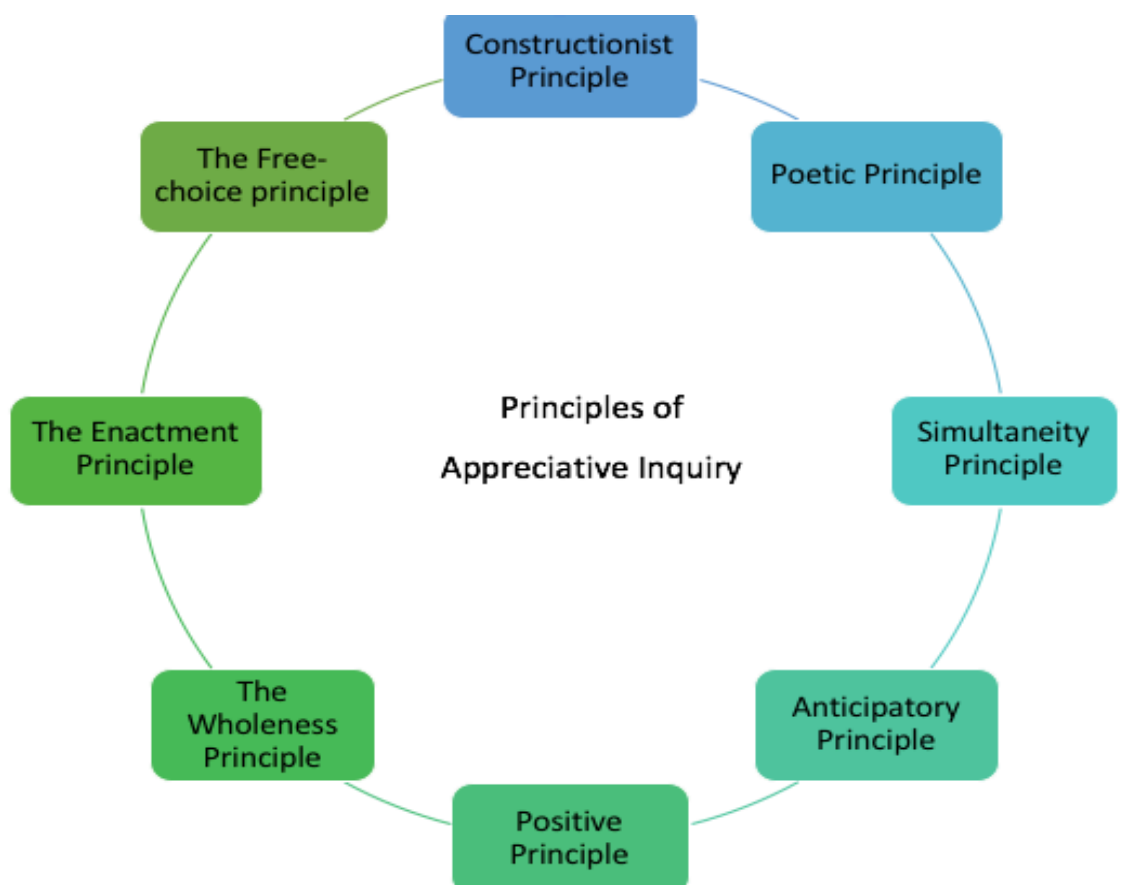
This principle states that positive change occurs only when the change process becomes a model of the future they anticipate. Hence, the members of the organization must be the change they seek to occur. This, they believe, is self-fulfilling (Whitney & Trosten-Bloom, 2010).

### 3.5.6.3 The principle of free choice

In the AI process, members of an organization perform better and commit to a change process when they have the freedom of choice concerning the extent to which they can contribute. Whitney (2003) said that the principle of free choice liberates the members of the organization and empowers them. The process of inquiry requires a widespread engagement by people who will ultimately implement change (Bushe, 1995).

The principles are presented in Figure 3-1 below.

Figure 3-1 Principles of Appreciative Inquiry

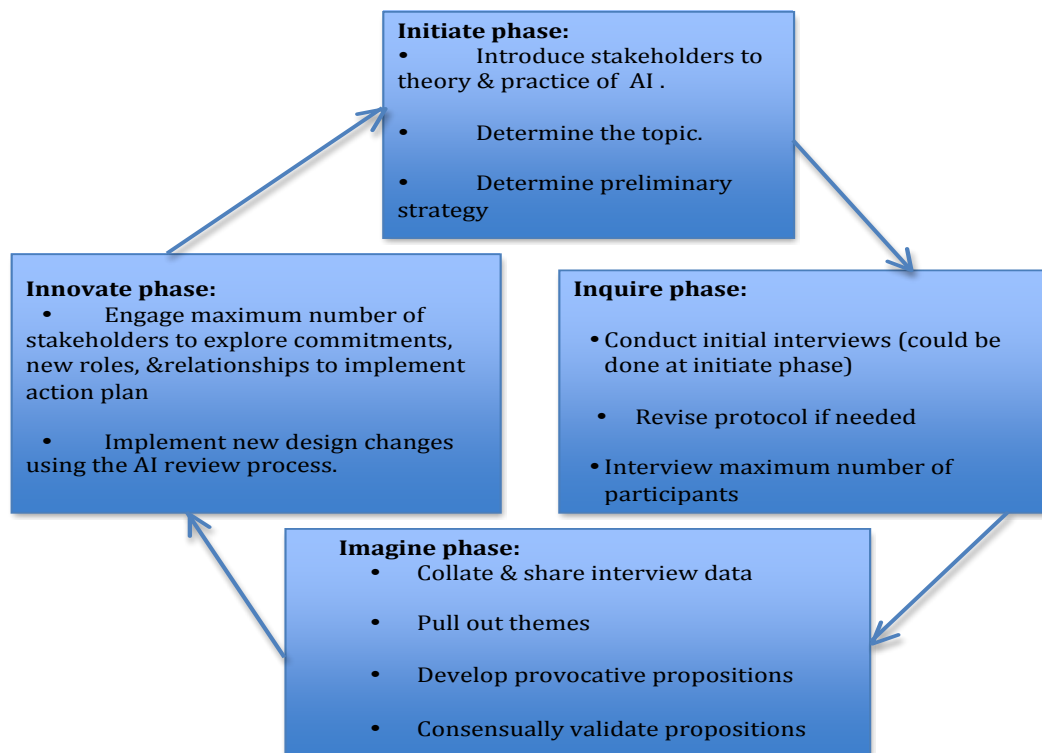


Adapted from Bukashe (2015)

### 3.6 METHOD OF APPRECIATIVE INQUIRY

Two main models have been developed for the implementation of AI; 4-D process: Discovery, Dream, Design and Deliver or Destiny (Cooperrider, Whitney, & Stavros, 2008) and 4-I process; Initiate, Inquire, Imagine and Innovate (Watkins et al., 2011). This study will adopt the 4-I model as it affords the researcher the opportunity to include the participants in the planning phase. The phases of the AI process that adapt to the 4I approach is presented in Figure 3-2 below.

Figure 3-2 The Appreciative Inquiry process



Adapted from Watkins and Mohr (2001)

The Initiate phase involves an introduction of the stakeholders to the theory and practice of AI and affords a corporate determination of the topic of inquiry (Coghlan et al., 2003). It is also the period where the affirmative topic for the inquiry is chosen. The affirmative topic is the central issue for the inquiry that is stated in inspiring and generativity oriented language (Kessler, 2013).

In the Inquiry phase participants are paired to interview, discuss and reflect on their best (Ludema et al., 2006) or life-giving experiences in the organization (Cooperrider et al., 2003) concerning the issue under inquiry. Bushe (2007) refers to these interviews as generative conversations. The conversations are techniques of inquiry that incorporates but does not require an unflinching focus on the positive, but instead focuses on creating a productive space for sharing feelings both positive and negative. This brings into focus the collective aspirations of the members of the organisation. The principles of wholeness, poetic and positive of AI are interwoven during the generative conversations. As participants are engaged in paired conversions, the sense of wholeness and personal responsibility is stimulated in members engaged in the process. Telling, seeking clarification and retelling the stories of others generates generalised engagement and helps in building relationships at the onset of the process (Kessler, 2013). Through storytelling (poetic) a positive stream of energy is created that catalyses for generativity and transformation (Fifolt & Lander, 2013).

The Imagine phase allows participants to share data generated during the conversations with the larger group and to identify the main life-giving forces in the organisation. This is a build-up of AI where the positive attributes identified are collectively used as a platform to envision a common aspiration on the issue under inquiry (Watkins et al., 2011). Members of the organisation engage in the process of authoring a new narrative of the organisation (Fifolt & Lander, 2013). Possibility statements also known as ‘provocative propositions’ are created as the structures, processes or relationships that will best support the vision (Bushe, 2011). These are stated in the affirmative to energise and remind participants of how things will be when the life-giving forces frequently occur (Moore, & Charvat, 2007).

The Innovate phase involves the development of concrete proposals for the achievement of the desired state of the organisation. Participants are invited to commit to take actions that are consistent with the possibility statements they made (Coghlan et al., 2003).

### **3.7 GENERATIVE POWER OF APPRECIATIVE INQUIRY**

AI is generative when new ideas are created that cause people to act in new ways that are beneficial to them and their organisation (Bushe, 2013). Bushe (2007) described

synergogenesis as a process of stimulating generative conversations and unraveling data arising out of the conversations in AI. This process requires a small group reading a set of rich stories centered on the research question.

The purpose of synergogenesis is to allow participants to engage in reflective thinking and to collectively generate new ideas to answer the research question by capturing and listing as many new ideas to answer the research question as possible (Bushe, 2013). Other forms of engagement such as the AI summit which involves a large group of people, has been applied successfully in large organisations and multi-layered systems to stimulate dialogue (Bushe, 2010).

Consensus building through dialogue at each phase of the AI process is necessary for generativity in AI to be gained (Bushe & Coetzer, 1995). Gergen et al. (2004) proposed that consensus building among the participants ensures joint-action that invariably contributes to the transformation process.

### **3.8 APPRECIATIVE INQUIRY AS A THEORETICAL FRAMEWORK AND METHODOLOGY**

AI has been used effectively as a framework and method for many research studies. Reed (2006) argues that AI is often used because it is a credible and effective approach to participatory research and organisational change. Its strength lies in the fact that AI takes a stance towards areas of study that are taken for knowledge and understanding (Burr, 2015). Reed (2006) avers that through the AI process, untold stories are deconstructed to gain insight into what is possible, and this instigates the process of transformation. Ruhe et al. (2011).

Most studies that have applied AI in healthcare have been explorative or descriptive. Only a few studies have applied AI as an intervention (Kavanagh, Stevens, Seers, Sidani, & Watt-Watson, 2008). However, even in instances where AI is not applied as an intervention, the principle of simultaneity imputes the fact that some form of transformation occurs during the data gathering processes (as explained under 3.4.2).

AI has been applied in many nursing research studies. Goodman (2014) argues that nursing attitudes are deeply entrenched. In recent times, criticisms about nursing and nurses in the public sphere (Dapaah, 2016), calls for an alternative framework for

inquiry into nursing practice (Ruhe et al., 2011). AI, therefore, offers that alternative approach for inquiry.

Dewar and Nolan (2013) applied AI to explore and develop strategies to enhance compassionate and relationship centred care for geriatric patients. The study reported a transformational change and the development of a model to support compassionate care.

AI has been effectively employed in acute care settings to explore best practices in paediatric pain management (Kavanagh, Stevens, Seers, Sidani, & Watt-Watson, 2010). Although the study was not powered to conclude AI's effectiveness on study outcomes statistically, there were improvements in participants knowledge and attitudes on pain and pain assessment post-intervention as well as unintended outcomes such as cultivated team spirit, and positive reception to change.

AI has also been applied successfully in system level and public/community scenarios to enhance strength-based practice in community health nursing (Lind & Smith, 2008), improve communication and collaboration among nurses and other health professionals (Havens, Wood, & Leeman, 2006), promote evidence-based practice in nursing (Marchionni & Richer, 2006), and quality improvement in primary health care (Ruhe et al., 2011).

### **3.9 JUSTIFICATION OF THE INTEGRATION OF AI AND IMCHB**

This study sought to explore factors that influence retention in the PMTCT programme. Both theories allowed for generative exploration of factors underscoring a phenomenon, albeit AI focused more on the positive factors.

The IMCHB provided the constructs by which the facilitating factors could be explored whilst AI provided the methods by which the study can be conducted.

Both theories focus on ensuring change. The IMCHB seeks to explore factors that can enhance behaviour change while AI seeks organisational change through collaboration. The two theories when jointly applied expounded the areas which could benefit from improvement strategies and enhanced the change process for participants and the PMTCT programme.

## **CHAPTER 4    METHODOLOGY AND**

### **RESEARCH DESIGN**

#### **4.1 INTRODUCTION**

This chapter presents the methodology and the research design applied in this study. It describes the underlying assumptions that guided the research process and outlines what was done and the reasons underlying decisions made during the process.

The first section of this chapter covers the research philosophy (4.2) upon which this study was designed. In the second section of this chapter, the research design and methods (4.3) that were employed are described in detail. This is followed by a description of the processes adopted to ensure the quality of the research (4.4) and the ethical considerations (4.5).

#### **4.2 THE RESEARCH PHILOSOPHY**

Research methodology denotes a philosophical worldview or paradigm that underscores and influences research (Ihuah & Eaton, 2013). Morgan (2007) refers to research paradigms as approaches and practices that impact the researchers' decisions concerning the questions they study, and methods employed to study them. The paradigm is concerned with how things are understood and perceived in the world (Saunders, Lewis, & Thornhill, 2009). It also speaks to the assumptions that underscore a research approach (Ihuah & Eaton, 2013) thereby providing the basis for researchers to align their decisions to their values and also with other researchers who have similar beliefs (Johnson, 2011). These assumptions are ontology, epistemology, axiology, methodology, research methods and rhetoric (Creswell, Plano Clark, Gutmann, & Hanson, 2003). These assumptions vary according to the various paradigms; hence, they influence how research is approached and carried out (Saunders et al., 2009). Shannon-Baker (2016) avers that providing information about the research paradigm and its assumptions gives the readers of the research a better understanding of the potential influences of the research. It is noteworthy that there is an ongoing debate on the usefulness of research paradigms due to their potential to dismiss other sets of beliefs that are useful in research (Maxwell, 2011).

In presenting this section, the researcher does not intend to undertake a full-fledged description or participate in the ongoing debate of the different philosophical paradigms that exist, but rather to clarify the research paradigm on which this inquiry stands.

### ***4.2.1 The Research Paradigm***

The study adopts the pragmatic worldview. It focuses on determining the outcome of the study and seeks to unearth the meaning of phenomenon (Johnson & Onwuegbuzie, 2004). The pragmatist emphasises the need for interaction, shared meaning-making and joint action so that practical solutions to social problems are reached. Its primary emphasis is on ‘what works’ as the reality concerning the research questions (Teddle & Tashakkori, 2003). As with other research paradigms, the assumptions that underscore the pragmatic worldview are philosophically determined. However, it rejects the distinctions and the need to choose between the two main paradigms; positivism and interpretivism, and the assumptions that underpin them. The sub-section presents the assumptions of the pragmatic worldview; ontology (4.2.1.1), epistemology (4.2.1.2), axiology (4.2.1.3), methodology (4.2.1.4) and rhetoric (4.2.1.5).

#### ***4.2.1.1 Ontology***

The first assumption is ontology, which concerns itself with the nature of reality (Saunders et al., 2009). It refers to how individuals view the nature of reality and what there is to know about the world (McManus, Mulhall, Ragab, & Arisha, 2017). In the field of social science, there are two main perspectives as to the nature of reality; objectivism and subjectivism (Saunders et al., 2009). The objectivists argue that the world existed before the individual. Hence, they see the world as being separate from the social factors (McManus et al., 2017). Therefore, in their quest to understand a phenomenon, they resort to using tangible and measurable approaches to inquiry (Saunders et al., 2009). Conversely, the subjectivist bloc argues that social actors co-construct reality through how they perceive and interpret the world in their context. Hence, reality is neither relative nor absolute (Petersen & Gencel, 2013).

Philosophically, the pragmatic paradigm accepts that reality exists but does not subscribe to the distinctions between realism and anti-realism (Morgan, 2014). It acknowledges that the world can be interpreted in different ways. Hence, no single

research approach can reveal the entire reality of a phenomenon (Collis & Hussey, 2013). To the pragmatist, reality is ever changing as it is based on human actions which result in outcomes around which human experiences are built (Morgan, 2014). It incorporates both the positive assertion that there can be an independent external reality which can be answered by hypothesis and the constructivist assertion of multiple reality (Teddlie & Tashakkori, 2003). The pragmatic paradigm allows that varied perspectives be incorporated in research. Consequently, when applied in this study, the phenomenon of retention can be studied from different perspectives.

#### **4.2.1.2 Epistemology**

Epistemology concentrates on the nature of knowledge acquisition (Saunders et al., 2009) and belief on how to generate, understand and apply valid and acceptable knowledge (Johnson & Onwuegbuzie, 2004). An individual's beliefs about what constitutes reality (ontology) influences their approach to knowledge acquisition (McManus et al., 2017). The objectivist or positivist adapts hypothesis testing as the primary approach to garner knowledge about reality (Saunders et al., 2009). Hence, the results are usually generalizable. On the contrary, subjectivists approach knowledge acquisition from the position of multiple realities (ontology) and therefore seek to understand the phenomenon under study by deep level inquiry and meaning-making. This perspective is referred to as interpretivism (McManus et al., 2017). Creswell and Plano Clark (2011) aver that in some inquiries, subscribing to only one of the main perspectives, i.e., positivism or interpretivism, may be unrealistic in practice as some research questions may require the merging of both perspectives to answering them. The pragmatic worldview gives an alternative epistemological worldview (Hall, 2013). In this worldview, knowledge acquisition is deliberate and occurs as a result of taking actions and the outcomes of those actions (Morgan, 2014). Thus, the pragmatist approach substitutes the traditional notion of epistemology with the principle of practicality (Creswell & Plano Clark, 2007).

The researcher aligns with this paradigm as it allows for the freedom of inquiry by framing the questions that matter and to pursue those questions in ways that are the most meaningful to the research without the restrictions associated with one perspective or the other.

### 4.2.1.3 Axiology

Hesse-Biber (2012) explains that axiology is concerned with being aware of the researcher's values, attitudes, and biases, and recognising how these would impact the research process in terms of the type of (a) questions asked or not asked, (b) data that are collected or otherwise, and (c) methods, measurements, analyses and interpretation that influence the research process. As with the other assumptions, the position of the positivists and interpretivists about the influence of values and beliefs in any inquiry differ. The positivists employ checks to ensure that biases are eliminated from the research process and outcomes. Conversely, the interpretivists believe that the outcome of the inquiry is contingent on the researchers' interpretations (Stewart, 2011) which are influenced by their values, beliefs, and attitudes. The pragmatists identify the researchers' values as essential during the interpretation of the results of the inquiry using both objective and subjective reasoning (Johnson & Onwuegbuzie, 2004). In adapting to the pragmatic paradigm, the researcher acknowledges her previous experiences, values, and beliefs and reflexively recognises their potential influences in conducting, interpreting and reporting of the outcomes of the research.

### 4.2.1.4 Methodology

Research methodology refers to the philosophy that guides knowledge acquisition in the systematic manner of research inquiry (McManus et al., 2017). The traditional methodological approaches are quantitative and qualitative (Stewart, 2011), and are aligned with the positivist and interpretivist worldviews respectively. Quantitative methodology subscribes to rigorous and formal approaches to inquiry that are embedded in deductive reasoning (Stewart, 2011). It concerns itself with hypothesis testing to determine whether previous generalizations are true (Creswell, 2009). Conversely, qualitative methodological approaches are grounded in inductive reasoning and useful when the subject of inquiry is unknown. Thus, this approach provides the basis for theory generation from the bottom-up (Creswell & Plano Clark, 2011; Stewart, 2011). McManus et al. (2017) purport that methodology presents in a continuum, with pure qualitative and quantitative approaches at the terminal ends and mixed methods researches (MMR) lying in-between. The pragmatic paradigm endorses the mixing of the two methodological approaches

(Johnson & Onwuegbuzie, 2004), thus gleaning multiple benefits for a single study. This study adopts both quantitative and qualitative methods to gain a multimodal understanding and answer for the research question (Teddlie & Tashakkori, 2003).

#### **4.2.1.5 Rhetoric**

Rhetoric refers to the language and styles of presentation of the research findings (Creswell & Plano Clark, 2007). It portrays the traditional approaches in which the community of researchers communicates and disseminates knowledge and sets boundaries as to what is acceptable (Stewart, 2011). The positivist fraternity presents their findings using formal language. On the contrary, in the bid to preserve the subjective interpretations and experiences of the original texts, the interpretivists use informal language and literary styles (Stewart, 2011). Being mindful of the differences in the styles of presentation and the languages of the two main approaches of inquiry, the researcher attempts a blend of both styles as is synonymous with the pragmatic paradigm, to glean the best of both approaches especially in reporting the findings of the inquiry.

#### **4.2.2 Justification for the Methodological Decisions**

Many scholars have critiqued and levelled arguments against the pragmatic perspective of inquiry. The critiques are mainly on the lack of an agreed nomenclature and basic definitions as well as pending disagreements on the design issues associated with making inferences from findings of mixed method inquiries (Teddlie & Tashakkori, 2003). In spite of these shortfalls, as well as the logistical demands that mixed method research presents to an individual researcher, this approach offered a blend of the advantages of different philosophical perspectives, hence the best opportunity to answer the research questions of this inquiry. It offered the opportunity to explore the factors influencing retention both objectively and subjectively. The paradigm provided a holistic approach to inquiry since a choice between quantitative and qualitative approaches would not completely address the research objectives. Its flexibility allowed the researcher to structure the questions and design the study in a manner that was most suitable for finding practical answers to the real-world issues such as is the topic of inquiry in this study; “Why I stayed when others left”: An Appreciative Inquiry of Retention in the Prevention of Mother to Child Transmission of HIV in Takoradi Government hospital.

## **4.3 RESEARCH DESIGN AND METHODS**

This sub-section of the chapter begins with a discussion on the research design (4.3.1). The Mixed Method Sequential Explanatory design (SED) (4.3.1.1) is elucidated and then justified as the most appropriate design for the study. The research question (4.3.1.2) which is central to the determination of the research design in the pragmatic methodology is then presented. Following this, the research methods (4.3.2) are expounded through the discussion of the purpose (4.3.2.1), the administrative processes that were necessary at the beginning of the research process (4.3.3), techniques employed in data collection and analysis (4.3.4 and 4.3.5) are presented. The strategies for ensuring validity (4.3.3.9) and trustworthiness of the study (4.3.4.10) are presented. Finally, the ethical considerations (4.5) of the study are outlined.

### ***4.3.1 The Research Design***

The research design provides the blueprint for conducting rigorous inquiries that can answer the research questions and achieve their objectives (Creswell et al., 2003). This subsection covers the sequential explanatory and the research questions applied in this study.

#### **4.3.1.1 The Mixed Method Sequential Explanatory Design**

This study adopted the Mixed Method Sequential Explanatory Design (SED) (Creswell, Plano Clark, Gutmann, & Hanson, 2007; Creswell & Plano Clark, 2011; Creswell, Plano Clark, Gutmann, & Hanson, 2003). In keeping with the characteristics of MMR designs, the research questions must seek to explore context-specific issues. That is achieved by applying quantitative methods to assess the magnitude and frequency of variables as well as harness qualitative approaches to explore the meaning and understanding of the constructs (De Vaus & de Vaus, 2001). This approach ensures that a holistic explanation of the phenomenon that can produce probable answers or a better understanding of the problem is established.

In most instances where SED is used, the emphasis is placed on the initial quantitative part of the study which is followed by the qualitative section (Creswell, 2003; Stewart, 2011). The sequence of this study, however, aligns with a variation of the design described by Creswell, et al. (2007) and Creswell and Poth (2017) that

places priority on the qualitative data collection and analysis. In this variant, findings from the initial quantitative section are necessary to set eligibility criteria of the study participants based on characteristics that align with the research. The criteria for selecting the most appropriate MMR design which includes implementation of data collection, priority and integration (Creswell et al., 2007) were applied in selecting SED as the most suitable MMR design for the study.

The implementation of data collection and analysis was sequential with the quantitative aspect of the study (Section A) initiated and completed prior to the qualitative section (Section B). The intent was to assess the socio-demographic, obstetric and clinical characteristics of women who test positive for HIV in pregnancy for the first time, and also determine the rate of retention, as well as, the points along the PMTCT cascade that the highest attrition in the programme occurs.

Following the analysis of Section A, the findings were introduced into the AI process in the qualitative stage (Section B) to set the stage for discussions among the health workers after the factors underpinning the mothers' decision to remain in care had been explored. The aspirations of the health workers to improve retention in care was also investigated.

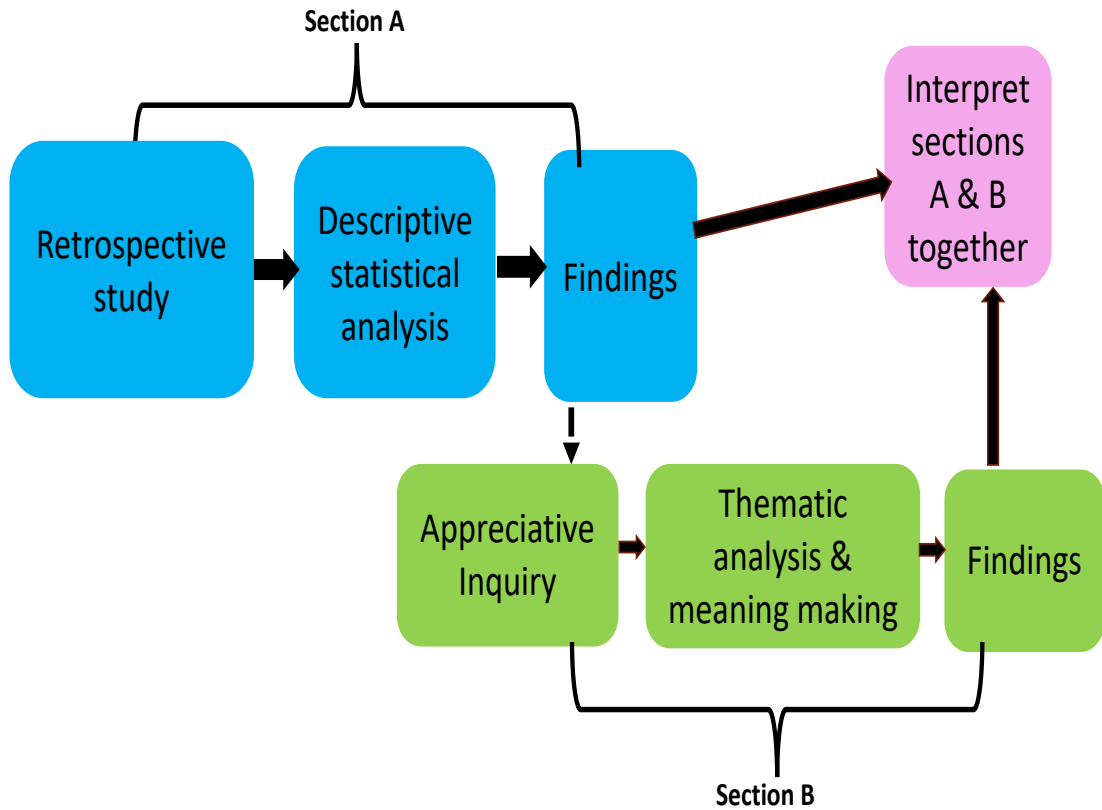
This variant was better suited as the researcher was able to determine the inclusion and exclusion criteria that enabled effective purposive sampling of the research participants (clients) for the qualitative phase (Creswell et al., 2007). It was also beneficial as the findings of the quantitative phase were used as a trigger to discussions in the Appreciative Inquiry sessions with the nurses.

The emphasis of this study was the qualitative section (Creswell et al., 2007) that applied Appreciative Inquiry as a process to enhance the midwives and nurses' efforts to improve retention and to design a practice guide for the study. The findings of the quantitative phase, however, set the stage by presenting the background of retention in the study facility.

Finally, integration of the two methods in this study occurred at two levels; during the development of the research question (Teddlie & Tashakkori, 2003) and interpretation stage (Creswell et al., 2007). Both quantitative and qualitative questions were designed to guide the study and the discussion of findings was based

on a convergence of the results of the two phases. Figure 4-1 below presents the implementation of research design.

Figure 4-1 Implementation of the Research Design



Adapted from Creswell et al. (2003)

### 4.3.1.2 The Research Question

The methodological assumptions and principles of the pragmatic paradigm places the research question as central to the choice of the design. This study was driven by the overarching question: “What factors will improve retention of women newly diagnosed HIV positive in pregnancy in the PMTCT programme?”

To answer this, six sub-questions were considered:

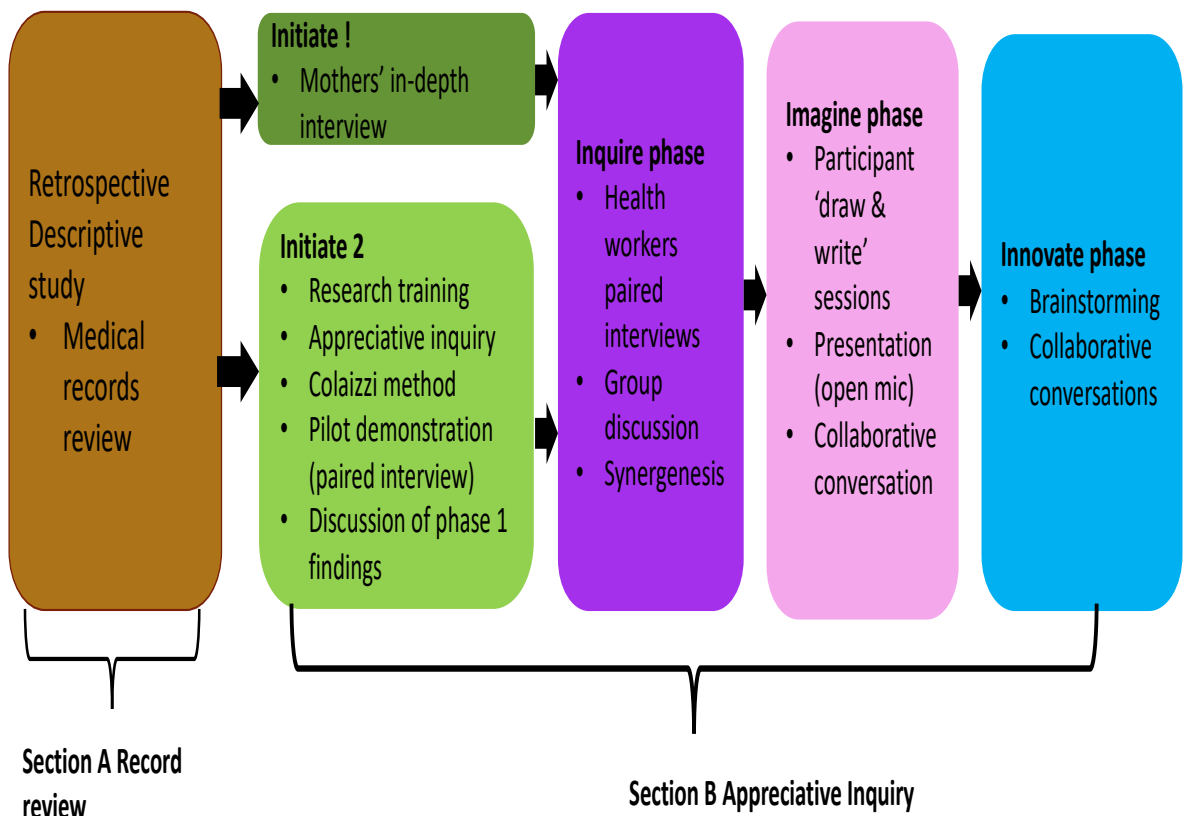
1. What is the retention rate of HIV positive pregnant women in the PMTCT programme?

2. What are the socio-demographic and obstetric characteristics of infected mothers who remain in the programme?
3. What point along the PMTCT cascade has the highest rate of attrition?
4. What are the experiences of health staff and HIV positive mothers while engaging in the PMTCT programme?
5. What factors underscore the HIV positive women's decision to remain in care?
6. What are the aspirations of the health workers for improving retention in the PMTCT programme?

### 4.3.2 The Research Methods

The research methods concern the techniques employed in data gathering and analysis in research (Creswell & Plano Clark, 2011). Figure 4-2 below presents the techniques adopted for data collection in each phase of the study.

Figure 4-2 Techniques for data collection.



In keeping with the characteristics of SED, the study was conducted in two phases. Hence, the objectives, gaining accesses, the sample and sampling methods, instrumentation, data collection, and analysis are presented according to the phases.

### ***4.3.3 Beginning the research process***

The study was approved by the University of Cape Town Human Ethics Review Committee (UCT HREC) (Appendix A) and the Ghana Health Service Ethics review Committee (GHS ERC) (Appendix B). Subsequently, permission was granted for access to the health facility, the patients' records and the participants (mothers, nurses and the midwives) by the regional and district health administrations as well as the management of the hospital (Appendices C, D, E).

### ***4.3.4 Section A***

This section presents the methods employed in the study. It covers the purpose of the study (4.3.4.1) and objectives (4.3.4.2). The study design (4.3.4.3), study participants (4.3.4.4), gaining access (4.3.4.5) are also presented. The data collection procedures and method of analysis are then covered under 4.3.4.7-4.3.4.10.

#### ***4.3.4.1 Purpose of Section A***

This section sought to determine the retention of women diagnosed with HIV and who started ART during the current pregnancy in the PMTCT programme in the Takoradi Hospital. That served as a basis for discussion among the health workers on retention in the AI process in Section B.

#### ***4.3.4.2 Objectives***

- i. Determine the rate and patterns of retention in the PMTCT programme.
- ii. Describe the socio-demographic, obstetric and clinical characteristics of expectant mothers who remained in the programme until six weeks postpartum for the DNA PCR for their exposed children.
- iii. Identify the lowest retention (highest attrition) points along the PMTCT cascade.

### **4.3.3.3 Study design**

A retrospective descriptive approach that used medical record review as the technique for data collection was employed.

### **4.3.3.4 Study Participants**

Records of women who tested positive for HIV at ANC in the Takoradi Government Hospital and initiated ART in the current pregnancy between January 2015 and December 2015 were selected. The study population was limited to a one year period (January-December 2015) because the findings relating to the number of mothers who remained in care within the period, was needed as a baseline for recruiting participants (mothers) for the AI session. It was also necessary because at the time of data collection the mothers should have remained in the PMTCT programme or enrolled their children in the child welfare clinic to determine retention in the programme. The study period was selected to ensure that all the health workers who participated in the subsequent AI session would have provided PMTCT care in the facility as was required by the inclusion criteria. Furthermore, the rate and patterns of retention within the period was needed to also enlighten the midwives and community health workers who offered care within the period on the prevailing outcomes of the care they rendered. This was to enhance ownership and improve participation in the subsequent phases of the study.

### **4.3.3.5 Gaining access to the Individual Clients' Records**

The hospital administrator facilitated access to the clients' records by contacting the unit manager of the antenatal/postnatal clinic, the health information officer and the chief pharmacist for support for the research. The support of these health workers was necessary as various records on PMTCT enrolment and uptake of records were documented across the various units in the facility. With their assistance, a list of all mothers that had tested positive to HIV in pregnancy was generated from the antenatal/postnatal clinic and PMTCT record books. The Health Information officer and chief pharmacist then facilitate access to the individual PMTCT folders.

### 4.3.3.6 The Sampling Procedure

The list of the women's records which were eligible for the study was extracted from the ANC registration book and the PMTCT book at the ANC unit. The list was then sent to the pharmacy where the folders are filed to retrieve the folders. The total number of expectant mothers who tested positive at the Takoradi Government hospital during 2015 was recorded as 43 (Dhims II) (Ghana Health Service, 2016).

The formula for calculating the required sample size:

$$n = \frac{Nz^2pq}{(E^2(N-1) + z^2pq)}$$

Where

- n is the required sample sizes
- N is the population size
- z is the value that specifies the level of confidence, set as 1.96.
- p and q are the population proportions, and each is set as 0.5
- E represented the accuracy of the sample proportions, and was set at 0.03 (Morris, 2004).

A sample size of 42 was calculated as required. As the total number of records were 43 (being all expectant mothers who enrolled in the PMTCT programme for the study period), all the records were included in the cohort for the study.

### 4.3.3.7 Data collection

The records of the expectant mothers were extracted to determine their attendance and participation in the PMTCT programme. Data for the analysis came from a review of routine medical records for all the women who tested positive in pregnancy and initiated care in the PMTCT programme between January and December 2015. Data was captured at the various points in the PMTCT cascade (as described in 1.2) to determine the points at which the lowest retention occurred. There was no direct contact with the patients in this section of the study.

#### **4.3.3.8 Instruments and Procedure**

Data extraction forms (Appendices F and G) were used to extract data. Appendix F was used to extract socio-demographic and obstetric characteristics of participants as well as data on HIV testing to ART initiation. Appendix G was designed to extract data on participants' engagement in the programme from ART initiation to 6 weeks postpartum throughout the PMTCT cascade.

#### **4.3.3.9 Validity and Reliability**

Two experts in the field of PMTCT programme reviewed the content of the data extraction form to ensure the face and content validity of the instrument. The experts, after reviewing the data extraction form, concluded that the instrument measured the variables stated in the research questions; the socio-demographic, clinical and obstetric characteristics of clients who are enrolled in the PMTCT programme as well as the appointment and attendance schedules. They also found the items on the data extraction form had clarity, were readable and comprehensive. Pretesting/ pilot testing was done in a Ghana Ports and Harbours Authority (GHAPPHA) hospital as it shares similar characteristics to the Takoradi Government hospital, to determine the suitability of individual items in the instruments. The researcher who had been trained in data extraction extracted the data, and was the only person doing this, therefore there was less likelihood of variation. Double entry of the sample of records was done to ensure that the data that was extracted was consistent and reliable. The pre-test did not result in any changes or reordering on the data extraction form.

#### **4.3.3.10 Data Analysis**

The data was entered using Statistical Package for Social Sciences (SPSS) version 20. Descriptive statistics were used to summarize the baseline characteristics of the study population. Bivariate associations were calculated using chi-squared tests for categorical variables. Time-to-event analysis was done to investigate the time of attrition from the programme. The person-time accrued from ART initiation to the end of the study or transfer out (TFO) to the adult ART clinic, or loss to follow up (LTFU). Kaplan Meier curves were generated to explore retention in the programme.

### **4.3.4 Section B**

This section presents the methods adapted for the AI process. The purpose (4.3.4.1) and objectives (4.3.4.2) are presented. Following this, the study participants and the processes for recruitment are presented from 4.3.4.3-4.3.4.6. Data generation, management and unravelling are then covered under 4.3.4.7-4.3.4.9.

#### **4.3.4.1 Purpose of section B**

To introduce the AI process as an intervention to develop action plans to improve retention in the PMTCT programme.

#### **4.3.4.2 Objectives**

- i. Explore the experiences of midwives, CHNs and mothers in giving and receiving care in the PMTCT programme.
- ii. Explore the factors that influence expectant mothers diagnosed with HIV in pregnancy to remain in care.
- iii. Explore the aspirations of midwives and CHNs for improving retention in the programme.
- iv. Develop an action plan to improve retention in the PMTCT programme.

#### **4.3.4.3 Study Participants**

There were two groups of participants; expectant mothers who had tested positive for HIV for the first time in the current pregnancy and health care professionals (midwives and nurses) who provided PMTCT services in the facility. Participants from the two groups were necessary as there were plausible differences in their experiences as recipients and providers of PMTCT health care.

#### **4.3.4.4 Inclusion Criteria and Exclusion Criteria**

Inclusion criteria: The Expectant mothers should have remained on the PMTCT programme and attained at least six weeks postpartum and returned for the DNA PCR test to be done for their babies, as this was seen as an indication that they were determined to remain on the programme. The midwives and nurses should have worked at least one year in the PMTCT programme and have received training on PMTCT care.

Exclusion criteria: Expectant mothers diagnosed HIV positive before their current pregnancy were excluded.

#### **4.3.4.5 Access to study participants**

A meeting was held with the Deputy Director of Nursing Services at the facility to inform her on the study, its purpose and the benefits that the study would bring to the nurses, the PMTCT programme and the facility. The meeting was to gain her support and her commitment towards the study. Thereafter, meetings were held with the unit heads of the antenatal/postnatal clinic, Labour ward and the in-service training coordinator to discuss the purpose of the study, to schedule the time for the AI workshop and the release of the CHNs and midwives for the study. Similarly, the nurse manager informed eligible CHNs and midwives about the study and permitted the researcher to engage with them on the study.

A two-step process was followed in gaining access to the mothers. The CHNs and midwives rendering services in the MNCH/PMTCT units acted as gatekeepers for the mothers enrolled in the programme and were understandably protective. To avert bias associated with recruitment based on social desirability, it was agreed that a list of all eligible mothers would be generated from the PMTCT and DNA PCR records of between January to December 2015. The CHNs and midwives also agreed to contact the eligible mothers enrolled in the PMTCT programme whose records were included in phase one and engage them about the study. Only mothers who had remained in the programme were contacted. Interested mothers then contacted the researcher. This promoted autonomy and upheld privacy (described in 4.5).

#### **4.3.4.6 Recruitment of Study Participants**

Two groups of participants were recruited for this study. This subsection presents the recruitment of the mothers (4.3.4.6.1), and midwives and CHNs (4.3.4.6.2).

##### **4.3.4.6.1 Recruitment of Mothers for the Individual Conversations**

In accordance with the study protocol, I arranged to recruit participants through the postnatal clinic. Midwives responsible for performing the DNA PCR test were solicited to inform the eligible mothers about the study and also make the mothers'

information sheet (Appendix H) available to those who met the inclusion and exclusion criteria. I was also available at the clinic to answer any immediate questions such clients might have had. The midwives were enthusiastic about the study and agreed to hand out the information sheets. However, patient flow was slow. As a result, only three patients were recruited through the clinic after four weeks.

The study proposal was therefore amended to expand recruitment to the child welfare clinics to potential participants who were eligible (completed the DNA PCR test). The list and contact addresses of mothers were retrieved at the PNC unit and handed over to the CHNs who contacted them to find out their next scheduled appointment for immunizations for their children. During home visits and outreaches, eligible mothers were informed of the study and given information sheets. Interested mothers were directed to me and clarifications were given where necessary (explained in 4.5.2). Those who were willing signed the Informed Consent Form (Appendix I). Appointments for individual conversations were then made. This approach proved successful as six mothers were recruited within two weeks. Three participants were also recruited during Child Welfare outreach clinics in the community. In all, twelve HIV positive mothers were purposively recruited into the study. The sample size was appropriate for the study as the participants were selected according to common criteria and the goal for the study was to describe a shared perception and behaviour relatively common to this cohort (Guest, Bruce and Johnson, 2006). In spite of the common criterion for recruitment, the researcher was able to purposively recruit women from different backgrounds, religious affiliations, marital status, age, and parity. That ensured that the data stemmed from a broad perspective. Data collection and analysis were conducted concurrently so that data saturation was established with the twelfth informant hence, further recruitment was not necessary.

#### 4.3.4.6.2 Recruitment of Midwives and Community Health nurses

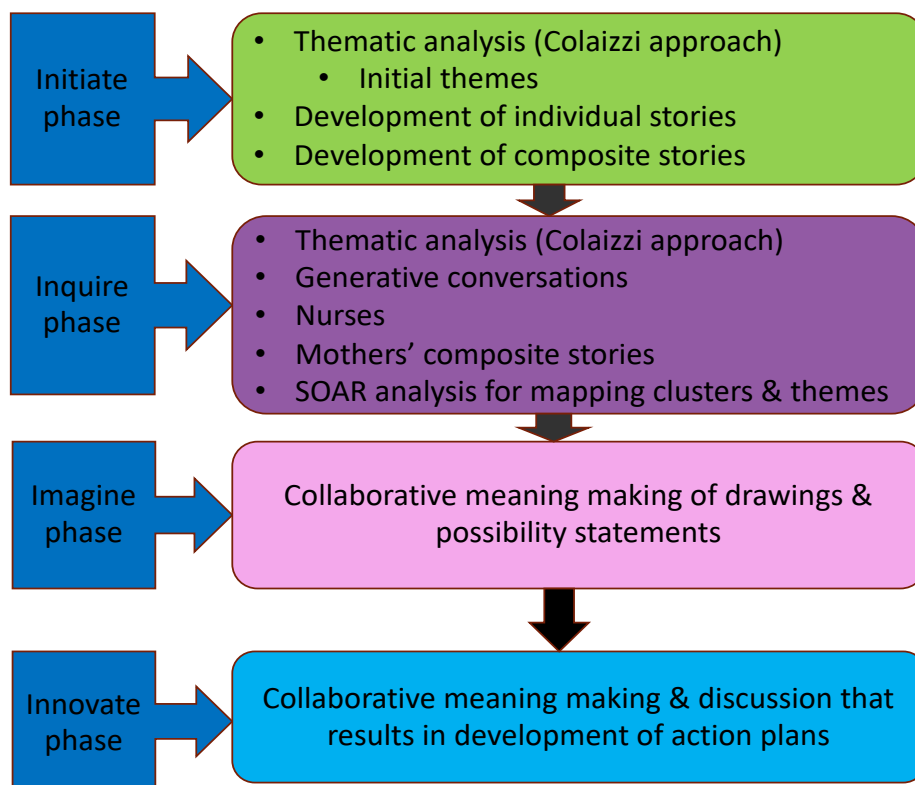
I engaged the midwives and nurses in charge of the Reproductive and Child Health units constituting the PMTCT cascade; Antenatal/Postnatal unit, Labour ward and Public health unit to discuss the purpose of the study and to request the release of the midwives and CHNs for the AI workshops. A list of midwives and CHNs trained in

the PMTCT programme and who had directly provided care to HIV positive clients for at least a year was generated. Midwives and CHNs who met the inclusion criteria were engaged on the purpose of the study. Information sheets for the midwives and CHNs (Appendix J) were provided, and clarifications were given where necessary. Twelve midwives and CHNs, four each from the three units were purposively recruited into the study. Although there were pre-determined criteria for inclusion, midwives and CHNs, i.e. years of experience in PMTCT care, age and job descriptions, were recruited. They completed the informed consent forms for participants (as indicated in 4.3.4.6.1) as an indication of willingness to participate. The list of the recruited midwives and nurses were submitted to the midwives- and nurses-in-charge of the various units to facilitate their release for the study.

#### 4.3.4.7 Data generation

Data generation in the AI process occurs in all the phases of the study. This section is presented accordingly: Initiate (4.3.4.7.1), Inquire (4.3.4.7.2), Imagine (4.3.4.7.3) and Innovate (4.3.4.7.4) phases. Figure 4-3 below presents the process for Data analysis process.

Figure 4-3 Data analysis process



#### 4.3.4.7.1 Initiate phase

Generally, in AI, participants engage together in all the stages. In this instance, however, protecting the identity of the expectant mothers was required since issues such as negative attitudes including stigmatization towards persons living with HIV (Nkansa-Kyeremateng & Attua, 2013), as well as non-disclosure (Kallem, Renner, Ghebremichael, & Paintsil, 2011) persist in Ghana.

The researcher had to find a way to ensure the women's voices were heard while still protecting their identity. Thus, the initiate phase was further divided into two sub-phases to allow for conversations between the researcher and the individual mothers on their experiences of receiving care in the PMTCT programme as well as conversations with the nurses and midwives on their experiences in giving care in the PMTCT programme.

##### 4.3.4.7.1.1 *Initiate Sub-phase One*

Individual conversations with the researcher were held with twelve HIV-infected mothers during this phase using the generative conversation guides for mothers (Appendix K) (Bushe, 2010). The conversations were done at the convenience of the participants. Five conversations took place in participant's homes. Of these, three participants requested for the presence of the community health nurse during the conversation although she was slightly removed from the sitting area while one respondent requested for the presence of her grandmother who was also her treatment supporter and caregiver. Five conversations were conducted on the premises of a church while two took place in the offices of the participants after working hours. The conversations lasted between thirty to forty-five minutes and were audio-recorded to enable the researcher to obtain the details and ensure an accuracy that could not be obtained from memory or field notes (Ryan & Denz-Penhey, 1996). The participants were aware when the recorder was switched on and their right to switch it off at any time. That had been discussed and agreed during the consenting process.

The conversations were structured using the principles of Appreciative Inquiry. The focus of the conversations was on positive experiences the participants have had in the PMTCT care (Bushe, 2007). The generative conversation adapted storytelling to elicit information about the mothers' experiences while accessing and utilizing

PMTCT care services. The first set of questions prompted the participants to reflect on their experiences of initiating HIV care through the PMTCT programme and remaining in the programme over time. The subsequent set of questions was theoretically guided by Appreciative Inquiry's positive and generative questioning approach. These questions sought to elicit factors that motivated the mothers' decision to remain in care and their best experiences since enrolment in the PMTCT programme. Participants were also asked to make three care-centred wishes that they believed will improve retention in the programme if implemented.

To understand each participant's individual experience from her perspective, the conversations were conducted with the stance of unconditional positive regard. The conversations were not disrupted when participants talked about bad experiences, but the focus of questioning was redirected to what they wanted more of, or what the programme ought to be so that new ideas for improving service delivery within the PMTCT programme could be generated.

#### *4.3.4.7.1.2 Initiate Sub-Phase Two*

Initially, an information session was held with the twelve midwives and CHNs. The administrator released the hospital conference room for this phase of data gathering. This was convenient as the venue was easily accessible to the staff and required no extra cost for transportation.

Participants were introduced to the purpose of the study, the theory and methods of the process AI. The findings from Phase One; the medical record review, (as explained in 4.3.1.2 and 5.2) were presented to set the stage for the AI process. The various strategies for data generation for the AI process were presented and role played to familiarise the participants of what would be expected of their participation. They were exposed to the Generative Conversation Guide for the Health Practitioners (Appendix L) that was to be used for the data collection and the Colaizzi's approach (Colaizzi, 1978) of data analysis. A demonstration of the paired conversation process and the use of the recording device was made with a participant to enhance understanding. The information sheet for the midwives and CHNs was also re-read to the participants, and the ethical issues of confidentiality, autonomy, beneficence, risk and compensation/reimbursement were discussed. To ensure confidentiality during reporting, Akan (most widely spoken Ghanaian language)

female day born names such as Akosua, Ama were assigned to the participants during the analysis and presentation of findings. Questions were invited and answered, and clarifications were given. The participants were then given the confidentiality agreement for group sessions form to sign (Appendix M).

The date and timelines for the AI sessions were communicated to them. They were also informed that the process was expected to last for three sessions and their commitment was required. The information session lasted for two hours and thirty minutes.

#### 4.3.4.7.2 Inquire Phase

During the Inquire phase, extensive data generation took place to explore and discover the exceptional experiences of the health workers, their values, aspirations and what they value about their work in the PMTCT programme. This section describes the data generation activities that were employed.

##### 4.3.4.7.2.1 Paired Generative Conversations

Paired generative conversations were employed for this phase of the study as they generate participation, excitement, ongoing discussions, and relationship building (Bushe, 2013) necessary for enhancing generativity in Appreciative Inquiry. Before the paired conversations, the twelve participants were grouped into three teams (Frankel & Beyt, 2017): Antenatal/Postnatal team, Labour ward team, and Public health team. That was necessary because the provision of PMTCT services in the various units was different and the inquiry was focused on stimulating discourse within the units that will eventually promote retention in the whole programme. Each group consisted of four participants. Participants in each team were paired using the improbable approach recommended by Frankel and Beyt (2017). That meant that participants with different ranks in their respective specialization, as well as, years of experience in the PMTCT programme were paired for the conversations. The notion was to break down existing barriers that existed among participants by building bridges across the boundaries of power and authority (Whitney & Trosten-Bloom, 2010) created by the differences in their positions.

The paired participants took turns to lead the conversations using the generative conversation guide. The conversations were audio recorded. They were encouraged

to probe deeply and seek clarifications on issues where necessary during the conversations as well as create mutual meaning of the experiences while having the conversations. The participants took notes of the life-giving factors. The conversations lasted between 14 and 45 minutes (the variation is addressed under 6.4.2). Upon conclusion of the conversation, the participants shared with their partners the meanings they had made of the conversations and clarifications or additions were made where necessary.

#### *4.3.4.7.2.2 Group Discussion*

Following the paired conversations, the three operational unit teams were reconstituted. The participants shared their partners' exceptional stories and the highlights that represented the important key factors, values, and resources. The highlights from the paired conversations were presented to the whole group. Each group also presented one story that they deemed captured most of the life-giving factors to the larger group. Whitney & Trosten-Bloom (2003) explains that this is critical because it creates the opportunities for participants to listen to stories about their organisation and make sense of what they hear so that they are energised to take action. They said that sharing experiences of best practices stimulate inspiration and the drive for change.

#### *4.3.4.7.2.3 Synergenesis*

Bushe (2013) first described Synergenesis in 1995 as Synergalysis. It requires that a small group of participants is presented with a small set of stories that have been written up from generative conversations for discussion to generate ideas to answer a central question (Bushe, 2013).

In this study, all twelve nurses and midwives were presented with two composite stories (Appendix N) of the narratives of the HIV positive mothers from Initiate sub-phase one. Participants in each group read the stories together. The nurses and midwives then discussed the ideas and images that emerged from the stories in relation to the mothers' experiences in receiving care in the PMTCT programme, as well as the factors that hindered or promoted retention in the programme. The CHNs and midwives compiled as many ideas as possible from the stories that answered the focal questions: (1) What were the mothers' reactions to the HIV positive test? (2) Why do mothers remain in care? and (3) What are the challenges mothers' face while

accessing care? This activity ensured that the health workers heard the voices of the mothers who accessed care in the PMTCT programme and their opinions and concerns are included in the development of strategies to enhance the programme. This approach was useful because the synergogenesis process created an opportunity for the nurses and midwives to become aware of the positive narratives of their clients concerning the services they render. The approach stimulated discussion about positivity and successes (Bushe, 2013). Cooperrider, Barrett, and Srivastva (1995) explained that an essential impact of the AI theory is its potential to redirect the conversations in an organisation towards generative topics that can yield positive change.

#### 4.3.4.7.3 Imagine Phase

The Imagine phase provided the opportunity to envisage big and bold possibilities for the PMTCT programme by challenging the status quo (Cooperrider et al., 2003). Cooperrider, Whitney, and Stavros (2008) said that activities in the imagine phase are practical and generative since they are based on the context-specific narratives of the organisation and seeks to stimulate its capacity for change. For this reason, participants were given time to reflect on the life-giving factors identified in the Inquire phase and their best experiences when outlining the future PMTCT programme. Through continued conversation and discussions in the groups, they identified a vision/image of the desired future for the PMTCT programme that will improve retention in their units.

Whitney & Trosten-Bloom (2003) outlines various activities including drama, drawing, painting, singing, poem writing and recitation for the Imagine phase. The idea is to enact the vision as if it already existed. Each group was given plain flip chart pages and markers to draw or illustrate their vision for the PMTCT programme in their respective units. I reiterated that the drawing skills would not be assessed, but the drawings would only be discussed as research data. This assurance promoted a positive and non-judgmental climate that enhanced participation and increased the fun.

Mair and Kierans (2007) averred that when drawing is used as a data gathering technique, it often entails participants' drawing and talking or drawing and writing about the meaning embedded in their draw. Participants were therefore asked to

write the description and interpretation of the visions on the flip charts. The groups presented their visions of the future of PMTCT programme that they believed would promote retention in ‘Open Mic’ sessions to the larger group. That enhanced the engagement of the participants.

Collaborative conversations were held to map out the key statements embedded in the interpretation of the drawings. The dreams were clarified with continued engagement among participants until consensus was reached and the desired future of the PMTCT programme that would promote retention was arrived at by the participants.

The participants were also engaged in creating provocative propositions or statements. They are statements that concern practice and enables the staff to design their action plans towards achieving their goals on retention, as well as, serve as a criterion to monitor the staff activities to ensure they are on course Cooperrider et al. (2003).

The criteria for generating a provocative statement include, it must be:

- Provocative and challenge the status quo
- Developed from real life experiences
- Bold and stated in the affirmative and present terms
- Owned by the people so that they are passionate about it enough to defend it (Cooperrider et al., 2003).

#### 4.3.4.7.4 Innovate Phase

The Innovate phase involved a review of the provocative propositions, life-giving statements from the mothers’ narratives and the nurses’ conversations to determine strategies to achieve the desired vision. That was important to ensure that the key elements were captured in the action plans. Participants in the three groups generated a list of potential actions that they felt were necessary for the successful implementation of the desired vision for each unit. The lists were then presented to the larger group for discussion and contributions. These potential actions were developed into action plans that included activities and new roles that will be important to sustain the implementation of the action. Participants then engaged in a

collaborative conversation to include activities that they felt were omitted but were necessary for the achievement of the desired future.

The AI phases were conducted within one week. This was necessary to maintain the momentum of the data collection process and ensure that the participants remained engaged in the process.

#### **4.3.4.8 Data Management**

The audio recording of the participants' conversations was uploaded into a folder created on a password protected laptop immediately after the conversation and deleted from the audio recorder. The conversations were filed using the participants' pseudonyms and the date of the data collection. The researcher did the initial transcription and translation of the conversations from Fante to English to ensure that all participants identifiers were masked. Subsequently, a language translator was solicited to do back-translation from English to Fante to ensure that the meaning of the conversations was not lost in the process of translation. Thereafter, the researcher being a native Fanti reviewed the transcripts and the translated document. Few grey areas were identified and subsequently rectified by listening to the tapes and translating the meaning of the narratives as is congruent with the Colaizzi method of analysis (Colaizzi, 1978).

The audio recordings and the transcriptions were stored on a hard disk and synchronized with Outlook 365 cloud. The researcher was the sole owner of the data and did not share it with any institutions or persons. The information was available to only the researcher and the supervisor. Figure 4-3 illustrates the data analysis processes.

#### **4.3.4.9 Unravelling the Data**

A multi-staged approach was employed so that the findings of each stage of data collection could be fed into subsequent stages to generate common thematic statements. The Colaizzi method of analysis (Colaizzi, 1978) and the SOAR (Strength, Opportunities, Aspirations, and Results) approach (Keene & Scott, 2016) were applied at different phases of the study to organize the themes and life-giving factors in the PMTCT programme for categories of participants.

#### 4.3.4.9.1 Initiate Phase

I began the analysis of the mothers' conversations by immersing myself in the narratives by listening to the tapes repeatedly and reading the verbatim transcripts before the formal analysis. This ensured familiarity with the data. The analysis was done manually to afford me the opportunity to engage with the dataset and to gain ownership of the work. As a native Fante speaker, I was in a position of being a translator of language, meaning and the culture that permeated through the narratives. Colaizzi's analysis method (Colaizzi, 1978) was employed. I read through each transcript several times to gather a general picture of the information. Identification and extraction of statements that were noteworthy and pertained to the mothers' experiences and the factors that motivated them to remain in PMTCT care were done. These statements were written in a thematic analysis tracking map (Appendix O) developed by the researcher, and coded based on the pseudonym of the respondent, the page and line numbers. This process was done with the assistance of a colleague to ensure inter-coder reliability. Forty-one (41) significant statements were extracted from the twelve transcripts.

Meanings were generated from the statements extracted from the dataset. Forty-one (41) meanings were gathered from the extracted statements. This process was reviewed by my supervisor to ensure consistency between the narratives and the meaning. Meaning making is also an essential step in the AI process. Whitney & Trosten-Bloom (2003) explained that it ensures active engagement of members of the group through discussions, exploration, and learning so that the possibility of the desired future comes into focus. Trosten-Bloom (2016) explains that this approach stems from the constructionist principle of AI which supports the assumption that meaning is constructed during the interaction between the partners and not during the reporting of the findings.

Thereafter, the formulated meanings were sorted into eleven (11) categories. Clusters of the categories that reflected a particular trend of thought were merged to form four sub-themes. One theme was finally developed. Two composite stories (Appendix N) that were de-identified were developed, capturing the essential experiences and meanings assigned by the mothers in the PMTCT programme and the factors that motivated their decision to remain in care.

#### 4.3.4.9.2 Inquire phase

I (researcher) facilitated the process of data unravelling undertaken by the midwives and CHNs (participants). Colaizzi's analysis method (Colaizzi, 1978) was used in the initial phase of the process. The midwives and CHNs were asked to collectively review and make meaning of the life-giving statements and the stories they shared. All participants confirmed the meanings as representing the stories that were shared by the midwives and CHNs, and the mothers' composite stories.

The participants at the group sessions then collated the meanings by identifying patterns and similar threads as well as outliers under the following headings Strengths, Opportunities, Aspirations, and Result (Keene & Scott, 2016) to form categories. The list they generated represented the key elements/core contributors of exceptional experiences in the PMTCT programme. The participants then mapped the similarities between the key elements of the three nurse groups. That resulted in a list of key elements for the midwives and CHNs' exceptional experience. They recorded the lists on yellow, green and white colour coded sticker pads for the key elements of the health workers.

The participants repeated the process of formulating meaning and sorting the meanings to generate a list of key elements for the mothers' composite stories. They recorded the lists on pink and orange colour coded sticker pads for key elements of mothers' composite stories. One hundred and six (106) elements were generated for the two groups.

They then posted the sticker pads on the wall of the conference room. AI is participatory and therefore required that participants actively engage in co-constructing the desired PMTCT programme that would promote retention to enhance ownership of the outcomes. Two volunteers together with the researcher clustered the sticker pads. The group then discussed, finalized and named 13 clusters to generate seven life-giving factors of the PMTCT process. Validation of the findings was done at the end of each phase of the process. Figure 4-4 below presents the outcome of the data unravelling process for this phase.

Figure 4-4 Outcome of data unravelling process



The list of life-giving factors was then written on a flip chart. Participants were asked to select the life-giving factors that they believed had the most significant impact in achieving the exceptional experience. The volunteers again assisted in this process by ticking beside points on the flip chart page. Five points that received the most ticks were carried on into the Imagine phase. Finally, the researcher returned to the transcripts for significant statements to support, illustrate or explain the themes that were generated. Seventy-two quotes were extracted from the transcripts.

#### 4.3.4.9.3 Imagine phase

Guillemin (2004) encourages collaborative meaning-making when analysing creative expressions in research. He explained that it allowed the drawer to give voice to what the drawing was intended to convey. Collaboration was vital mainly because a specific individual produced a drawing in a particular space and time. The analysis in

this phase was done using this approach. Each group presented their drawing with the story it carried. The midwives and CHNs discussed and generated a list of statements from the interpretations they were derived from the drawings and the stories they carried. That was necessary because the drawings represented the participants' vision for a PMTCT programme that would improve retention and were based on the life-giving factors identified in the Inquire phase. The list that was generated served as the basis for the development of the provocative statements and the action plans.

#### **4.3.4.9.4 Innovate phase**

Participants engaged in discussions in the groups to review the potential actions listed to achieve their vision of retention in the PMTCT programme. Then, the larger group was constituted to discuss and arrive at a consensus on the actions included in the action plans (presented under 5.2.4). The researcher facilitated the process. The format of the action plans was; priority, objective, action step, unit responsible and timeline.

### **4.3.4.10 MEASURES TO ENSURE TRUSTWORTHINESS OF STUDY FINDINGS**

The constructs proposed by Lincoln and Guba (1985) for ensuring trustworthiness of a study was used as a measure to ensure the rigor of this study. They include credibility (4.3.4.10.1), transferability (4.3.4.10.2), dependability (4.3.4.10.3) and confirmability (4.3.4.10.4).

#### **4.3.4.10.1 Credibility**

Lincoln and Guba (1985) posit that for a study to be credible, the participants should be able to confirm that the research findings were derived from the original data and that the meanings given to a phenomenon or condition in the study accurately reflect their original views in their social context. In this study, credibility was established by prolonged engagement (4.3.4.10.1.1), member checking (4.3.4.10.1.2), triangulation (4.3.4.10.1.3) and peer de-briefing (4.3.4.10.1.4).

#### *4.3.4.10.1.1 Prolonged engagement*

Polit and Beck (2012) aver that prolonged engagement involves devoting a lot of time to the data collection process to the extent that a relationship of trust is built between the researcher and the participants. Given (2008) explains that spending much time with the participants in their social context affords the researcher the opportunity to fully immerse in their culture to better understand their values, social relationships, and behaviours.

Before the data collection, the researcher spent a considerable amount of time in the ANC/PNC and Public health clinics as well as the community through outreach and home visits, engaging with the midwives and CHNs who provided PMTCT services to the HIV-infected pregnant women and mothers. This ensured the establishment of rapport and stimulated the interest of the midwives and CHNs to commit to the study by inviting eligible clients and opting to participate in the study themselves.

Prior to and during the data collection process, the researcher undertook non-participant observation of the PMTCT service delivery. The researcher developed a deeper understanding of the milieu in which the PMTCT services were provided and the reactions of pregnant women who tested positive for HIV for the first time in this current pregnancy. The researcher also nurtured an appreciative perception of the relationships that were established between the healthcare providers and the clients in the context of PMTCT service delivery. Furthermore, the data collection extended over a period of three months with four AI sessions held with the health workers, thus providing sufficient time for a trusting relationship to be built. The researcher also engaged with the mothers over a period before the time of the generative conversation. The quality of engagement was ensured as the researcher established rapport, patiently interacted and heeded the concerns of the participants.

#### *4.3.4.10.1.2 Member checking*

Rager (2005) describes member checking as confirmation by the participant. Through this process, participants can validate the study findings as reflecting their views, experiences, and feelings. Creswell (2007) posits that member checking involves the researcher summarising or re-stating the information gathered during the conversation to afford the participant the opportunity to determine the accuracy or clarify aspects that were not well presented.

In this approach, the analysed data and reports were sent back to the participants for confirmation of its accuracy or clarification of misrepresented portions.

During the individual conversations with the mothers, the researcher and the participants ensured the accuracy of the data immediately before termination of the conversation. The information was summarised for the mothers to indicate if their experiences and the meaning generated had been captured well. Subsequently, the data from the mothers' conversations, were analysed and developed into individual stories/narratives. These narratives were then revisited with each participant individually for validation. The individual stories were reconstructed into composite stories that were de-identified and later introduced in the AI sessions with the nurses and midwives.

Member checking for the AI sessions with the nurses and midwives occurred during the sessions and immediately before the completion of the data gathering. During the inquiry phase, the participants were entreated to cross check with their partners if the highlights had been accurately captured during the paired conversations. Participants also presented their partners' stories to the larger group thus allowing for the opportunity for clarifications where views were not properly captured. Furthermore, a recap of findings of each stage of the study was done during the following AI session to ensure that information gathered were accurate.

#### *4.3.4.10.1.3 Triangulation*

Triangulation is a process of ensuring the credibility of a study by incorporating multiple points of views and methods of data gathering to benefit from the individual strengths of the various methods while overcoming their deficiencies (Yeasmin & Rahman, 2012).

In this study, data were collected from HIV-infected mothers as well as midwives and CHNs who provide care in the PMTCT programme (Cohen & Crabtree, 2006). That was essential to ensure a comprehensive understanding of the phenomenon was incorporated in the study. The researcher adopted both quantitative and qualitative methods for the study by using several data collection techniques including; medical records review, individual conversations, paired conversations, group discussions and participants created documents such as the drawings. The data was also gathered at different times and dates scheduled with the participants. That was necessary to

ensure that biases were minimized as far as possible, and to ensure consistency across the study.

#### *4.3.4.10.1.4 Peer-debriefing*

Lincoln and Guba (1985) state that peer-debriefing offers the researchers the opportunity to expose themselves to disinterested peers to review aspects of the research that might otherwise have been left unexplored.

The researcher engaged in scheduled sessions with colleagues, who were familiar with the cultural, social and professional context of the study context, the qualitative method, and analysis, as well as the supervisor of the study to examine the experiences gathered during the research process. The various aspects of the research process being undertaken at the time of the meetings were also reviewed. During these sessions, flaws in proposed activities and alternative approaches were discussed. That helped the researcher to reflect on her personal biases, preferences and competing interpretations of data (Billups, 2014).

#### *4.3.4.10.2 Transferability*

Polit and Beck (2012) explain transferability as the extent to which research findings can be applied in different settings with different participants. While the goal of qualitative research is not to generate findings that can be generalized statistically, Lincoln and Guba(1985) state that it is the responsibility of the researcher to provide contextual information about the study sites and settings to enable others to determine if transferability to other research settings, populations, situations and time is possible. The research setting has been described under 1.8. They recommend that providing a thick description of the context allows other readers to determine the extent to which they can confidently transfer to other settings, the findings and conclusions arrived at a study (Lincoln & Guba, 1985).

At the time of the study, the PMTCT programme in the Takoradi programme was integrated with the MNCH services. The option B+ treatment regimen (as described in 1.2) had been rolled out and fully operational at the facility. HIV counselling and testing was performed by the midwives and nurses at the various points along the PMTCT cascade and followed the opt-out policy (as explained in 1.3). Although the national policy for ANC service delivery was focused antenatal care, this was not

practiced due to lack of infrastructure and staff. During the study period, PMTCT service delivery was guided by the PMTCT handbook for healthcare workers in Ghana (Ghana Health Service, 2014). There were no staffing changes or modifications in the PMTCT policy that was being implemented during the period of the study.

Shenton (2004) also explains that a thick description of the phenomenon being studied must be documented to ensure that readers develop an understanding so that they can accurately assess the credibility of the findings reported by the study regarding the situation and setting. Thus, to ensure transferability, a detailed description of the phenomenon under study (1.5), research process (4.3.3 & 4.3.4) and background information of the participants (Table 5-5 and 5-6) was documented in the research report. Transferability was enhanced by purposefully sampling the participants and providing an accurate description of the participants.

#### 4.3.4.10.3 Dependability

Dependability refers to the stability of the findings over time (Bitsch, 2005). The findings should be consistent over time and across conditions (Miles, Huberman, & Saldana, 2014). To ensure dependability, a colleague doctoral student was asked to review a sample of the transcripts. My colleague read the transcript in both English and Fante. Themes that were highlighted by my colleague were compared with my themes and the conversation transcripts. Discussions were held with the goal to agree on the themes and the meanings generated from the transcripts. The supervisor reviewed the transcripts and validated the themes and the descriptors that were identified to support the themes. The researcher compared the back-translated documents with the transcripts, and grey areas were rectified by referring to the audio tapes and translating the meaning of the conversations. Member checking was also done to ensure that the transcripts captured the thoughts of the participants.

#### 4.3.4.10.4 Confirmability

In this study, confirmability was ensured through various techniques. This subsection is presented under Audit trail (4.3.4.10.4.1) and Reflexivity (4.3.4.10.4.2).

#### *4.3.4.10.4.1 Audit trail*

Carcary (2009) explains that audit trail documents the sequence of development of a completed study. To achieve this, the researcher must keep a detailed record of all decisions and choices taken about the theoretical, methodological and analytic aspects of the study (Koch, 2006) so that a second party can audit and confirm its findings as trustworthy. Creswell and Miller (2000) posit that to maintain a detailed trail of the research process, a log of all research activities, data collection and analysis procedures as well as memos and research journals should be maintained.

In this study, the researcher kept a detailed record of the recruitment of participants, the challenges experienced and how this was surmounted, the data collection and analysis processes, as well as, the decisions taken, and how these impacted the study. The researcher also kept a paper trail of all the activities that were undertaken in the study, as well as, the description of the setting (1.8), the people and the context in which the study was conducted (the context of the study has been described under 4.3.4.10.2).

Akkerman, Admiraal, Brekelmans, and Oost (2008) further assert that an audit trail must include the researcher's personal reflections on how the study evolved throughout the phases of the study. In this regard, the researcher reflected on her preconceptions, experiences, actions as well as inner conflicts and how they informed the study.

#### *4.3.4.10.4.2 Reflexivity*

Koch (2006) states that confirmability can be established through the use of a reflexive journal. The researcher kept a reflexive journal and documented personal thoughts and self-examinations that could have a bearing on the study at each phase/step of the research process. That ensured that I was aware of my assumptions, beliefs, biases, and perceptions that I brought into the study. A reflexive report is presented in 6.5.4.5.

## **4.5 ETHICAL CONSIDERATIONS**

Ethics refers to a set of principles that can influence considerations, choices, and actions (Johnstone, 2015). Ethics in research ensures that the interests of the study participants supersede the interests of science and society at all times (World

Medical Association, 2013). To ensure this, the ethical considerations outlined in the Helsinki Declaration of Scientific Research (World Medical Association, 2013) involving human subjects guided the development of the proposal and the research process. The clauses that have particular relevance for this study include risk, burdens, and benefits; vulnerable groups and individuals; privacy and confidentiality, and informed consent.

This subsection is organised under; autonomy (4.5.1), informed consent (4.5.2), beneficence (4.5.3), non-maleficence (4.5.4), confidentiality (4.5.5), justice (4.5.6), researcher preparedness (4.5.7) and dissemination of Findings of the Study (4.5.8).

### *4.5.1 Autonomy*

Respecting the autonomy of individuals participating in research is a fundamental ethical principle. This principle entails protecting the vulnerable individual by not imposing the researcher's decision on them (Owonikoko, 2013). In addition to this, respect for autonomy includes creating the necessary conditions for the eligible participants and those who finally enrol to make autonomous choices with regards to the study (Cosac, 2017).

The information about the study was provided to the participants both in oral and written form. The mothers were made aware of their choice to participate or decline without any repercussions on access to healthcare in the PMTCT programme or other health services. They were also aware of that participation in the study was voluntary and that they could withdraw from the study at any time without any explanation. The opportunity to switch of the audio recorder during the conversation was also made known to the mothers. Thus, the mothers who enrolled wanted to share their stories and did so under no duress. In this study, the researcher fully recognized that using the gatekeepers as the first contact for participant recruitment may have a coercive effect as the potential participant may have felt they were obligated to participate. Hence, the researcher personally engaged the mothers throughout the study to ensure that their right to participate or otherwise was respected.

Likewise, the midwives and CHNs who opted to participate in the study were informed of the purpose of the study and the fact that participation was voluntary. They were engaged on their rights to decline participation without recourse to their employment. They were also reassured that there would be no repercussions for their

decision to withdraw from the study. Furthermore, the researcher actively engaged with the hospital management to undertake that the midwives and CHNs who chose not to participate will not be penalized.

#### *4.5.2 Informed Consent*

Mavroudis, Jacobs, Siegel, and Mavroudis (2015) aver that a person must knowledgeably and voluntarily give consent to participate in a study. The potential participants should be made aware of the purpose of the research, what participation involves, the ability to freely decide whether and on what terms they would participate (Guillemin & Gillam, 2004).

Information sheets (Appendices H and I; as indicated under 4.3.4.6.2) were prepared for each mothers, and midwives and CHNs respectively. The information sheets explained the purpose of the study, as well as what a participant's decision to enrol in the study entailed. The information sheets were translated into Fante, the predominant language in Takoradi. The researcher informed potential participants that the research was intended to yield data for a Ph.D.

The mothers were made aware that they were being contacted because of their experiences in the PMTCT programme and were therefore aware of the information being sought prior to the conversation sessions. The gatekeepers were provided with the written information sheet to refer to when informing eligible mothers about the study. They then directed the mothers who showed interest to the researcher or compiled their contacts details for the researcher to contact them when they decided to participate in the study. Some mothers requested to be introduced by the midwives and CHNs at the first meeting.

The researcher ensured that the purpose of the study was reiterated at each contact (a minimum of three for the mothers) before the conversation so that the participant's decision to enrol in the study was based on an informed choice. The researcher thoroughly discussed the study with the eligible mothers and answered questions they had before their recruitment and again before the generative conversations. A date, time and venue were then agreed for the generative conversations. The participants were given ample time to consider participation in the study, usually about a week. The participants who were literate gave verbal and written consent at

the start of the study. For the mothers who could not write, oral consent was obtained in the presence of a witness, and they were assisted to thumb print the consent form.

The researcher personally contacted the midwives and CHNs after the nurse unit managers had identified those eligible for the study. Information sheets were provided, and clarifications made where necessary. After they had signed the consent form, a list of names was presented to the nurse manager to facilitate their release for the study period. The midwives and CHNs who opted to participate in the study signed the consent form prior to the start of the AI sessions.

### *4.5.3 Beneficence*

The principle of beneficence places a responsibility on the researcher to act in ways that benefit others (Mavroudis et al., 2015). This ethical principle requires that the researcher increase the potential benefits of the study (Fouka & Mantzorou, 2011). Beauchamp (2007) avers that the benefits can be to the participant or the society as a whole. Mothers who showed limited knowledge on infant feeding were referred to their counsellors for more education. That was realistically part of the counsellor's responsibility and did not present an additional burden on the health system. The health system also experienced immediate changes in aspects of service delivery including team building, enthusiastic and motivated staff. The location of the waiting area of the assigned for HIV counselling and testing was also changed away from the testing room, and other services such as confirmatory testing enrolment in the programme and ART refill were initiated in the ANC units by the midwives.

The participants were made aware that participation in the study had no financial remuneration. The researcher explained that by sharing their experiences, the participants would contribute to the improvement in the PMTCT service delivery thereby enhancing the experiences of newly diagnosed HIV positive mothers in pregnancy and the health outcomes of the unborn children. The participants were also informed that knowledge generated to inform the study would be useful for training of nurses and midwives who provide care in PMTCT programme.

Furthermore, the researcher explained that their participation would yield benefits for the nation, by informing policy on PMTCT retention strategies, enhancing retention that will invariably improve the health of the mother and the child as well as improve

the country's chances of achieving an HIV free generation. The health workers received a certificate of participation, and refreshments during the sessions.

#### *4.5.4 Non-maleficence*

Non-maleficence requires minimising probable risks associated with participation in a study (Mavroudis et al., 2015). Fouka and Mantzorou (2011) argue that identifying and preventing intentional harm, as well as reducing the incidence of potential harm must be paramount to the researcher. Discomfort and harm can take the form of emotional, physiological, social and economic effects (Mavroudis et al., 2015).

The researcher did not anticipate any harm or discomfort associated with participation in the study. However, she recognized that due to the vulnerability of the mothers enrolled in the study, there was a possibility of mothers becoming distressed during the conversation about their initial experiences with the HIV diagnosis and their enrolment in care. To err on the side of caution, the researcher approached the HIV counsellors and explained the study to them and sought their support. The counsellors were informed that permission would be sought from mothers who experienced any form of distress and those mothers will be referred to them. During data collection, one mother was distressed when sharing her story about the death of her eldest daughter to AIDS. She was informed that the session could be postponed to a later date and that counsellors were available to assist her. She however declined and insisted on finishing the conversation. She was allowed time to recover, and the session ended successfully. Thus, no participant required further counselling. The researcher also engaged the mothers at the end of the conversations to reflect on their experiences during the sessions and to offer to refer them to the appropriate staff for assistance where necessary (Burns & Grove, 2005). The study was also intentionally designed to ensure that the voices of the mothers were heard in the AI sessions without compromising their identities.

The study did not unduly disrupt PMTCT service delivery in the facility as the initial participant recruitment was done alongside the normal clinic activities.

Subsequently, only a core group of CHNs and midwives were recruited for the AI sessions for limited periods of time which were prearranged at a time that was convenient for the service. Any burden or inconveniences was offset by the benefits of the study which were instituted during the process.

### *4.5.5 Confidentiality*

Confidentiality in research refers to the ethical principle that seeks to protect research participants so that they remain unidentifiable throughout the research process (Kaiser, 2009). This entails removing participant identifiers, keeping records secure, ensuring people who have access to the data do not discuss issues arising from the conversations or divulge information that might reveal the identify the participants, and anonymising individuals who participate and the setting in the research report prepared for dissemination also protect them (Wiles, Crow, Heath, & Charles, 2008).

There was minimal risk associated with the study. There was a potential risk of breach of confidentiality during data collection and management. Thus, measures were put in place to ensure that confidentiality was maintained at all times.

For the record review in Section A, the completed data extraction forms were kept in a locked cabinet and electronic versions were stored in a password-protected computer programme. Once the data was captured, all distinctive participant identifiers were deleted to ensure that the final data was anonymous. The participants names and addresses were or not extracted as data during the study. Furthermore, the participants' personal details were kept confidential throughout the study.

In Section B, participants were encouraged to choose pseudonyms during the data collection. These pseudonyms were used during recording, analysis and subsequently the research report writing. The mothers' conversations were reconstructed into composite stories to ensure that the midwives and CHNS, as well as other readers, could not identify them. The midwives and CHNs who participate in the AI sessions were informed that confidentiality could not be guaranteed as group members may disclose what was discussed outside the research setting. The group was a small stable group where they may have been some level of commitment to each other's contribution. Participants were however entreated to respect the confidentiality of other participants and were requested to sign a confidentiality agreement for the group sessions (Appendix M).

### *4.5.6 Justice*

The principle of justice requires that there is a fair distribution of the risk and benefits associated with the research. Guillemin and Gillam (2004) argue that this

principle has a broad scope and does not state how participants should be treated justly in a research study. They go further to explain that participants should be treated alike and to use language common to all participants during the research process. Greaney et al. (2012) also aver that people who are vulnerable and/or in the minority should not be excluded from participating in research and that researchers must provide a rationale for any exclusion.

In ensuring justice in this study, the participants were recruited from the district hospital that served a large catchment area. The hospital is a public health facility, thus creating an opportunity for selection of participants with different socioeconomic status was ensured. Data gathering was conducted in both English and Fante thus, no participant was excluded on the basis of language competence. Information sheets and consent forms were translated into Fante before data collection, to ensure that potential participants who could only read Fante were duly informed hence literacy level was not a basis for exclusion from the study. The study was conducted at locations convenient to the participants and thus access and transportation for participation was ensured.

#### *4.5.7 Researcher preparedness*

The researcher is a trained public health nurse who has worked in the HIV unit in addition to the Medical/Surgical units. She lectured at the School of Nursing and Midwifery at the University of Cape Coast, Ghana before her enrolment in the PhD programme. The researcher has also conducted two research studies in HIV/AIDS and PMTCT in partial fulfilment for the Bachelors' and Masters' degrees:

- Acceptability of Voluntary Counselling and Testing among pregnant women at the Maamobi Polyclinic.
- Enhancing student nurses' attitude towards persons living with HIV. A view through Attitude theory (Cognitive dissonance) lens.

The researcher has attended lectures and seminars on qualitative and quantitative research methods to enhance her knowledge. Specifically, she participated in the Appreciative Inquiry Facilitators' Training organised by the Appreciative Inquiry Foundation in Johannesburg, South Africa in November 2015. The research was conducted under the supervision of an approved supervisor and, where necessary, consultations with an AI methodology expert was done.

#### *4.5.8 Dissemination of Findings of the Study*

The findings of the study will be published in peer-reviewed scientific journals and presented at local, regional and international conferences in collaboration with the supervisor to advance further research and scholarship. Feedback on the findings would also be presented to the participants, health service managers, the regional and district health directorates.

## **CHAPTER 5 FINDINGS OF THE STUDY**

### **5.1 INTRODUCTION**

This chapter focuses on the findings of the study. The chapter has been organized under two sections. Section A presents the findings of quantitative baseline study that involved a record review of the PMTCT programme in the Takoradi Hospital during the period of study. Section B covers the findings of the appreciative inquiry process.

### **5.2 SECTION A: RECORD REVIEW**

This section presents the findings of the record review of the PMTCT programme for the cohort of pregnant women who were enrolled from January-December 2015. The findings are descriptive in nature and cover the trends of enrolment and retention for all women who registered at the antenatal clinic under the integrated MNCH and PMTCT programme. The profile of only those who tested positive could be captured when the PMTCT records were reviewed. Thus, records of those who were negative and did not enrol in the PMTCT programme could not be accessed. The socio-demographic, obstetric and clinical characteristics of the HIV-infected women enrolled in care, socio-demographic characteristics of HIV-infected mothers and PMTCT enrolment status, the HIV-infected women's characteristics and survival time in the PMTCT programme of mothers who remained in the programme during the study period are also presented. These findings were presented to set the stage for the AI process and to enlighten the health professionals of the trends of retention in the whole continuum. Such a database has not been previously established for the health facility.

#### ***5.1.1 HIV Counselling, Testing and PMTCT enrolment***

A total of 1 252 pregnant women were booked at the antenatal clinic at the Takoradi hospital from January–December 2015. Of this number, 1 178/1 252 (94.1%) received pre-test counselling on HIV and were also informed about the opt-out testing policy. Thus, 74/1 252 (5.9%) women who were antenatal clinic registrants were not counselled for the HIV testing. There was no record as to whether this was

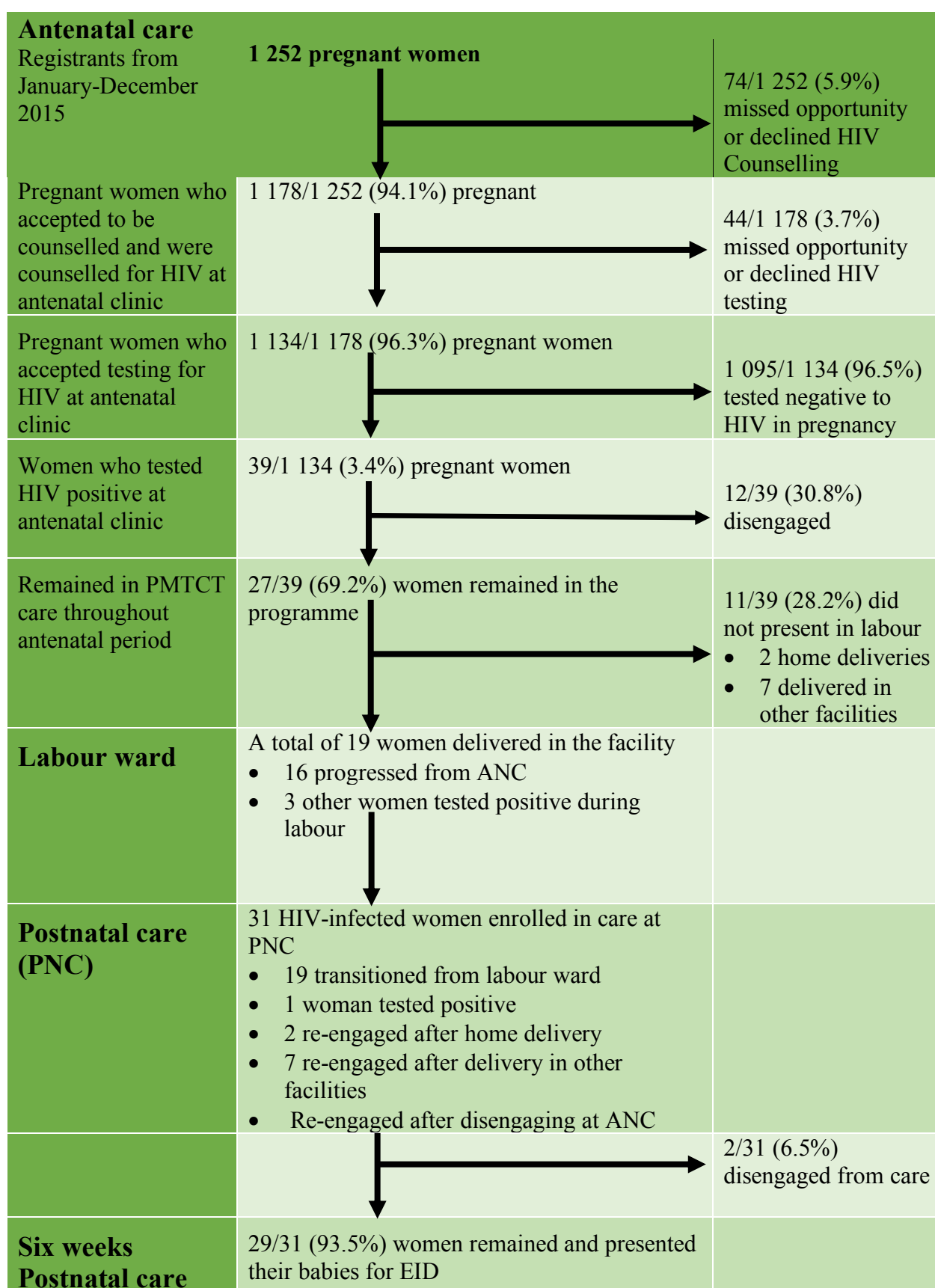
a missed opportunity for HIV counselling or the clients exercised their rights to opt-out from the service.

Of those who were counselled for HIV, 1 134/1 178 (96.3%) were tested for HIV in the current pregnancy under the opt-out approach. A total of 44/1 178 (3.7%) women missed the opportunity or refused to be tested. Of the number who tested for HIV, 39/1 134 (3.4%) women tested positive in the current pregnancy and were enrolled into the PMTCT programme at antenatal clinic. At the end of the antenatal period, 27/39 (69.2%) women who tested HIV positive were still receiving both antenatal care and ART in the PMTCT programme. Hence, 12/39 (30.8%) disengaged from the programme during the antenatal period.

Of the 27 who remained until the end of the antenatal period, only 16/27 (59.3%) gave birth at the labour ward of the facility and received treatment for their infants at birth. The remaining 11/27 (40.7%) did not present for labour. Tracking efforts revealed that two of the eleven women (18.2%) had home deliveries, seven of the eleven women (63.6%) gave birth in other health facilities whilst the remaining two out of eleven women (18.2%) could not be tracked due to wrong addresses and contact details. Three mothers who had not tested during pregnancy tested positive during labour. Thus, a total of nineteen HIV-infected women gave birth at the facility and received the treatment for their infants.

Thirty-one women accessed postnatal/postpartum care under the integrated MNCH/PMTCT programme in the facility during the period under study. This included the 19 women who transitioned from the labour ward, 1 woman (with no previous record of testing) who tested positive in the postnatal period, two mothers who re-engaged after home deliveries, seven mothers who gave birth in other health facilities but returned for postpartum care and two other mothers who re-engaged after disengaging during the antenatal period. Of the 31 HIV-infected women who started postpartum care, 29/31 (93.5%) mothers were engaged in the programme and presented their infants for the early infant diagnosis (EID) at six weeks postpartum. Two of the 31 women (6.5%) disengaged from the programme during the postnatal period. There was no indication of the exact time at which the disengagement occurred. All the exposed babies who were presented for the EID tested negative for HIV at the end of the study period. The trends of HIV counselling, testing and PMTCT enrolment are present as a flow chart in Figure 5-1 below.

Figure 5-1 The trends of HIV counselling, testing and PMTCT enrolment



### 5.1.2 Rate of retention in the PMTCT programme

A total of 1 178/1 252 and 1 134/1 252 women opted for HIV testing and counselling (HTC) respectively under the integrated MNCH/PMTCT programme during the study period. Of this number, 43/1 134 (3.8%) of the women tested positive for HIV and enrolled in the programme across the PMTCT cascade. The majority of the infected mothers, 39/43 (90.7%) were diagnosed at ANC, while 3/43 (7.0%) and 1/43 women (2.3%) were tested at labour and postnatal periods respectively. Of the total number who tested positive, 16/43 (37.2%) HIV-infected women disengaged at various stages of the PMTCT cascade. Thus, the total number of women who disengaged from the programme at the end of the study period was 14/43 (32.6%) who tested positive for HIV in this cohort. A total number of 29/43 (67.4%) HIV-infected women enrolled and remained in the PMTCT programme until six weeks postpartum period when the EID was done. The rate of retention in the PMTCT programme at the study setting during the data collection was 67.4%. Table 5-1 presents the levels of engagement, disengagement, and re-engagement in the PMTCT.

Table 5-1 Engagement, Disengagement and Re-engagement in the PMTCT programme.

Variable	Tested positive N (%)	Remained N (%)	Disengaged N (%)	Re-engaged N (%)
Antenatal care	39/43 (90.7%)	27/39 (69.2)	12 <sup>3</sup> /39 (30.8)	-
Labour	3/43 (7.0%)	19 <sup>4</sup>	2 <sup>5</sup> /19 (10.5%)	-
Postnatal/Child welfare care	1/43 (2.3%)	29 (93.5)	2 (6.5)	2
Total	43/43 (100)	29/43 (67.4)	14 <sup>6</sup> /43 (32.6)	2

<sup>3</sup> Two women re-engaged at PNC after disengaging at ANC

<sup>4</sup> The total of 19 includes sixteen women who transitioned from ANC and three who tested positive in labour. Of the 27 women who completed ANC, 2 had home deliveries and reported at the facility with their babies, 7 women reported they gave birth in other health facilities under supervised delivery. The remaining 2 were not accounted for.

<sup>5</sup> Two women could not be accounted for after data collection. Attempts at tracking yielded no results.

<sup>6</sup> Total number of women who disengaged from care = (disengaged – re-engaged)

### 5.1.3 Socio-demographic characteristics of the HIV-infected women

The mean age of the 43 women at PMTCT enrolment was 31 years, with the youngest being 16 years. Most of the women, 29/43 (67.4%) had at least secondary education. Majority of the infected mothers, 35/43 (81.4%) were self-employed. Majority of the women, 24/43 (55.8%) were married, while one was divorced. These findings are presented in table 5-2 below.

Table 5-2 Socio-demographic and obstetric characteristics of the women

Variable/Demographics	N (43)	(%)	Mean
<b>Age (years)</b>			31.0
<20	2	4.7	
20-29	15	34.9	
30-39	21	48.8	
40-49	5	11.6	
<b>Level of education</b>			
Primary or no education	11	25.6	
Secondary or higher	29	67.4	
Not Recorded	3	7.0	-
<b>Employment</b>			
Unemployed	3	7.0	
Self employed	35	81.4	-
Formal	3	7.0	
Not recorded	2	4.6	
<b>Marital status</b>			
Single	9	20.9	-
Married	24	55.8	
Divorced	1	2.3	
Cohabiting	7	16.3	
Not recorded	2	4.7	

### 5.1.4 Obstetrics and clinical characteristics of women enrolled in care

Twenty of the 43 women (46.5%) were nulliparous at the time of testing. Majority of the women, 38/43 (88.4%) were classified as WHO clinical stage I and II at the time of ART enrolment. Of the 26 women for whom disclosure status was available, 13/26 (30.2%) had disclosed. Of the 33 women that had adherence counselling schedules recorded, all had received at least the first counselling before ART initiation while 17/35 (39.5%) had completed all three adherence counselling sessions (as explained in 1.2). The findings are presented in Table 5-3 below.

Table 5-3 Obstetric and clinical characteristics of the women enrolled in PMTCT

Variable/Demographics	N	(%)
Obstetric history (Parity)		
0	20	46.5
1	11	25.6
2	10	23.3
3	1	2.3
4	1	2.3
HIV history		
WHO stage at screening		
I & II	38	88.4
III & IV	4	9.3
Not recorded	1	2.3
Disclosure status <sup>7</sup>		
Disclosed	13	30.2
Not disclosed	13	30.2
Not recorded	17	39.5
Adherence counselling sessions <sup>8</sup>		
1	33	76.9
2	25	58.1
3	17	39.5
Not recorded	10	23.2

<sup>7</sup> Disclosure status recorded in the patients ART folder at the time of the study.

<sup>8</sup> Three adherence counselling sessions required per PMTCT protocols

### 5.1.5 Socio-demographic characteristics of mothers and final PMTCT status

Of the 43 women included in the analysis, 29/43 (67.4%) had remained in care or transferred out to adult ART care while 14 (23.3%) had disengaged from the programme by the sixth week postpartum period. Demographic characteristics were similar between mothers who remained in care and those who defaulted. Descriptive characteristics of women stratified by their final retention status in the primary analysis are displayed in Table 5-4.

Table 5-4 Socio-demographic characteristics of women stratified by final retention status

	Remained in care		Disengaged	
	N	%	N	%
<b>Number of women</b>	<b>29<sup>9</sup></b>	<b>67.4</b>	<b>14<sup>10</sup></b>	<b>32.6</b>
<b>Demographics</b>				
<b>Age (in years)</b>				
<20	1	3.4	1	7.1
20-30	8	27.6	7	50.0
31-40	18	62.1	5	35.8
>40	2	6.9	1	7.1
<b>Level of education</b>				
Primary or less	6	20.7	5	35.7
Secondary or higher	20	68.9	5	35.7
Not Recorded	3	10.4	4	28.6
<b>Employment</b>				
Unemployed	20	68.9	8	57.1
Self employed	3	10.4	0	0.0
Formal	2	6.9	1	7.1
Part time	2	6.9	1	7.1
Not recorded	2	6.9	4	28.7
<b>Marital status</b>				
Single	6	20.7	3	21.4
Married	17	58.6	7	50.0
Divorced	0	0.0	1	7.1
Cohabiting	4	13.8	3	21.4
Not recorded	2	6.9	0	0.0

<sup>9</sup> The denominator for calculating the demographics of the woman who remained in care was 29.

<sup>10</sup> The denominator for calculating the demographics of the women who disengaged was 14.

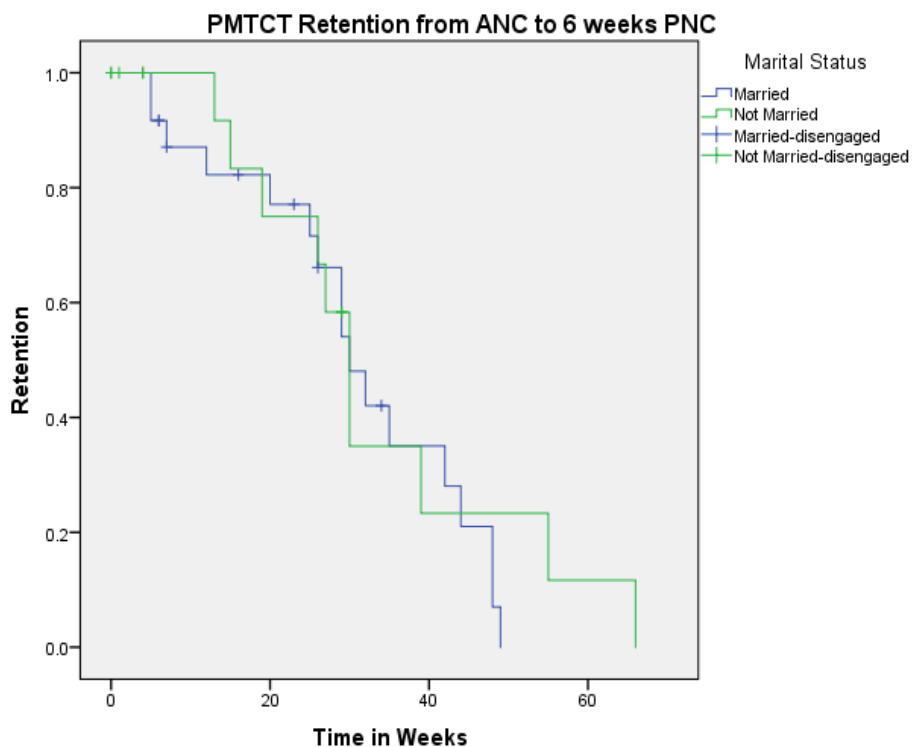
### 5.1.6 HIV-infected women's characteristics and survival time in the PMTCT Programme

Retention times were estimated to determine how the socio-demographic characteristic of the HIV-infected women influenced retention. Three socio-demographic characteristics - marital status, employment status, and education were measured. A total of sixty weeks of observations were done during the study period.

#### 5.1.6.1 Estimates of retention time by HIV-infected mothers' marital status

The mean estimated retention time (LTR) was 31.0 weeks (95% CI 24.7-37.3) for married women compared to 34.0 weeks (95% CI 23.3-44.7) for women in the study who were not married. Statistical differences could however not be determined due to lack of power. The retention plot in Figure 5-2 shows that those who were not married stayed longer in the programme compared to the women who were married.

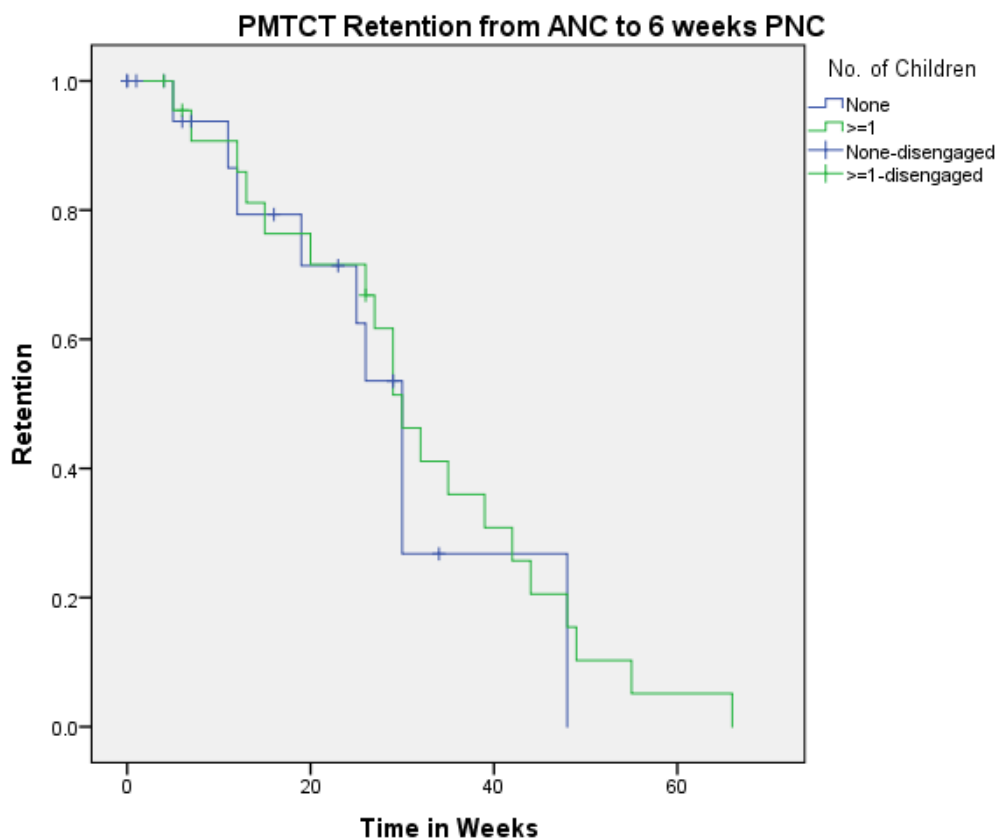
Figure 5-2 The Kaplan Meier curve of retention for the PMTCT period by marital status



### 5.1.6.2 Estimates of retention time by HIV-infected mothers' parity

The retention plot based on the parity on the participants showed that multiparous women stayed longer in the programme compared to nulliparous women. The mean estimated retention time (LTR) is 28.9 weeks (95% CI 20.5-37.3) for nulliparous women compared to 31.7 weeks (95% CI 24.6-38.7) for women in the study who were multiparous. The median time of retention is 30 weeks regardless of parity. However, a differences could not be established due lack of statistical power of the study. Figure 5-3 presents a retention plot below.

Figure 5-3 Kaplan Meier curve of retention for PMTCT period by parity

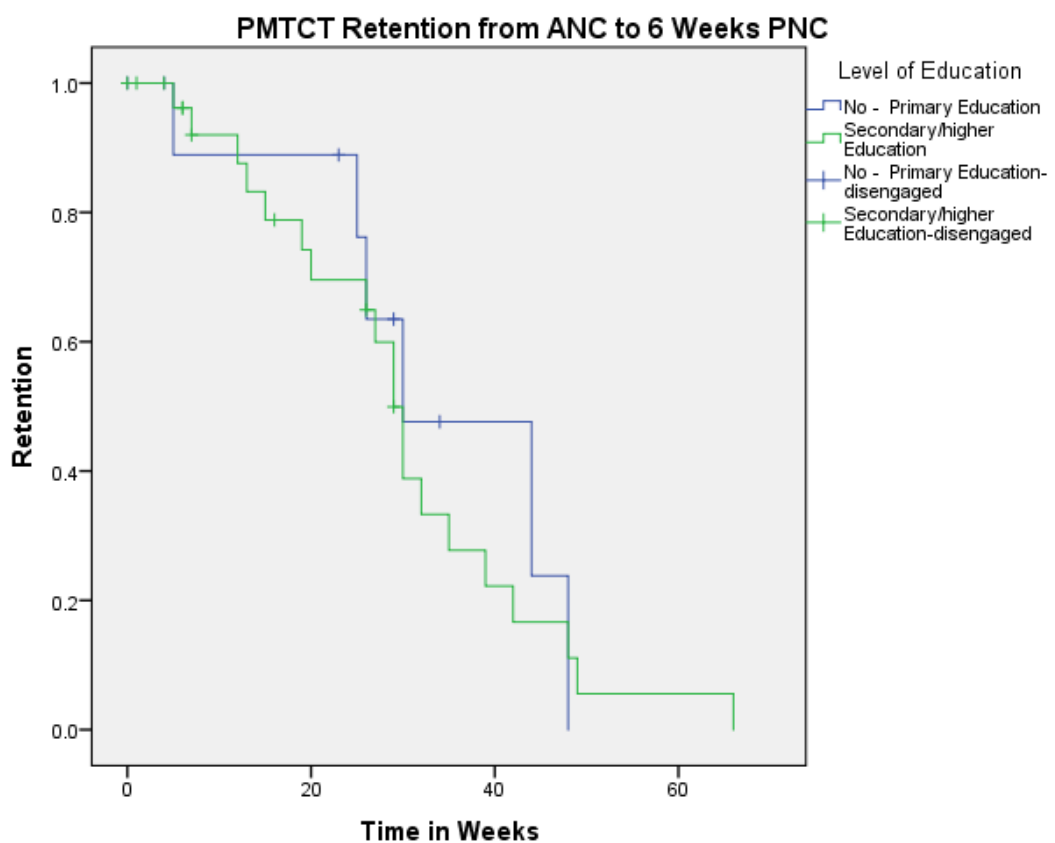


### 5.1.6.3 Estimates of retention time by HIV-infected mothers' level of education

The mean estimated survival time (LTR) was 30.1 weeks (95% CI 23.6 – 36.5) for women with no- or up to primary education compared to 33.7 weeks (95% CI 23.4 - 44.0) for women with secondary and/ or tertiary education.

However, a statistical differences could not be determined due to lack of power. The survival plot for the level of education is presented in Figure 5-4 below.

Kaplan Meier curve of retention for PMTCT by the level of education



### ***5.1.7 Conclusion***

Majority of women who test positive for HIV in pregnancy are in the early stages of the infection, usually WHO stage I and II. Disengagement from the programme occurs at all stages of the cascade but more frequently in the antenatal period. The socio-demographic characteristics of the infected mothers were similar to that of those who disengaged, hence could not be a predictor for retention. The retention plots portray a longer duration of retention among women who were single, had children before the HIV diagnosis and formal education.

## **5.2 SECTION B FINDINGS OF THE APPRECIATIVE INQUIRY**

This section presents the findings of the Appreciative Inquiry process. The profile of the participants is presented under 5.2.1. Thereafter, the findings and themes that emerged from the analysis of the HIV infected women's narratives, the nurses' conversations and generated documents as well as the researcher's field notes are presented under 5.2.2. The findings are qualitative in nature.

### ***5.2.1 Profile of participants who engaged in the Appreciative Inquiry process***

Two categories of participants were enrolled into the Appreciative Inquiry process. This sub-paragraph presents the profile of the HIV-infected mothers (5.2.1.1), and midwives and CHNs (5.2.1.2).

#### **5.2.1.1 Profile of the mothers**

Twelve mothers engaged in the Initiate sub-phase 1 of the AI process. The names are pseudonyms that were chosen by the participants for the purposes of the study. The youngest of the mothers was 18 years while the oldest was 38 years old. In this study, half of the participants (6/12) were married women. An equal proportion of the women (6 /12) had no/primary education, and secondary education or higher. With the exception of three women; one unemployed and two students, the other mothers (9/12) were self-employed. Eight of the mothers had disclosed their HIV status to either their husbands or to an immediate family member. The profile of the mothers is presented in Table 5-5 below.

Table 5-5 Profile of the mothers engaged in the AI process

Pseudonym	Age	Parity	Marital status	Education	Employment status	Disclosure status
Jane	32	2	Single	None	Petty trader	Not disclosed
Mary	34	3	Divorced	Primary	Petty trader	Not disclosed
Rejoice	27	2	Married	Vocational	Caterer	Not disclosed
Vera	18	1	Single	Secondary	Unemployed	Disclosed
Irene	35	1	Married	Secondary	Seamstress	Disclosed
Felicia	25	2	Married	Tertiary	Student	Disclosed
Lydia	38	4	Married	Primary	Petty trader	Disclosed
Blessing	20	1	Single	Secondary	Student	Disclosed
Comfort	27	2	Married	Vocational	Caterer	Disclosed
Grace	26	1	Married	Primary	Seamstress	Disclosed
Mercy	36	5	Widow	Primary	Petty trader	Not disclosed
Esther	33	4	Single	None	Petty trader	Disclosed

### 5.2.1.2 The profile of the midwives and community health nurses

A total of 12 healthcare professionals, eight midwives and four CHNs participated in the AI sessions. About 41.7% (5/12) of the participants were between the ages of 30-39 years. The participant with the most professional experience had worked as a community health nurse for 31 years. The longest serving participant in the PMTCT programme had worked as a counsellor for 11 years. The cumulative years of experience of the participants in the PMTCT programme was 64 years. The profile of the midwives and CHNs is presented in Table 5-6 below. Pseudonyms are used to represent the participants for the purposes of the study.

Table 5-6 Profile of midwives and Community health nurses

Pseudonym	Age	Profession	Professional experience (years)	Unit	Experience in PMTCT (years)
Baaba	33	Midwife	8	ANC/PNC	2 6/12
Araba	31	Midwife	7	ANC/PNC	3
Ekuba	30	Midwife	7	ANC/PNC	2 6/12
Adwuba	45	Midwife	23	ANC/PNC	13
Ekua	28	Midwife	4	Labour	4
Yaa	29	Midwife	3	Labour	3
Esi	56	Midwife	16	Labour	8
Afua	43	Midwife	12	Labour	5
Akosua	56	CHN <sup>11</sup>	31	Public health	5
Ama	43	CHN	19	Public health	11
Adwoa	31	CHN	7	Public health	4
Abena	34	CHN	9	Public health	3

### 5.2.2 Themes from the Appreciative Inquiry process

The themes addressed the participants' experiences of giving and receiving HIV care through the PMTCT programme, best experiences while engaged in the programme, their motivation for continuously engaging in the PMTCT programme, as well as their wishes for service delivery within the PMTCT programme. The themes captured the essence and meaning of the participants' narratives. Four main themes emerged from the data:

- Transitioning into a 'new' woman
- Journeying with committed companions
- Glimpses of Triumph
- Tying up the loose ends: A daring new path

<sup>11</sup> CHN is an abbreviation of Community health nurses

The themes and the sub-themes are presented in Table 5-7. The findings are subsequently presented according to the 4I phases of the Appreciative Inquiry process: Initiate (5.2.2.1), Inquire (5.2.2.2), Imagine (5.2.2.3) and Innovate (5.2.2.4).

Table 5-7 Themes, sub-themes and categories

Phase	THEMES	SUB THEMES	CATEGORIES
<i>Initiate phase</i> (5.2.2.1)	THEME ONE: Transitioning into a 'new' Woman (5.2.2.1.1)	Celebrating health (5.2.2.2.1)	-
		<ul style="list-style-type: none"> <li>▪ Dealing with disbelief (5.2.2.1.1.2)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Denial (5.2.2.1.1.2.1)</li> <li>▪ Double sure: Confirmatory test (5.2.2.1.1.2.2)</li> <li>▪ Shock and tears (5.2.2.1.1.2.3)</li> </ul>
		<ul style="list-style-type: none"> <li>▪ Shattered dreams (5.2.2.1.1.3)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Hopelessness (5.2.2.1.1.3.1)</li> <li>▪ HIV positive: A death sentence (5.2.2.1.1.3.2)</li> <li>▪ A constant risk to others (5.2.2.1.1.3.3)</li> </ul>
		<ul style="list-style-type: none"> <li>▪ Journey of hope (5.2.2.1.1.4)</li> </ul>	<ul style="list-style-type: none"> <li>▪ A second chance: Treatment is available (5.2.2.1.1.4.1)</li> <li>▪ Negotiating disclosure (5.2.2.1.1.4.2)</li> <li>▪ Coping with HIV as a chronic disease (5.2.2.1.1.4.3)</li> <li>▪ My faith, the anchor of my hope (5.2.2.1.1.4.4)</li> <li>▪ Optimism for the future (5.2.2.1.1.4.5)</li> </ul>
<i>Inquire phase</i> (5.2.2.2)	THEME TWO: Journeying with committed companions (5.2.2.2.1)	Engaged nurse-patient Relationship (5.2.2.2.1.1)	<ul style="list-style-type: none"> <li>▪ Committed to confidentiality (5.2.2.2.1.1.1)</li> <li>▪ Building a trusting relationship (5.2.2.2.1.1.2)</li> <li>▪ Approachable and accessible staff (5.2.2.2.1.1.3)</li> <li>▪ Constant encouragement (5.2.2.2.1.1.4)</li> </ul>
		Two is company, more even is better (5.2.2.2.1.2)	<ul style="list-style-type: none"> <li>▪ Involving others (5.2.2.2.1.2.1)</li> <li>▪ Supported to provide supportive care (5.2.2.2.1.2.2)</li> </ul>
		Celebrating health (5.2.2.2.2.1)	<ul style="list-style-type: none"> <li>▪ My baby is HIV negative (5.2.2.2.2.1.1)</li> <li>▪ A 'healthy' mother (5.2.2.2.2.1.2)</li> </ul>
		The empowered client (5.2.2.2.2.2)	<ul style="list-style-type: none"> <li>▪ Empowered through knowledge sharing (5.2.2.2.2.2.1)</li> <li>▪ Empowered to actively participate (5.2.2.2.2.2.2)</li> </ul>
THEME THREE: Glimpses of triumph (5.2.2.2.3)	Changing perceptions about midwives and nurses (5.2.2.2.3)	Midwifery and nursing care in PMTCT: A different experience (5.2.2.2.3.1)	<ul style="list-style-type: none"> <li>▪ The new rhetoric about midwives and Nurses (5.2.2.2.3.2)</li> </ul>
		Continuity of care (5.2.2.2.3.1)	-
		Continuity of carer (5.2.2.2.3.2)	-
		Conducive service delivery environment (5.2.2.2.3.3)	-
THEME FOUR: Tying up the loose ends: A daring new path (5.2.2.2.3)	Engaging the religious (5.2.2.2.3.4)		-
			-

### 5.2.2.1 Initiate phase

Findings in this phase of the study focus on the HIV infected women's experiences in the PMTCT programme from the time of HIV testing and diagnosis until the mothers were transferred to adult ART care. It begins with their experiences with testing positive to HIV in pregnancy at ANC, followed by their enrolment in the programme and how they negotiated access to care throughout the PMTCT cascade until the Early Infant Diagnosis (EID) was done for their babies at six weeks. The mothers' life stories are presented in Appendix P. The findings were presented as a catalyst for the AI process held with the midwives and CHNs. One theme emerged in this phase: Transitioning to the 'new' woman (5.2.2.1.1).

#### 5.2.2.1.1 THEME ONE: Transitioning to the 'new' woman

The study revealed mothers who, early on thought of HIV as a distant phenomenon, were then confronted with reality of being HIV positive. All the women remembered the exact moment that they received the test results. The mothers reported varied emotional experiences after being informed of their HIV positive diagnosis. The experience was irrespective of their prior preparation or lack of it before the HIV test. Acceptance of a positive diagnosis was a process that evolved over time. The intensity of the emotions they experienced when informed of being infected with HIV reportedly decreased with time. The narratives showed the phenomenon of transitioning for the women who initially experienced hopelessness, fear and suicidal thoughts when informed of their diagnosis become empowered to live healthily with HIV. Four sub-themes were developed under this heading; Pregnant and healthy (5.2.2.1.1.1), Dealing with disbelief (5.2.2.1.1.2), Shattered dreams (5.2.2.1.1.3) and Journey of hope (5.2.2.1.1.4).

##### 5.2.2.1.1.1 *Pregnant and healthy*

Pregnancy was welcoming news for most of the participants in this study. The mothers expressed great expectations for their unborn children. The babies represented victory over infertility, a bond between couples and a future. A participant shared this experience:

*“I found out I was pregnant shortly after our wedding and my husband was also happy because children strengthen the bond between couples and they also expand the family. In our culture, if you don’t have children, you always have problems with your in-laws. Many marriages have been broken because of childlessness. So that is why when I found out I was pregnant we were happy.”* Grace

Several of the participants reported being healthy at antenatal booking. Thus, their attendance at the clinic was for confirmation of the pregnancy and to secure care for the mother. HIV testing was not a priority for most of the participants. Only a few had prior experience with HIV testing in their previous pregnancies. For most of the mothers, HIV testing, and counselling was accepted because they believed it was a protocol that needed to be followed by all women at antenatal booking. A statement by a mother buttressed this point:

*“Initially, I didn’t want to do it, but she insisted and said it was required of all pregnant women so that they can protect the child. So, I said aaaah ok.”*  
Grace

The narratives give instances of how pre- and post-test counselling<sup>12</sup> had been done. Several of the mothers recalled they were told it was essential to test for the sake of the child with no reference to the possible test result and how it would impact their lives. For some mothers, the manner in which the pre-test counselling was done ignited fear, unease or indifference towards HIV testing. In the case of Blessing, she reported that her attention was drawn to her risk of HIV infection during counselling. She said:

*“When I came back, she [midwife] told me that I had to do the HIV test to be sure my baby was not infected. So, she took me to the room in the corner and pricked my hand with the needle. She asked me my knowledge on HIV, and when I told her, she asked me what if you test positive and I told her I don’t*

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<sup>12</sup>The use of the term ‘counselling’ in the participants’ narratives usually referred to information giving by the health professionals. This was entirely the opinion of the participants. The researcher acknowledges that counselling entails more than information giving. This is discussed in 6.3.2.1.1.

*have it... then she said if you are pregnant then you may have it. That was when I became scared.”* Blessing

The effectiveness of counselling was dependent on the attitude of the counsellors and the pregnant women during the counselling session. A previous HIV negative result in pregnancy and the perception of low risk to HIV were associated with indifference to the counselling session. Narratives from the mothers revealed hurried counselling sessions by the counsellors and disinterest on the part of the clients. This statement of Felicia denotes this:

*“I had gone through this test before with my first pregnancy, and I knew that if you were negative, they usually said “congrats, you are negative” and inform you about steps to take to remain negative. Honestly, I didn’t even hear anything she said.”* Felicia

Counselling underscored the clients’ preparedness or otherwise for the outcome of the test and most importantly their reaction after that. Thus, all the participants did not easily accept a positive HIV result. It represented the beginning of the transition process of the women from their initial position of nonchalance about HIV to live healthy lives with HIV.

#### *5.2.2.1.1.2 Dealing with disbelief*

Pre-and post-test HIV counselling was offered in this facility as indicated by national policies on HIV testing (GHS/MOH, 2014). However, inadequate counselling before testing was evident in the mothers’ narratives. The mothers accepted HIV counselling and testing as fulfilling a requirement for all pregnant women. None of the mothers had expected a positive test result. Most of the mothers were informed of the positive HIV result by the midwives a few minutes after the test. Two participants were referred to another nurse who broke the news to them while another read the results from the test strip. A positive result was mostly a shock and a blow to their expectations. The mothers’ reactions to the initial positive test is presented under Denial (5.2.2.1.1.2.1), Double sure: Confirmatory test (5.2.2.1.1.2.2) and Shock and Tears (5.2.2.1.1.2.3)

### 5.2.2.1.1.2.1 Denial

Denial as a defence mechanism is usually temporal and employed as a means of coping with the unpleasant and unwelcomed positive results (Nicol, 2011). In this study, as the news of being infected with HIV was unexpected and unwelcomed, denial was the reaction of most of the participants.

The physical reactions of the women to the news of their diagnosis portray the enormity of the diagnosis. Denial was depicted by covering their ears and verbally refuting the diagnosis. Blessing did not accept the result that revealed she was HIV positive and denied the diagnosis as true:

*“...it is not true...it cannot be true... I immediately covered my ears with my hands and refused to accept that I was infected.”* Blessing

A positive HIV diagnosis does not only affect the emotions of the client; there are physical effects too. Although some mothers blocked the thought, it unconsciously impacted their daily activities such as sleep and feeding. This statement by Irene revealed this fact:

*“No, I did not accept the news at that instance. I did not believe it. Even when I went home, I was very disturbed. I thought so much about it and could not sleep. I was really disturbed... So, the next month, when I went for antenatal, I had lost weight.”* Irene.

The denial of a positive HIV result was mainly due to the mothers' opinion of lack of perceived risk associated with being faithful to one sexual partner at a time, being religious and not having signs of ill-health at the time of the diagnosis. In the words of Comfort:

*“I have been with only one man, my husband since I married... I have been faithful to him...”* Comfort

Denial affected most of the women's decisions to accept enrolment in the PMTCT programme. Some women reported not returning to the clinic again for a period, while others requested for time to assimilate the diagnosis and to accept what it meant for their lives before initiating treatment.

### 5.2.2.1.1.2.2 Double sure: The confirmatory test

A confirmatory test was vital as it buttressed the accuracy of the initial test and established that their positive HIV result was accurate. Almost all the participants reported they had a confirmatory test usually done in the laboratory before they accepted the reality of their definite HIV diagnosis. Like most of the participants, Felicia reported she undertook a confirmatory test which brought finality to the outcome of her HIV test.

*“I did a confirmatory test the same day. She [midwife] directed me to the lab. I had to wait for a while before the result was returned to me. It confirmed the earlier results. I was positive!” Felicia*

A positive confirmatory test aided the transition of the participants from their state of denial to reluctant acceptance that usually resulted in shock and depression. For others, however, a single confirmatory test in the same facility was not convincing. Some of the participants moved from one hospital to another or private laboratory facilities for a retest to be doubly sure the results were accurate. Some participants reported undergoing a third or fourth HIV test. That showed a probable lack of trust in the health system, deficiency of the counselling offered or part of the denial response.

*“I tested positive during my second ANC visit at hospital A, but I did not accept to be enrolled in care. I told them that I needed time to accept the diagnosis, but I went to hospital B the very next day and reported at ANC without informing them that I had visited another hospital. When the test was done, and I was positive I just sat silently feeling numb, so the midwife told me to go to the lab for a confirmatory test...it was when the lab result came out positive that I accepted the I had the virus...” Esther*

The phenomenon of “hospital shopping” was reported by other participants. Mary did the test in two hospitals; the first being where her HIV positive child was admitted and the second when she reported at ANC in another hospital. Grace also did the test in a hospital while on admission but took steps to confirm her positive diagnosis in a private laboratory for a retest although she had already done the second test at the ANC. The dread and stigma that is attached to a positive HIV

diagnosis influence the decision of the participants to undergo a confirmation of the initial test result before they accept their fate.

### 5.2.2.1.1.2.3 Shock and tears

Participants reported strong emotional reactions at the news of a positive HIV result. Almost all the mothers remembered the exact moment they were informed of the HIV positive diagnosis. Several of the mothers mentioned that they experienced feelings of devastation and shock when informed of a positive HIV status. A mother said:

*“When I was told I was positive I was shocked. I was devastated! I did not believe it. I sat there silently for some time. Truly, I felt that I was already dead...”* Jane

The participants’ shock when they finally accepted the HIV positive result was not minimized by the number of times they received a positive result. Thus, although most clients reportedly denied the outcome of the first test, their previous knowledge of the result did not minimise the intensity of their reactions when they finally accepted the result and understood the import of the result on their lives. The news of an HIV positive result was reported to be paralysing and numbing. Esther recalled:

*“I walked slowly from the office where the test was read to me, through the corridor where the other women were sitting, waiting to be tested...my mind was blank... I remember as I descended the stairs, the midwife run after me and held me by the waist and said... Madam, we have to sit and talk... I guess I was in shock...”* Esther

The means by which mothers found out their HIV positive result also contributed to the intensity of the reaction they experienced. Chancing upon the positive test results without any post-test counselling intensified the emotions of devastation Mary had. Although being informed by the nurse also elicited an intense reaction, their calming presence and reassurances were welcoming and beneficial to the client. On reading the positive test result, Mary recounted:

*“When she did the test, she placed it in a way that I could see the results myself...So when the two lines appeared on the test, I just knew I was finished. I cried... I was shocked eeh! (EXCLAMATION) How did I get this*

*disease? Many things run through my mind, but she kept on talking and talking. Truly I did not pay much attention.” Mary*

Crying was the one act that allowed them to articulate their distress as they were informed of the news they most dreaded and never expected to receive in the first place. Rejoice reported that prolonged crying expressed her emotions:

*“When she told me that I had the HIV; I cried so much, I was devastated. I couldn’t even answer the questions she asked; I just kept on crying...”*

Rejoice

Irene reported a similar reaction:

*“I wept. I was devastated... In fact, when they broke the news to me, I wept bitterly.” Irene*

The narratives revealed that crying was a typical response associated with the realization and accepting the diagnosis of HIV positive in pregnancy.

### **5.2.2.1.1.3 Shattered dreams**

Most of the participants said they had come to the hospital because they were pregnant and not because they were ill. Being pregnant instils in mothers a sense of a future and dreams of an extension of their families. They came in the hope of confirming their pregnancy and receiving care towards delivering healthy babies. Thus, receiving a positive HIV result was a blow to the dreams of the bright future the women had. The feeling of hopelessness, fear of imminent death and being a source of risk to the unborn child and even to other people contributed to the perception that their lives had ended with a diagnosis of HIV. That may be a result of the lack of accurate information about HIV in the communities these women resided. Findings under this subtheme are presented as follows: Hopelessness (5.2.2.1.1.3.1), HIV positive: A death sentence (5.2.2.1.1.3.2), and A constant risk to others (5.2.2.1.1.3.3)

#### **5.2.2.1.1.3.1 Hopelessness**

The mothers’ narratives revealed demoralisation in the face of a definite HIV diagnosis. Hopelessness in this instance referred to giving up dreams with the assumption that the future was bleak. Most of the mothers who previously had

expectations for their lives and that of the unborn child reported feeling dejected. Their diagnosis caused some mothers to reflect on life and how they perceived the world and their existence.

*“... then I realised that the world was not... the world, it changed my mind about the world.”* Lydia

Things about life that some mothers felt were worthwhile lost its value in the face of the diagnosis. In the case of Rejoice, the joys of getting pregnant and the reward of having a baby after many years of waiting were lost with the HIV diagnosis.

*“When I suspected I was pregnant, I was very happy. I have been married to my husband for about two years without getting pregnant. So, when I realised that I was pregnant, my prayers had been answered... I had great expectations for her [unborn child]. You see, she [unborn daughter] had cleared my shame with my in-laws. ... When she [midwife] told me that I had the HIV; I cried so much, I was devastated.”* Rejoice

The diagnosis affected various aspects of the infected mothers' lives that had pointed to the desired future. For instance Blessing, a student dropped out of school because of her diagnosis. Although the diagnosis did not have any effect on the schooling of the respondent, she was demoralized and felt that there was no need to pursue her education as the diagnosis meant an end to her prospects.

#### **5.2.2.1.1.3.2 HIV positive: A death sentence**

All twelve mothers of the mothers felt they had nothing to live for anymore. That may be because of the perception that being HIV positive meant imminent death. The thoughts of death and suicide that were expressed by some participants showed the finality associated with a positive HIV diagnosis. Accepting and dealing with the HIV diagnosis in pregnancy was a big challenge to most participants. In the case of Blessing who was a student, she contemplated suicide as an end to her woes:

*“I am just a student... finding out I was pregnant was a blow in itself but finding out I was HIV positive at the antenatal felt like the end of my life... I felt dead...dead... how could this happen to me?”* I decided to end it all...”

Blessing

The enormity of the HIV diagnosis pushes the women towards social isolation and suicidal thoughts. Lydia also recalled feeling dead inside and recalled whispering her dread through her tears:

*“When she informed me that I was positive, I felt numb inside, I knew I was dead I remember whispering through my tears, I am dead, I am dead, I am dead... .. I thought that the disease would kill me. So, I felt that if I even died where nobody knew me, it was better. I thought that ending my life and that of the fetus was a better decision. So, I decided to commit suicide. That was how I felt initially.”* Lydia

Previous experience with suffering and death of a spouse associated with AIDS reinforced the perception that HIV infection meant imminent death. This perception was captured in an account of Mercy, whose husband had died from AIDS leaving behind three children:

*“When my husband was admitted he was seriously sick; coughing and sweating and had diarrhoea... he was in so much pain... aaah, I was told he had AIDS and shortly after his [death] ... I also have AIDS. So, I will also die too...”* Mercy

The narratives revealed the perception that a definite HIV diagnosis is a death sentence for both the mother and child. This perception contributed to the seriousness of the diagnosis. The mother’s concern for the future of her children, even when she felt the diagnosis robbed her of the possibility to be a part of their lives reveals the pain and despair that the definite HIV diagnosis brought to the participants.

### **5.2.2.1.1.3.3 A constant risk to others**

A definite HIV test result in pregnancy was reported to kindle guilt in the pregnant woman for exposing the child to the risk of HIV infection. Most of the participants reported the fear of vertical transmission and also posing a risk to people with whom the HIV-infected mothers interacted. The fear heightened because of the inaccurate information about the modes of transmission of HIV and the knowledge gaps on the availability of treatment to prevent vertical transmission the women had subscribed to before their counselling. Although pre- and -post-test counselling sought to correct

the misconceptions, eight mothers confessed that they did not pay attention to the counselling because they were emotionally distraught at the time.

*“She kept on giving me advice and counselling me. Truly I didn’t even hear anything she said.” Felicia*

The narratives revealed that most of the mothers battled the fear of infecting their unborn children. Mary recounts her experience of losing her eldest daughter to AIDS:

*“The older nurse at the paediatric ward informed me that my daughter was HIV positive and that they had initiated her treatment... That was a big blow. Where did my daughter get this disease? ... So, I was scared I would infect this [unborn] child too, very afraid.” Mary*

The death of one’s child as a result of HIV infection acquired through vertical transmission is painful and carries with it, guilt. Thus, the fear of vertical transmission was real. Another participant, a mother of three and a trader reported the fear of infecting her children and customers, which resulted in abandoning her fruit-selling trade.

*“I wanted to end it...end it all... I thought hard about the issue and felt that I could infect my children if I cut myself while cooking or even slicing the fruits that I sold. I also thought about the future of the baby inside me, and I felt it was not fair to be a source of risk to these innocent children... I felt I had had a chance at life and it was not fair to cut their chance short... there is nothing, nothing in this world for me anymore.” Lydia*

The data revealed that the presumed risk affected their social relationships as some mothers reported isolating themselves from people. Lydia contemplated changing her trade as a fruit seller to selling used clothes as a precautionary measure against infecting her customers. For those who did not know the HIV status of their partners, fear of infecting them caused them to withdraw from conjugal activities.

#### *5.2.2.1.1.4 Journey of hope*

The journey of hope started when the midwives provided post-test counselling and encouraged the infected women to enrol in the PMTCT programme. The assurance of maintaining their health and a possible healthy child amidst the fear of vertical

transmission was refreshing news to all the women. Through counselling, the HIV-infected mothers' transition from hopeless to hopeful women who believed they could live healthy lives with HIV. Hope stemmed from the knowledge that treatment was available (5.2.2.1.1.4.1) for managing the HIV infection. Findings are presented under the sub-themes Negotiating disclosure (5.2.2.1.1.4.2), Coping with HIV as a chronic disease (5.2.2.1.1.4.3), My faith, the anchor of my hope (5.2.2.1.1.4.4) and Optimism for the future (5.2.2.1.1.4.5).

#### **5.2.2.1.1.4.1 A second chance: Treatment is available**

Several participants mentioned that it was a relief to know that drugs were available to protect their unborn babies from being infected with the HIV. The participants expressed a sense of hope when the midwives and counsellors told them about the opportunity to protect their children from being infected and maintaining their health. The children represented a future that initially felt bleak with the HIV positive diagnosis. Having a negative baby also removed the guilt associated with infecting an innocent child. Exploration of the narratives revealed that being informed that children of other infected mothers were living HIV free lives was a source of hope for the newly diagnosed HIV positive pregnant woman. Jane reported that, although she was devastated by the diagnosis, what was important was the further information that the baby could be healthy:

*“She told me that we had to plan for the child, how we can ensure that the child will not get the disease... She told me to agree to take the drugs to reduce the viral load so that the baby will not get infected... She even used other people as examples, even a nurse who tested positive in pregnancy and decided to take her treatment and now her child is 20 years and still negative.”* Jane

The knowledge that they could access the drugs immediately was welcoming for most of the mothers. The urgency in preventing vertical transmission was found to be associated with the infected mothers' desire to atone for the guilt they had for exposing the child to the risk of HIV as well as contributing to a worthy cause of saving the life of an innocent child.

*“I started the treatment the same day because I felt that it was not the baby's fault and I have put her at risk. So, I wanted to do everything to make sure*

*that she did not get infected. So, I can say that now I have cleared my conscious...” Grace*

For Mary, who had lost her eldest child to HIV while pregnant with the current child, the treatment provided the opportunity to make things right.

*“She [Community Health Nurse] talked about protecting the unborn child from getting infected, and that my eldest child would have been negative if I had known my status and had taken treatment when I was pregnant. She told me of the need to take the treatment, and because I recall my eldest daughter had recovered and become well when I gave her the treatment, I decided to try the treatment for the period when I was pregnant.” Mary*

The knowledge that the drugs were free and could be accessible at the hospital was a source of hope for some participants who were constrained financially.

*“It is very beneficial. The drugs are free, so even poor people like me can stay healthy with this disease.” Mercy*

The accessibility of the drugs to people with different socioeconomic levels was a source of reassurance for the mothers.

#### **5.2.2.1.1.4.2 Negotiating disclosure**

The narratives also revealed that the decision to disclose or conceal their HIV diagnosis was an important phase in the transitioning process. It propelled the mothers from being fearful and isolated to being confident enough to seek support and assistance from others. In most instances, the decision to disclose or otherwise was made by the infected woman after counselling. However, for women who missed appointments, who could not provide a valid address or in instances of teenagers like Blessing and Vera, who had tested positive to HIV in pregnancy, they were required to present treatment supporters, which required disclosure, before initiation of treatment. Blessing said:

*“I wanted to tell my grandmother about the pregnancy but not the HIV... I knew she would be angry about the pregnancy, but I didn't know how she will react to the news that I had HIV... but the midwife insisted that I need a treatment supporter before I could get the drugs, so I had no option...”*

Blessing

The choice of whom to disclose to was dependent on the infected mothers' assessment of the acceptance and reaction of the people who mattered most. From the narratives, most participants who chose to disclose their HIV positive status confided in the spouses or intimate partners. Some participants disclosed their status to their husband immediately when they had confirmation and reported spousal support concerning reminders of hospital appointments and supply of baby's drugs. Felicia, on the other hand, received initial spousal support which was later withdrawn when he tested negative for HIV. However, some mothers chose other family members including the grandmothers, mothers, and fathers whom they felt will provide the needed support.

*"She [nurse] counselled me and suggested that I disclose to my mother so that she will serve as my treatment supporter. So, when I got home, I thought hard about it and decided to tell my grandmother...My grandmother was very supportive and encouraged me... She [nurse] talked about the need to adhere to the treatment and the role my grandmother had to play to assist me to adhere to the treatment. After the discussion, she helped us register."* Vera

A few of the participants disclosed their status as a means of gaining treatment supporters and a confidante to ease the weight of loneliness the diagnosis brought. That is captured in a statement by a mother:

*"Initially I did not want to tell anyone... I confided in my aunt. She is my confidant and knows all my secrets. She is very supportive. She frequently enquires about my health and the treatment. Sometimes when I have to go for my treatments, she is always available to babysit for me."* Irene

Because of the support gained, to some mothers:

*"I think disclosing to her was the best decision... (Smiles)..."* Blessing

Others, however, did not disclose for fear of stigmatization and other social consequences such as abandonment, divorce, domestic violence and fear of blame as the source of the infection. Grace did not disclose for fear of being blamed as the source of the infection but later realized that the husband was a known HIV client who had been on treatment for seven years but had defaulted. She reported support when she found out that he was also positive. Rejoice who is married but has a strained relationship with her in-laws, decided not to disclose her status to her

husband for fear of domestic violence and the risk of his informing her in-laws without her consent. She explained that:

*“My husband is quick-tempered. So, I have not told him. But he is there for us. My in-laws are at loggerheads with me. We don’t even talk. But my husband has a good relationship with them, so if something happens, he goes and informs them. That is why I have not informed my husband.”* Rejoice

Esther also reported fear of abandonment by her intimate partner as the reason for her non-disclosure, as they are cohabiting and not married.

#### **5.2.2.1.1.4.3 Coping with HIV as a chronic illness**

HIV is classified as a chronic illness (Deeks, Lewin, & Havlir, 2013). It, therefore, requires lifelong management. Unlike other chronic diseases, however, stigmatization of persons living with HIV is common because unprotected sex with an infected person is the most common mode of transmission (GHS/MOH, 2014) in a large number of cases. Hence, HIV infection is associated with promiscuity. The narratives revealed strategies employed by infected mothers to cope with living with HIV. These included understanding the chronic nature of the disease by seeking knowledge about the disease and its management, as well as, making friends with the health workers. Educating clients that HIV was a chronic disease just like diabetes and hypertension was found to reduce the anxiety associated with the positive HIV diagnosis greatly. Jane reported that understanding that HIV was a chronic disease was reassuring:

*“...You see, it is like diabetes, they [diabetics] will also take the treatment for life, so that is how life is. Moreover, anybody can die at any time, someone in my area died in an accident, but I am still here. So, such is life...”* Jane

To the mothers, routinisation of the intake of the medication as a daily activity was an important way of coping with the disease. A few mothers reported experiencing adverse drug reactions that ranged from mild to severe. However, accepting that treatment was lifelong and required adherence on their part to remain healthy was essential in coping with the disease. Grace explained that:

*“We all take the drugs after breakfast and in the evening when we return home from work. We don’t argue about it anymore because we live in a*

*compound house and we don't want people to hear about it, so that is it."*

Grace

Lydia also said that:

*"So, I take it twice daily. If I have to travel very early in the morning and I have not eaten, I usually take the drugs along with me. But even if I forget to carry my drugs with me, I usually take the evening dose."* Lydia

Managing the HIV infection as a chronic disease required adjusting their lifestyles and other social engagements to allow for meeting medical and treatment refill appointments. This required negotiation with health workers for scheduling appointments. For instance, Blessing had to negotiate with the pharmacist for scheduling of her refill appointments after school as she was still a student.

#### **5.2.2.1.1.4.4 My faith, the anchor of my hope**

Most of the infected women reported being religious. Thus, the belief that HIV was a spiritual disease and could therefore be averted by God was mentioned by some mothers. The perception that being prayerful and not promiscuous was a mode of prevention of HIV infection could be gathered from the narratives. The role of the faith leaders especially the pastors in promoting this belief was also identified in the study. In the words of Esther:

*"As for me I am a prayerful person, I attend prayer meetings a lot on the field and I have heard that it [HIV] can be bought and spread by our enemies. You know the witches, so I prayed against it constantly and thought that God will never let that happen to me, that is why I still don't accept it. My pastor confirmed it that the devil was at work, but God is on my side. So, I will receive divine healing."* Esther

The mothers' faith in God was a strong source of hope and motivation during their transitioning into women living healthily with HIV. This belief influenced the health-seeking behaviours of some infected mothers and their family members who acquired HIV or AIDS. In her case, Mary sent her daughter to the church when her daughter started gasping for breath although she was a known HIV positive client. Similarly, Mercy's husband sought divine healing at the prayer gardens as the first

option before coming to the hospital. Both persons living with HIV died shortly upon arrival at the hospital.

With continuous engagement in the health system, the women understood that accepting treatment was an act of faith and not necessarily an act of disbelief in the divine healing ability of God. From the narratives, some pastors encouraged acceptance of the ARTs, adherence, and disclosure of their diagnosis. In the case of Blessing, the pastor facilitated disclosure by encouraging the grandmother with scripture. Esther also narrated that:

*“I stayed because I wanted to protect my child and my pastor also told me that I had to diligently take the treatment even as God worked in the spiritual realm to grant me healing. So that is the main reason.”* Esther

For most of the women, their faith in the divine healing abilities of God provided a form of inner motivation. Rejoice said:

*“I keep praying whenever I take the drugs; that God will turn it into the blood of Jesus so that I will be healed. Even though I am not healed yet, I am all right, I have maintained my weight and look presentable. So, God is allowing the treatment to work.”* Rejoice

The women also believed that by partnering with God through adhering to their treatments and prayers, they could prevent vertical transmission. In the words of Irene:

*“If you follow their [nurses] instructions and God also has mercy upon you, your baby will not get infected.”* Irene

Thus, for Rejoice, her faith gave her an assurance of a negative baby that kept her in care. Faith was an indispensable component of most of the women’s journey of transition.

#### **5.2.2.1.1.4.5 Optimism for the future**

Optimism for the future stemmed from the mothers’ experiences garnered throughout their journey with HIV. Their initial beliefs of HIV as an indication of imminent death overtime changed to the conviction of a bright and healthy future. This transition in thoughts and actions of the women presented a ray of hope that women who are HIV infected can and do live healthy lives. Reports from the mothers’

personal experiences contributed to the transitioning process and retention in the PMTC programme. Jane shared her joy of receiving a negative result for her daughter DNA PCR at six weeks and her optimism of the same result after complete cessation of breastfeeding:

*“Now the child is negative. If I could afford the milk, I would stop the breastfeeding. But now, I am taking the drugs, and I also buy septrin for her, 2.5mls every time so that when she is one year six months old we will test finally, and I know she will still be negative by God’s grace.”* Jane

Several mothers also showed their optimism for the future by referring to the possibility of extended life as a result of being on medication. Rejoice corroborated with this view and puts it that:

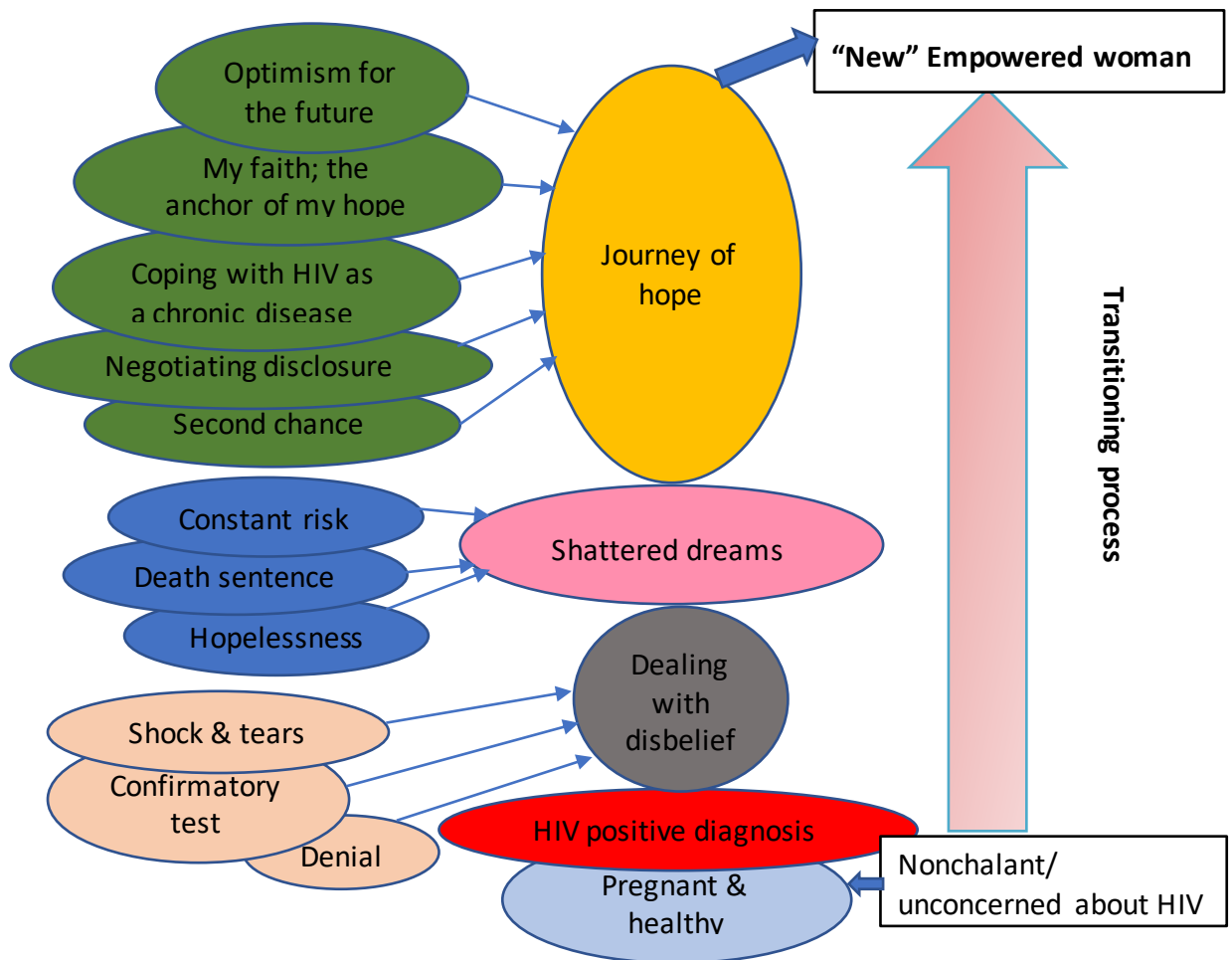
*“Early on, when someone acquired the virus, they fall sick and die but now because of the programme and the free drugs, I am healthy, and no one can even suspect that I have the virus...”* Rejoice

Several women mentioned that the midwives helped them by informing them that babies of other infected mothers had tested negative. Lydia and Grace asserted that their motivation to remain in care and adhere to treatment stemmed from the knowledge that people had achieved the desired goal of having negative children and others had undetected viral loads respectively. Lydia rescinded her decision to commit suicide while Blessings returned to school to further her education.

#### *5.2.2.1.1.5 Conclusion*

HIV counselling and testing in pregnancy present an opportunity for women to become aware of their status, initiate treatment and maintain their health as well as prevent vertical transmission. In spite of its benefits of HIV counselling and testing, a positive HIV result in pregnancy kindles intense emotional reactions in the mother that requires professional support and guidance. The prospects of a bright future on treatment and faith in God promotes the development of personal convictions and tenacity that propels the mothers from the initial states of denial to acceptance and coping. The experiences of HIV positive mothers in the PMTCT programme is illustrated in Figure 5-5 below.

Figure 5-4 Theme One-Transitioning into a “new” woman



### 5.2.2.2 Inquire Phase

Findings of this phase were generated collaboratively with the nurses from the outputs of the Synergenesis process on the two composite stories of the mothers (Appendix N) and the data from the group analysis of the nurses’ paired conversations (as explained in 4.7.10.2). The findings were aggregated to form synthesised themes of both groups of participants’ stories. It focused on their best experience in giving and receiving care in the PMTCT programme, the factors that influenced continuous engagement with the PMTCT programme as well as aspects of care they believed needed improvements to enhance retention. The data generation occurred in groups, hence a strategy to isolate supporting quotes was applied to the

process. As indicated in 4.7.10.2, quotes were extracted from the original transcripts of the mothers, midwives and CHNs to support or explain the themes generated.

Three main themes were generated under this phase; Journeying with committed companions (5.2.2.2.1), Glimpses of Triumph (5.2.2.2.2) and Tying up the loose ends: A daring new path (5.2.2.2.3).

### **5.2.2.2.1 THEME TWO: Journeying with committed companions**

Although initial moments of the nurse-client interactions in the programme were marred with the mothers' unexpected diagnosis of HIV in their current pregnancy, participants recounted incidents that they felt were noteworthy and enhanced their experiences in the PMTCT programme. The participants' exceptional experiences centred on the interactions and relationships they built while engaging in the PMTCT programme. Two sub-themes were developed under this heading; Engaged nurse-patient relationship (5.2.2.2.1.1) and Two is company, more is even better (5.2.2.2.1.2).

#### ***5.2.2.2.1.1 Engaged nurse-patient relationship***

Interactions between HIV positive mothers and nurses began when the women agreed to be tested for HIV during pregnancy. A successful interaction built on confidentiality, trust, and support, caring and approachable staff resulted in the development of a partnership that enhanced the commitment of the participants and promoted retention. This sub-theme is organised under four headings; Commitment to confidentiality (5.2.2.2.1.1.1), Building a relationship of trust (5.2.2.2.1.1.2), Approachable and accessible staff (5.2.2.2.1.1.3) and Constant encouragement (5.2.2.2.1.1.4).

##### **5.2.2.2.1.1.1 Commitment to confidentiality**

From the narratives, the maintenance of confidentiality of clients' HIV status was important for all the participants. The midwives and CHNs emphasised that maintaining confidentiality contributed to positive client-carer interaction and inevitably enhanced the clients' continued engagement with the PMTCT programme. From the stories, maintaining confidentiality involved protecting the client from

unintended disclosure and also keeping in confidence the mothers' HIV positive diagnosis. The midwives and CHNs felt that keeping the diagnosis of the client in confidence as required by the professional codes was essential. Confidentiality was an important consideration of mothers in deciding to remain in care. A midwife shared an account of her experience with a client who was escorted to the labour ward by her elder sister, a close friend of the midwife:

*“She [client] called me and told me that... nobody knows that she has that disease [HIV], so she does not want me to inform her sister. So, I reassured her that, I was not like that... She asked me ‘madam, are you sure that you will not disclose my status to my sister?’ And I reassured her again, that I will not do that. But I realized that she was still worried... I am sure she was waiting to see if her sister will get any hint [about her status] from me. So, for a long time, I kept on communicating with her... I have not disclosed to her sister... a positive relationship had developed between us up till now. I know that to me and the client this is exceptional.”* Midwife Afua

Similarly, from the midwives and CHNs' reflections of the mothers' stories, confidentiality was identified as contributing to their exceptional experiences in the PMTCT programme. Some mothers appreciated the health workers for their collaboration in keeping their diagnosis secret. Rejoice shared her experience of confidentiality as the best experience she could recall since her enrolment in the PMTCT programme. She explained that:

*“When I went for the six weeks postnatal, I was admitted because my blood pressure was so high. Unfortunately for me, the nurse [Nana] who was on duty that day is the wife of my husband's friend and co-worker. They happen to be family friends. I became so afraid that she would inform my husband of my status, so I call Sister [Community health nurse Ama] the nurse who registered me. She came over to the ward and reassured me that the nurse [Nana] would not disclose my secrets to my husband. I think sister [Nurse Ama] went to speak with the nurse because the lady also came and promised to keep my secret. I was on admission for one week, and she was very kind to me. Till date, she has not informed my husband. Anytime I have to go for a refill, I contact her and then she will assist me when I get there.”* Rejoice

It is evident from the narratives that prioritising the clients' need for confidentiality above their social relationships and commitments kindled trust in the client. The participants also affirmed that confidentiality should be ensured at the various care points on the PMTCT cascade by all categories of health workers providing care in the PMTCT programme. In the light of this concern, Felicia expressed her gratitude to the pharmacist for the sensitive handling of her medication. Felicia recounted an incident:

*“I remember an instance where I met a friend at the hospital. We both went to the pharmacy to collect our drugs. She placed her folder in the first window when I had to place my folder in the other window, I could not; I became self-conscious. I called [Pharmacist B] on the phone and explained the situation to him. He asked me to enter the pharmacy and he served me inside. So, my friend did not get the slightest idea about my situation. She would have suspected it if [Pharmacist B] had not helped me. He also escorted me outside... so my friend did not suspect, she even got angry that I didn't add her folder to mine for the same special treatment...”* Felicia

Clients felt reassured and continued to remain in the programme when they realised that the staff were committed to assist them keep their status confidential.

#### **5.2.2.2.1.1.2 Building a trusting relationship**

For most of the participants, the initial interaction they had in the PMTCT programme occurred during counselling and testing for HIV and for those clients who tested positive, midwife Baaba described the situation as “difficult”. However, establishing a relationship of trust during the client-carer interaction contributed to most of the participants' exceptional experiences in the programme. This sentiment is captured in this statement:

*“The fact that someone is in need of assistance and you have the opportunity to counsel her, gain her trust and then she takes her drugs makes us happy.”*

Community health nurse Akosua

She further emphasized that gaining the client's trust did not occur spontaneously but with commitment on the part of the nurses. She said:

*“We show love to the clients and accept [them] so that they feel they can establish a trusting relationship with you. This makes the women open and can discuss their challenges with us by calling you or even coming to the facility just to see you. This makes them stay because they realize that they may not receive that kind of treatment from elsewhere.”* Community health nurse Akosua

Similar sentiments were unearthed from the mothers’ stories. To most of the mothers, trust meant being sure that they could express their fears and frustrations to the health workers without fear of being judged or stigmatized. Comfort explained that;

*“It also gave us the opportunity to talk to people we trust... You come here, find the person you trust and pour your frustrations and fears... it is a good place to be.”* Comfort

Most of the participants believed that, the interaction grew beyond client-carer relationship as it progressed towards friendship and even sisterhood. A mother explained that:

*“You know that it is difficult to find a trustworthy person these days. But I can rely on him [health professional], whenever the need arises. As I said earlier, sometimes you don’t have anybody you trust to talk to. My husband does not want to talk about it, so I am alone with my thoughts. So, when he [health professional] talks to me and encourages me, I feel that he [health professional] is my friend. Just that, a friend I can trust.”* Felicia

Although professionalism was maintained throughout their interaction with clients, the midwives and CHNs felt that opening up to the client, promoted trust and enhanced the clients’ commitment to remain in care. Trust built between a nurse and client did not extend to others automatically. A midwife shared her experience:

*“When they see me, as soon as they see me, aunt nurse, like the way I relate to them, they are like sisters... So, they come out. When they come, and I am even not around... they want nurse Baaba.”* Midwife Baaba

The development of friendship as a result of the client-carer interaction in the PMTCT programme was cited by most mothers as exceptional. These interactions

were not limited to only nurses but to other healthcare professionals providing care in the PMTCT programme.

#### **5.2.2.2.1.1.3 Approachable and accessible staff**

Further exploration on the factors that contributed to building an engaged nurse-patient relationship revealed that accessibility and approachability of the midwives and CHNs was significant. From the midwives and community nurses' narratives, accessibility involved being easily reachable when the need arose as well as presenting a welcoming and comforting presence. Almost all the midwives and CHNs had provided their phone numbers to a client they interacted with in the programme. A midwife gave an in-depth account of her relationship with her client who tested positive at the latter part of her pregnancy. She said:

*“She calls me at any time... she is so comfortable with me. And I see her in the market, she calls me and like [to say] Aunt nurse, here is your baby [Fante]. Anything with her baby, she tells me and even her life, her normal life, everything aside her condition, she tells me everything. I have bonded with her like a sister, like a relative. So, I think she is the one that I can say that I did my best... So that is how far we have gone... She has become like my sister... she is somebody that whatever you tell her, I don't know whether it's because its coming from me, I realized that whatever you tell her, she follows it.”* Midwife Araba

An engaged relationship between the carers and the clients provided some positive motivation that enhanced the clients' decision to remain in the programme.

To the mothers, an approachable health staff was welcoming and helpful. Thus, an opportunity to engage the health professional outside the hospital premises was an indication of approachability. Mary recalled an occasion when the pharmacist went out of his way to assist her in accessing the drugs:

*“When the Pharmacists went on two months strike nationwide... I needed a refill for my treatment and that of the baby. I had heard of the strike and knew the pharmacy was closed. About a day later, I met the Pharmacist outside the hospital, and I informed him that I needed a refill. He spoke to me nicely and reassured me that he would assist me. Later in the afternoon, he came to my shop and asked me to follow him. He opened the office and*

*looked for my PMTCT folder and supplied the drugs. In truth, I appreciated him so much, because the folders were many, but he spent time looking for mine and all the while he was chatting with me. He told me how he admired my seriousness in taking my treatment to protect my child. He encouraged me and reassured me that if I continued that way, my baby would be negative. He made me feel cared for that day... ”*

Mary explained that she valued the experience because:

*“It made me know that he cared about me and also wanted to help me.”*

Mary

Approachable health workers exuded professional confidence and friendly attitude through their verbal communication and nonverbal gestures.

#### **5.2.2.2.1.1.4 Constant Encouragement**

The challenges that HIV-infection brought to the pregnant women or the postpartum mothers were identified as enormous. It included but not limited to anxiety about the fate of the (unborn) child as well as managing adherence to ART for both mother and child; and for those who have not disclosed, managing family carer situations to avoid unintended disclosure. Hence, efforts to remain in care demanded commitment from both the clients and health workers. Encouragement of the HIV-infected mothers by the service providers was important in promoting retention. Mary shared a positive experience she had with Pharmacist B:

*“He [Pharmacist B] told me how he admired my seriousness in taking my treatment to protect my child. He encouraged me and reassured me that if I continued that way, my baby would be negative.”* Mary

Midwife Yaa said that the midwives in the PMTCT programme are supportive and also encourage the mothers. Lydia’s statement affirms this assertion:

*“The nurses always encouraged me... and I was reassured...”* Lydia

To the mothers, the encouragement of the midwives and CHNs was important when they faced challenges associated with collecting treatment in the programme. The study showed that the impact of staff encouragement on the clients’ decision to remain in care could not be overemphasized. Irene summed it up that:

*“They should keep on with whatever they are doing; keep on encouraging and bonding with us, being kind and especially show concern. They do this already, but they should continue.” Irene*

Participants indicated that interactions between caregivers and clients in the PMTCT programme ought to be laced with encouragement to boost the confidence of and motivate the mothers to remain in care.

#### *5.2.2.2.1.2 Two is company, more is even better*

In furtherance of an engaged relationship between the clients, midwives and CHNs, there were instances when involving others improved the partnership and journey in the PMTCT programme. For both the client, midwives and CHNs, receiving support from other people who were not part of their initial engagement provided avenues for motivation that positively enhanced their engagement in the PMTCT programme.

That was, however, possible if there was disclosure and consent was agreed by the partners. This subsection is presented under the following headings: Involving others (5.2.2.2.1.2.1) and Supported to provide supportive care (5.2.2.2.1.2.2).

##### **5.2.2.2.1.2.1 Involving others**

The positive relationship was not only limited to the carers and the clients but extended to the family members when the clients permitted it. It was evident from the narratives that, it impacted the clients’ experiences positively and also enlightened the family on HIV and its management. A few of the women were emphatic that their decision to remain in the programme was based on the support they received from family. This support was attained when the mothers made full disclosure. Disclosure eased the weight of loneliness and reduced stigma. The forms of support provided by the family included treatment compliance support, psychological and emotional care, and assistance with chores and childcare. According to Blessing, the teenager who was dependent on the benevolence of her grandmother for support:

*“My grandmother was my motivation to continue treatment. She took care of me... even when I had the drug reaction. And I am the only child of my father, so I thought I also had to do my part to make her happy.” Blessing*

This view is also shared by Grace who referred to the support she received from her husband as the main reason why she remained in care:

*“The main reason is that I have good support from my husband; we all take the drugs, so we support each other, we monitor each other and sometimes when our treatments are about to finish, one of us goes and collect it for both of us.”* Grace

Other participants also reported family support as valuable during their enrolment in the programme. Irene stated that support from her aunt in the care of the baby and her constant inquiry about her compliance to treatment was very beneficial. Vera also reported support from her family in the care of the baby and accessing PMTCT services. Vera said:

*“My mother always checks my appointment book to remind me of the date of my next appointment. She also gives me money to go to the hospital when the date is due. My grandmother also helps me care for the baby, gives her the treatment and supports me stick to the feeding plan we agreed with [community health] nurse Ama.”* Vera

Vera recounted how the CHNs established a relationship with members of her family that promoted a unified source of knowledge between the various generations of women taking care of the exposed child:

*“Nurse Ama [community health nurse] calls and visits me at home sometimes. She has established a relationship with my mother and grandmother which I believe is very good because, she is always available to provide answers, clarify issues and guide us especially in issues related to caring for the baby; her feeding, immunizations...”* Vera

For the healthcare worker, widening the relationship net to include other family relations and carers was beneficial as it allowed them to perform their moral and professional responsibility of preventing the spread of the virus to family carers, and encourage testing and treatment of their sexual partners if they are positive. Midwife Baaba expressed her thoughts in this narrative:

*“I had to encourage her more because I can’t break the news to him... [the husband]. So, through counselling, one day she was able to break the news. So, by God’s grace, now the husband too is taking the drug... When they*

*deliver too, you go for counselling...taking care of the... even the caretaker who is coming to take care of you... you have to protect the person so that the person doesn't get it. All those things, we go through so that you know how to protect the one who is coming to take care of you so that person doesn't get it."* Midwife Baaba

Additionally, the responsibility for encouraging and supporting the client is shared with others and therefore relieves the health workers of solely carrying the emotional load associated with caring for the infected mothers.

#### *5.2.2.2.1.2 Supported to provide supportive care*

The midwives and CHNs also reported receiving technical support which enhanced their ability to deliver quality service in the PMTCT programme. This was also cited as contributing to the exceptional experiences they had whilst providing the service. Technical support included the training of the midwives by the laboratory technicians on how to take blood samples for DNA PCR for the babies who gave birth in their facility. This ensured that all babies in their care took the test. Midwife Ekuba also recounted the support of the unit manager when the midwives indicated the need to initiate Midwife-led DNA PCR testing as part of PMTCT routine work in their unit. The support included liaising with other facilities for training on documentation, provision of logistics and lobbying with management.

The provision of this additional service ensured that the midwives were able to track the results of the babies unlike when the exposed babies were referred to other facilities for the test. To midwife Araba knowing the outcome of the exposed babies' tests was important as it relieved their anxiety and also served as a source of joy and hope when the baby tested negative to HIV.

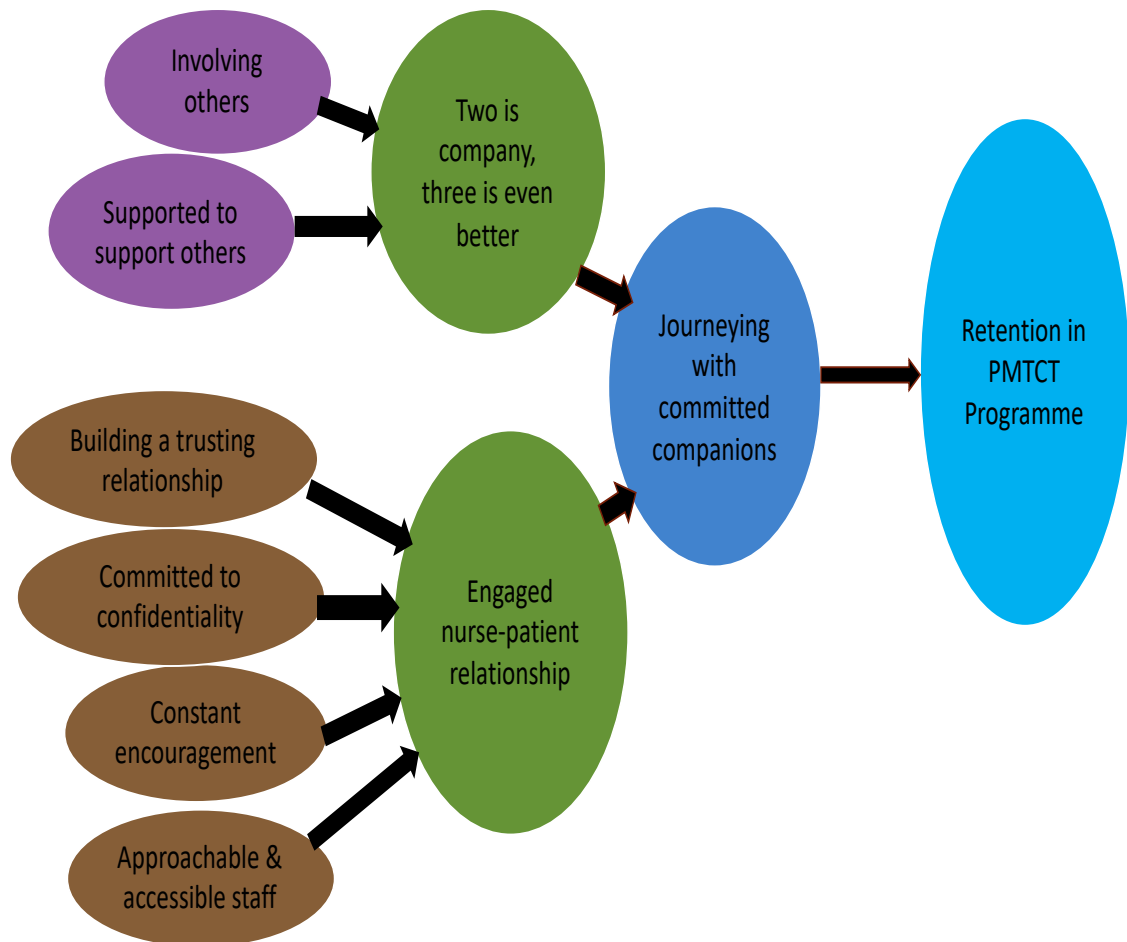
Receiving adequate information from more knowledgeable midwives and CHNs in instances where it was required was noted as a source of technical support for some midwives and CHNs. That enhanced their knowledge base and confidence in providing care to their clients. The following comments from a midwife capture this point:

*"Initially, I didn't have much knowledge about the breastfeeding options, so I contacted a midwife... She educated me very well and later I relayed to the lady [client]."* Midwife Ekua

The role of positive client-carer interaction in the exceptional experiences of both categories of participants cannot be overstated. It is evident that it was necessary for enhancing the retention of infected mothers and their exposed babies in the PMTCT programme.

Figure 5-6 below illustrates the theme clusters that contributed to the emergent theme two.

Figure 5-5 Theme Two-Journeying with committed companions



## 5.2.2.2.2 THEME THREE: Glimpses of Triumph

The enthusiasm to continuously engage in the PMTCT programme was reinforced when the participants experienced positive outcomes of their commitments to the programme and each other. The participants expressed a sense of joy and satisfaction when they shared these positive outcomes and referred to them as achievements. The positive outcomes resulted in Celebrating health (5.2.2.2.2.1), Empowered clients (5.2.2.2.2.2) and Changing perceptions about midwives and nurses (5.2.2.2.2.3).

### 5.2.2.2.2.1 Celebrating health

The PMTCT programme seeks to achieve two primary goals; ensure that HIV positive mothers survive and live healthy lives, as well as to eliminate new HIV infection among exposed babies (WHO, 2013). The achievement of these goals required commitment from all stakeholders including midwives, nurses and the infected mothers; hence, a cause for celebration for the midwives, CHNs and mothers. It also served as a source of motivation for continuous engagement in the programme. The subsection is discussed under the following subheadings: My baby is HIV negative (5.2.2.2.2.1.1), and A healthy mother (5.2.2.2.2.1.2).

#### 5.2.2.2.2.1.1 *My baby is HIV negative*

The midwives and CHNs gathered from their own narratives and the mothers' stories that the desire to have an HIV negative baby was a strong motivation for women remaining in the programme. This motivation influenced the information that was stressed during the counselling sessions for the midwives, CHNs and mothers. The desire to protect the child from future emotional heartaches associated with an HIV diagnosis was identified as a motivation for the nurses to commit to promoting retention of the mothers. Besides, the midwives and CHNs felt that every HIV negative child born to an infected mother was a victory against HIV. The statement by a midwife captured this point:

*“A child who is now coming to the world, knows nothing, then you will be taking a drug for the whole lifetime. If the child doesn't die at an early age [no], then this child will grow up one day ... will come and ask the question*

*one day, that why this drug, and if she finds out that it's because of this condition, it's heart-breaking. So, me, to protect, to prevent, to break that eeh chain, alone gives me the motivation to go on.*" Midwife Baaba

All the midwives and CHNs reported instances when babies of HIV infected mothers they had attended tested HIV negative. That was expressed as personal achievements by the midwives and CHNs and showed how engaged and committed to the process the midwives and CHNs had become. The personal ownership attached to the infants' HIV negative diagnoses by the midwives and CHNs is evidenced from their narratives. This success story represented evidence of their efforts as providers. It was also a source of motivation for the midwives, CHNs and mothers.

A midwife who had worked in the PMTCT programme for two years and six months at the time of the conversation shared the outcome of her engagement with a 26-year-old primigravid woman. She said:

*"When the baby was delivered, I had to do the EID [early infant diagnosis], and by God's grace, it came out negative. Even so far, I haven't gotten a positive child."* Midwife Baaba

A community health nurse, Akosua echoes this and recounted that the baby of her client (who had contemplated suicide when diagnosed HIV positive) tested negative at two years and had since been discharged from PMTCT care. In like manner, community health nurse Adwoa told of how the baby of the defaulted client she had tracked and assisted to re-engage in the programme also tested negative at eighteen months and had since been discharged. These all speak to the determination and the commitment of the nurses and reflects on the importance of the relationships built with the clients and their professional pride.

Exploration of the various narratives revealed that the maternal instinct to protect the unborn child was also a significant motivation for retention. That stemmed from the perception that babies are innocent and had prospects of a better future without the infection. According to Mary, whose eldest daughter had died from AIDS, the fact that the counsellor stressed about protecting her unborn child from being infected and the knowledge that drugs were available to prevent vertical transmission, was welcoming news that strengthened her resolve to remain in care. She said:

*“She [community health nurse] talked about protecting the unborn child from getting infected, and that my eldest child would have been negative if I had known my status and had taken treatment when I was pregnant... I decided to try the treatment for the period when I was pregnant... She came to the house and stressed the need to continue the treatment so that I save the life of my unborn child. I believe that this was what actually made me resolve to continue with the treatment.”* Mary

Comfort shared her experience of an adverse drug reaction while pregnant and explained that In spite of that, protecting the unborn child was paramount. She explained that:

*“When I took the drug, I had all that; I saw a lot of horror things; it was a bad thing ... [but]the only thing I know is that I had to continue taking the drugs for my baby; so that I don't make things worse... That is what motivates me.”* Comfort

Most mothers recounted enduring difficult situations to ensure that the child will be negative. Thus, an HIV negative result of an exposed baby was an achievement worth celebrating by the midwives, CHNs and mothers as was the case of the babies of mothers in this study. Most mothers reviewed the news as gratifying. In the words of Blessing, an HIV positive teenage mother:

*“I think my best experience was when I was called that my baby's test results had come. When we did the test, they told us that it would take two months for results to be released. The wait was long and stressful. Then one day, [midwife Araba] called my grandma and told her we had to come to the hospital for the test results. I was anxious, so we kept on probing, but she will not tell us outright on the phone. But the way she was laughing and happy on the phone, we sensed the baby was negative. Then when we went there she said congratulations, the baby is negative. I cried, and my grandmother also cried and then [midwife Araba] hugged me.”* Blessing

For the mothers, the HIV negative result of the babies at six weeks of life provided interim relief although, for mothers who breastfeed, the risk of transmission was still present. That served as a motivation to remain in the programme as it gave them

hope that the child would remain negative upon re-testing at 18 months. This statement underscores the point:

*“Oh yes, she tested negative. (LAUGHTER)... Eeeei Yes! My efforts have been crowned with success. Now I am only waiting to test her when she is one year and six months. But even now, I have stopped breastfeeding, so I believe the risk has been reduced. She will continue to be negative in Jesus name (LAUGHTER)!”* Mary

This ray of hope that the negative result of the EID also represented a possible future for the couple and family. It represented a state of health that eluded the adult members of that nuclear family.

Grace shared this optimism:

*“Yes (Laughs) she is negative... It has become a great motivation. You see we can see that we have a future. We can build our family without fear.”* Grace

A negative EID represented a victory against misinformation, misperception, hopelessness, and death that the maternal HIV positive diagnosis represented.

#### *5.2.2.2.2.1.2 A ‘healthy’ mother*

Although not stated by most of the mothers as the primary reason for enrolling in care, maintaining and improving the mothers’ health was reported as a source of motivation to remain in the programme in the postpartum period. Emphasis on the effectiveness of the drugs to maintain the mothers’ health during their interactions was established as an important consideration in their decision to remain in the programme by all the participants. According to Vera and Rejoice, knowing the drugs could make them appear healthy as well as provide the additional benefit of not raising the suspicion that they were infected with HIV motivated them to accept treatment and remain in care. The midwives and CHNs also supported this assertion, and this statement by a community health nurse captures that:

*“I also think that when we tell them that the treatment will prolong their lives...is also a contributing factor... They come to understand that the disease does not kill when they take their treatment. They do not want people to suspect them, so we advise that when they adhere strictly to the treatment*

*regimen, they will maintain their weight and look healthy so that no one can suspect that they have the disease.”* Community health nurse Ama

The propensity of the treatment to prolong the life of the infected mother was also an important motivation to remain in the programme. One of the women stated that she would not leave her child as an orphan because she could be well enough to look after the child as it grew up. The reassurance was a deciding factor in Mercy’s decision to remain in care. She explained that:

*“I stayed because I wanted to remain well... So now I know that if I take my drugs as they have instructed me, I will not die that shameful death. And it is true I am feeling well. So, I will not stop taking it.”* Mercy

Consequently, remaining healthy was a triumph over their fears of falling ill, exposing their status or dying with AIDS. From the mothers’ narratives, the maintenance of health was associated with the absence of signs of HIV infections such as weight loss and opportunistic infections.

*“Early on, when someone acquired the virus, they fell sick and died...I am all right. I have maintained my weight and look presentable...”* Rejoice

This contributed to the mothers’ sense of wellbeing and brought joy, confidence and a sense of security that influenced the participants’ decision to remain in the programme. The mothers’ fear of exposing their HIV positive status when they fell ill was motivating enough to remain in care. Thus, remaining overtly healthy was reported to be worth celebrating. Jane also explained that:

*“They told me that if I stop taking the drugs, my resistance (Immunity) will go down and I will start to get sick. And the drugs are good. Look, look at me now (LAUGHTER). I look normal. I look good. Nobody will suspect that I have the disease. If I ever tell you myself maybe you won’t believe (LAUGHTER).”* Jane

A few of the mothers attributed health to a reduction of the viral load and improved immune response. Grace said:

*“We make sure that the other person takes the drugs so that we will not increase each other’s viral load and reduce the potency of the drug. She also*

*told us that, some people like us cannot find the virus in their blood now because they had diligently taken their treatment.” Grace*

For those mothers who had witnessed the death of a loved one from HIV/AIDS, remaining alive and healthy was an achievement. The narratives revealed that the midwives and CHNs valued their role in attaining these goals and this contributed to the positive experiences of all the participants. Midwife Ekuba expresses that in a comment:

*“My motivation is seeing that the baby and the mother at the end of everything are happy; Healthy mother, healthy baby.” Midwife Ekuba*

#### *5.2.2.2.2.2 The empowered client*

Rodwell (1996 p. 309) defined empowerment as a “process of enabling people to choose to take control over and make decisions about their lives. It is a process which values all those involved.” The power dynamics during the initial interactions between the midwives, CHNs and the infected mothers in the PMTCT programme were usually imbalanced as a result of the inadequate information on the parts of the clients and their sense of vulnerability. However, narratives from this study revealed efforts to empower the client by the midwives and CHNs, and an enhancement in the clients’ level of engagement in the programme. For the participants, this was a reason for celebration. This sub-theme is presented under two headings: Empowered through knowledge sharing (5.2.2.2.2.1) and Empowered to participate actively (5.2.2.2.2.2).

##### *5.2.2.2.2.2.1 Empowered through knowledge sharing*

Myths and misconceptions have been known to negatively impact decision making about HIV testing and treatment (Haile, Chambers, & Garrison, 2007). Thus, knowledge sharing was an important aspect of the PMTCT programme in this study. Two types of knowledge sharing was identified in this study - knowledge sharing between professional and client, and professional to professional.

An effective nurse-patient interaction was an integral part of the PMTCT programme that enhanced mothers’ acceptance of their diagnosis and their decision to remain in the programme. Mothers described receiving an HIV positive diagnosis as shocking and devastating, and often resulting in denial and sorrow. Three mothers

misconstrued an HIV diagnosis with AIDS, and this was a barrier to uptake of the PMTCT services as AIDS was equated to a death sentence and hopelessness.

From the midwives and CHNs' perspectives, every interaction was an important avenue to correct misconceptions, educate and get the client to understand the hope that the PMTCT programme offered them. It also created the avenue to establish a trusting relationship between the client and the healthcare provider. Midwife Araba felt that when the mother understood the counselling and agreed to enrol in the programme, it simplified the process. She explained that:

*“Why do I think they [client] came? ...it is [because of] the counselling we [midwives] give them. You see with the counselling; I am able to get the person to understand what the condition really is. I am able to get the person to understand that that is not the end of her life... so then there is hope for her. So, if she is able to go by the rules especially with the medications, then she can move on. And when she accepts that, you [midwife] too it makes everything so easy for you, because she [client] knows that I am doing this for the reward I am going to get for myself and my baby. So, if she really understands what she is doing, then everything becomes so easy for you [midwife].”* Midwife Araba

Midwife Baaba emphasized the need to explain the diagnosis especially the difference between HIV and AIDS, the availability of drugs for its management and the disease outcomes to the client during counselling. Educating the mothers on the effectiveness of the drugs to prevent vertical transmission was reported as greatly contributing to their decision to remain in the programme. The study revealed that knowledge acquired in the programme was beneficial to the mothers. Vera said that:

*“It is very beneficial, very informative. You gain knowledge about how to reduce your viral load and stay healthy, how to take care of your child.”*

Vera

Midwife Ekuia indicated that continuously educating and counselling the mothers equipped them with the knowledge to make informed choices. Upon reflection of the mother's stories, the midwives and CHNs determined that the attitude and approach of the counsellor was an important measure of its effectiveness in addition to the content covered during the sessions.

Knowledge sharing between experienced midwives and CHNs and the newly trained staff was a means of empowering the novices in the PMTCT programme and boosting their confidence to provide quality service. Midwife Akua reported that receiving information on feeding for HIV infected mother options from an experienced PMTCT midwife enabled her to counsel her client confidently.

Peer-to-peer information sharing was however not identified in this study. Mothers in this study sought to maintain their HIV diagnosis private and made efforts to ensure that other clients would not identify them. Hence, limited interaction between participants (mothers) was identified.

#### *5.2.2.2.2.2 Empowered to participate actively*

It was established that during the initial interactions, some mothers felt powerless and felt that the health care workers were more knowledgeable and therefore relinquished their power to make decisions to them. In the words of Rejoice:

*“What could I do she was a doctor and more knowledgeable than I was? So, I accepted the result.”* Rejoice

The midwives and CHNs reported great satisfaction when the mothers gained knowledge about their conditions and participated meaningfully in decision making concerning living healthy with HIV. A midwife explained that:

*“It’s like I give them [mothers] all the information I have concerning their health, the drugs, care of the child... I mean everything; they [mothers] understand and participate fully in each phase of the care process... so it is like I have empowered them [Laughs].”* Midwife Adwuba

Client empowerment does not only impact decision making concerning healthy living with HIV but all facets of the clients’ lives. Blessing and Lydia variously recounted the impact of empowerment on their lives. The former narrated her re-enrolment in school after giving birth as a result of being counselled, coupled with the support of the headmaster and family while the latter shared her story of how she resumed her trade of fruit seller through counselling as she had quit selling fruits for fear of infecting her customers.

Being empowered also influenced the mothers to accept their status and even stand up against stigmatisation. Accordingly, Vera requested a transfer from the facility where she was tested to a different one when she felt she was not receiving adequate care. Mercy also reported the undertaker who informed her in the presence of relatives that her husband had died of AIDS.

The impact of empowerment is illustrated in the experience of CHN Adwoa. According to her, a client she counselled stood her ground not to disclose when the pharmacist demanded a treatment supporter before refilling her treatment. She said:

*“I was in the counselling room one day when my client came to me... she had missed a treatment refill appointment by a few days, and so the pharmacist had refused to serve her unless she presented a treatment supporter. After counselling her on adherence, we went together to the pharmacist, and the client I would say rather educated the pharmacist. She said 'I need the drugs now, I have decided not to disclose my status, and you can't make me...' Most clients would have broken down to weep or left without the drugs, but she knew her rights...”* Community health nurse Adwoa

Midwife Afua also indicated an instance where a client had complained about service delivery, and this had stirred the staff to action. She said:

*“There was once a patient on our ward whose wound [caesarean section] gaped. She complained that the midwives did not come to her bedside to care for her. It was a very sad situation. But when we heard that complaint, we all sat up and started visiting her bedside.”* Midwife Afua

Over time as the women acquired knowledge and maintained their health and that of their babies, the decision to remain in the programme was based on personal motivation and not from coercion, persuasion or fear of stigmatization. Lydia alluded to this in her narrative:

*“Collecting drugs at the pharmacy has always been a problem for me... but for me, it is not really a problem anymore because I do it for the child. So, I don't care if people see me and talk about me ... I am not the only infected person, and I know the reason why I still collect the drugs.”* Lydia

In most instances, self-stigmatisation would have caused the mothers to succumb and endure, but these mothers having been empowered by the knowledge they received from the programme ensured that they received the best of care and made the choice to remain in the programme.

### 5.2.2.2.3 Changing perceptions about midwives and nurses

The public image of the nursing profession has been reported to be diverse and influence clients' attitudes to accessing care (Meiring, 2013). Providing individualised care to mothers and exposed babies in the PMTCT programme afforded the midwives and CHNs the opportunity to correct any negative perception and positively project the image of nursing. Exploration of the narratives revealed that the attitudes of the midwives and CHNs, as well as their work values, impacted how patients perceived the profession.

The sub-paragraph is presented under two headings; Midwifery and nursing care in PMTCT: A different experience (5.2.2.2.3.1) and New rhetoric about midwives and nurses (5.2.2.2.3.2).

#### 5.2.2.2.3.1 *Midwifery and nursing care in PMTCT: A different experience*

Because of the rhetoric about nurses<sup>13</sup> in the Ghanaian public domain, mothers anticipated stigmatisation or discrimination when accessing care in the PMTCT programme. The study revealed a different experience of midwifery and nursing care from what mothers anticipated. The show of professional and technical competence in the provision of midwifery care was recognised and acknowledged by some mothers. Application of universal precaution ensured that the midwives and CHNs were able to provide quality care without exception to the infected mothers. That was evidenced in a mother's narrative:

*“The midwife who attended the birth was very kind. When she came for the first vaginal examination, she was gentle. It was very painful, but she was very patient... But what made me appreciate her was, even though she knew*

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<sup>13</sup>A section of the Ghanaian public does not distinguish between nurse and midwives in their perceptions and rhetoric about the professions

*my status, she wore the gloves and inserted her hands in my womb (sic) rubbed my abdomen at the same time and drew out the after-birth (retained placenta). She cleaned me up and then she assisted me to my bed... Even when I delivered my first child, at that time, I didn't have this disease, but the midwife kept on shouting at me.” Jane*

It was evident in the narratives that some of the mothers felt unworthy of quality care as they experienced self-blame that result in self-stigmatization. Thus, a show of acceptance by the midwives and CHNs was unexpected and much appreciated. A mother narrated:

*“The way the midwives, talk, laugh and generally relate to me makes me very happy. I was afraid that they would shout at you and segregate us from the other pregnant women. But that did not happen. They treat us equally. So, no one will be able to know my status just from my interaction.” Irene*

This speaks to the cultivation of a sense of dignity and self-worth among clients that leads to wholeness and health. The participants received both psychological and emotional care when they accessed PMTCT services. The midwives and CHNs' synthesis of the mothers' stories revealed that psychological care included the sense of acceptance, reassurance, and encouragement that some mothers received while in the programme. A mother reported that:

*“She [midwife Esi] treated me as a human being and not an HIV patient... The care the midwife gave me, made me feel special. She treated me like a human being.” Jane*

Some mothers narrated instances of emotional support when they went through difficult moments while in the PMTCT programme. The physical presence of the midwives and nurses, and provision of comfort was reported as a form of emotional support. That included narratives of companionship and empathy. In the account of Mercy:

*“She [medical ward nurse] told me I had to do the test to know my status since I was pregnant. She went with me to the midwives upstairs and stayed with me throughout the period. She was there even when they told me I was positive. She held me as I cried and comforted me... they went with me to the pharmacy to begin my treatment.” Mercy*

Providing culturally sensitive care was also identified in the narratives as contributing to mothers' exceptional experience. Mercy reported that the CHN went out of her way to assist her acquire the baby's treatment when she was in seclusion as part of the widowhood rites. Mary shared an experience of support and care from the CHN who acted as her adherence counsellor during the death of her daughter from AIDS. Similarly, Esther narrated her experience of kindness from the midwives when she gave birth at home and reported to the hospital with the baby, even though they had been advised against giving birth at home.

Providing midwifery and nursing care to mothers in the PMTCT programme afforded the midwives and CHNs the opportunity to project their profession positively. A midwife shared her experience with her client who felt nurses could not maintain confidentiality. At the end of the interaction, she recounts that:

*“When she [mother] calls... she tells me, I am wonderful and when I ask her why she says that I thought you would disclose my status, then I reassure her that my profession does not allow me to do that.”* Midwife Afua

A show of appreciation by the mothers was a source of motivation for the midwives and CHNs, and an indication of patient satisfaction of the PMTCT service and quality of care.

#### *5.2.2.2.3.2 The new rhetoric about midwives and nurses*

Most mothers described the midwives and CHNs with positive attributes and reported exceptional experiences while receiving care in the programme. Comfort described the midwife who attended her delivery as *“patient and kind... she loves her work.”* Comfort

Blessing said the midwife who attended her birth was *“gentle and kind”* and the CHNs she interacted with were *“good.”*

The mothers' narratives revealed that the midwives and CHNs accepted the mothers' choices concerning healthcare after they had informed them of the best options. They provided the needed assistance when the patient re-engaged without being judgmental. Esther who went against the nurse's advice and gave birth at home also reported that:

*“The midwife was good. She cleaned me up and sutured me. Even then [during the suturing], she was patient.”* Esther

A mother stated that she was willing to recommend the hospital to anybody who tested positive for HIV because;

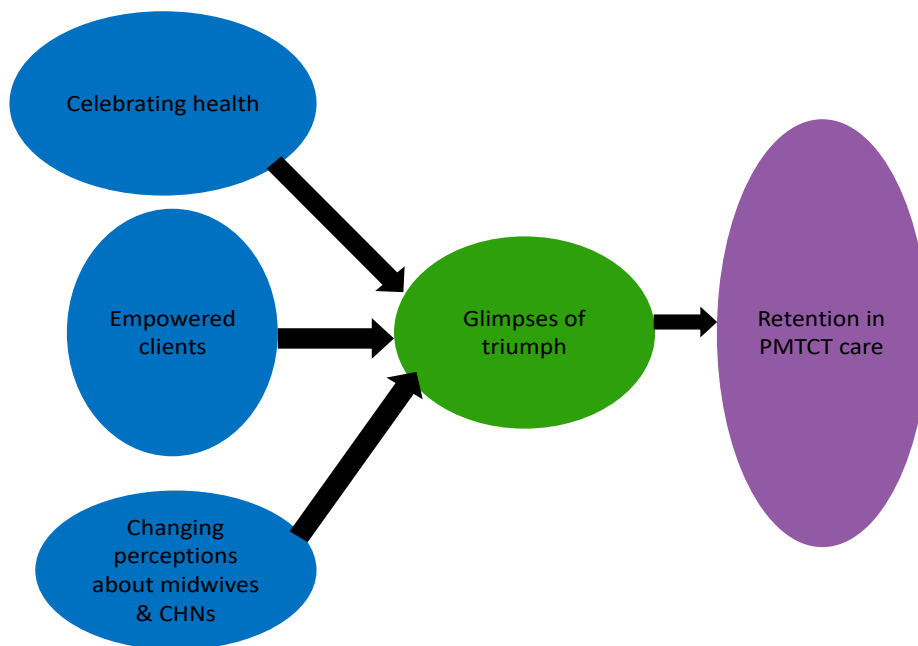
*“They [nurses] will not scare you. They will speak nicely to you so that you are encouraged and gain the confidence to take care of your baby.”* Vera

A CHN accentuated that their individual positive actions reflected positively on the image of nursing.

*“Most patients always have negative perceptions about nurses, sometimes it may be true of some nurses, but I believe that with the little efforts that I made, at least my client will also feel that there are some good nurses around... maybe she will even mention my name [Laughs].”* Community health nurse Abena

Figure 5-7 below illustrates the theme clusters that contributed to the emergent theme three.

Figure 5-6 Theme three- Glimpses of triumph and the contributing factors



Achievement of the goals for which a mother, midwife and CHN entered into a nurse-patient relationship in the PMTCT programme was a vital source of motivation. The exceptional moments' participants experienced in the PMTCT programme were varied. These narratives point to the fact that the type of midwifery and nursing care provided in a PMTCT programme impacts the quality of care and clients' decision to patronise and recommend the facility

#### **5.2.2.2.3 THEME FOUR: Tying up the loose ends: A daring new path**

The conversations sought to find out participants' perception of what PMTCT care ought to be. Although the conversations were focused on the positive as is consistent with AI, some of the narratives were descriptions of negative experiences or limitations in service delivery that participants felt could have influenced their decision to default or change the hospital where they accessed PMTCT care. Following the recommendations of Bushe (2007), generative conversations on how these clients' experiences could enhance retention in the PMTCT were held. Creation of an enabling environment for active client participation in the programme was necessary to enhance retention. Four sub-themes emerged: Continuity of care (5.2.2.2.3.1), Continuity of carer (5.2.2.2.3.2), Conducive environment for PMTCT care delivery (5.2.2.2.3.3) and Engaging the religious and traditional leaders (5.2.2.2.3.4).

##### **5.2.2.2.3.1 Continuity of care**

The researcher observed that PMTCT services were formally integrated within the MNCH services as stipulated by the National HIV/AIDS policy guidelines. There was, however, fragmentation of service delivery across the various units which posed a challenge to the clients enrolled in the programme. The midwives and CHNs gathered from the mothers' stories that several mothers encountered challenges when they progressed from one unit to the other within the PMTCT programme due to the fragmentation.

Lack of a well-articulated patient flow pathway affected patient care experience. The midwives and CHNs appreciated concerns by several mothers about the gap in care created after the six weeks postnatal visit and the final DNA PCR testing of their

children at one year and six months. Although to the midwives and CHNs, the service was continuous with the adult HIV clinic, they realised that the transition was not smooth for the mothers. A mother narrated her experiences after postnatal care:

*“When we finish the six weeks postnatal visit, we don’t go to them [midwives] again, so sometimes no one checks on you. I even forgot about the baby’s test, it was later when Sister [midwife Baaba] asked about the results [PCR] that I remembered... after the six weeks postnatal visit, you visit the hospital only on appointment by the pharmacist, so if you didn’t make a friend while pregnant, you are on your own. It is difficult ooh. They should transfer us to a nurse [CHN]... so that we can still get the care and answers when we need it.”* Rejoice

The midwives and CHNs indicated the need to standardise the existing care pathway for HIV-infected pregnant women and postpartum mothers. In addition to this, they believed it was essential to disseminate the information to all staff who work with HIV infected women within the integrated PMTCT/MNCH services.

The need for the integration of PMTCT/MNCH activities to be centred around the client instead of around the health service and its workers, were also identified in the narratives. Although the PMTCT/MNCH services were integrated at some points, it was evident from the patients’ narratives that some clients still encountered challenges in receiving care as the integration was centred around the service points and not the clients. Integration of the PMTCT/MNCH should not be limited to service integration alone but must be patient-centred in its approach.

The midwives and CHNs pointed out that it is essential to inform mothers during enrolment that multiple trained health professionals including doctors and pharmacists were involved in providing care in the integrated PMTCT programme at various stages of the peripartum period. Additionally, it is essential to give them insight into the phase when additional trained staff is involved in care. That shows the midwives and CHNs’ commitment to their clients where they ensure continuity amidst the necessary departures. The following narrative from a midwife outlined how she facilitated a mother’s progression to another unit:

*“I had already psyched her that I would not be the only person to take care of her... I had already told her that at a point in time, some people might come*

*in; when she comes for weighing, she has to go down there [child welfare clinic] and continue from there. I would not be the only person taking care of her throughout. So, when the time came for me to go on leave, even before she came for her six weeks, I had introduced her to those at RCH [Reproductive and Child Health unit] so that when she comes, she would not have to go and explain so many things. So [when] she comes [to the hospital], she just goes there [RCH], and they know that she comes because she is this [HIV positive].”* Midwife Araba

The information ensured that the client knew what to expect and adjust their expectations to suit the service delivery approach. Informing the client may not necessarily ease the clients’ distress with the situation. It pointed to the power dynamics in the health system and indicated that the client was not the centre of care. Facilitating and enabling the next significant professional relationship speaks to the values of the midwives and CHNs.

*“I educate them that when it gets to a point, you will leave me... after delivery you will leave me, you will go... where you are taking the baby too, the baby has to be monitored, you too you have to be monitored. So, you go here... so I make them understand. So, after the... this thing, I just don’t push them, I take them myself to the person.”* Midwife Baaba

When the initiating nurse/counsellor, who usually builds a trusting relationship with the mother, introduced the mother to a new PMTCT trained midwife or nurse in another unit where the mother was required to continue receiving care, mothers reported receiving exceptional care. A mother said:

*“The nurse... led us back to the ANC clinic and helped us register and left me in the care of two nurses whom she asked to assist me whenever I come for treatment and report back to her whenever the need arose.”* Vera

Unfortunately, although the midwives at ANC reportedly facilitated mothers’ progression to the labour ward, the midwives at the labour ward admitted that they did not continue the process. A midwife, therefore, proposed that:

*“I think we have to ensure continuity of care for up to some time until we are convinced that as for this woman, both mother and baby are doing well. That they come for their refills and the baby too is doing well... Yes, we need to*

*link the labour ward with the PNC unit. It is like we end contact with the patient as soon as the client delivers. Yes, I think that when we do that it will help us. We can document their names and make them special so that after she delivers, we can take their telephone numbers and if she does not have a telephone number and you think that she lives within the catchment area of the CHNs, you can inform them so that they can follow up on her...*” Midwife Esi

This proposal has benefits beyond the PMTCT programme. It has the potential to greatly enhance the ANC/labour and PNC experience of clients.

All participants acknowledged the need for facilitation of the transition of HIV-infected mothers in the PMTCT programme to adult care by the midwives and CHNs. That was necessary for all mothers enrolled in the programme and not for only those who established a relationship with the health workers.

#### 5.2.2.2.3.2 Continuity of carer

Although PMTCT care was integrated within the MNCH services, multiple providers attended to infected mothers during a visit. The need for continuity of carer within each unit providing PMTCT services across the various units in the programme was identified as essential to promoting effective service delivery and retention. The midwives and CHNs gathered from the review of the mothers’ stories that the mothers’ felt engaging with different healthcare providers every time they accessed care within the PMTCT programme was de-motivating for retention in the programme. Engaging with different health workers required an ongoing process of disclosure, explaining and trying to establish trust, and was emotionally stressful for the client.

Mothers expressed their distress with the frequency in which they had to engage with new caregivers, as the people they had established relationships within the PMTCT programme were either transferred or reassigned. That increased the number of people who were privy to their diagnosis. Grace, Felicia, and Jane felt that this could result in unintended disclosure and also brought the additional burden of re-establishing a trusting relationship. The following comment from Irene captures this point:

*“The staff we interact with keep on being changed. For instance, the man at the pharmacy is not there anymore. They have brought a new person, so indirectly, the number of people who know your diagnosis keep increasing. That is worrying because you may never know who will break your trust. It is also difficult explaining things to the new people the first time and even more difficult establishing the kind of relationship that will allow us to ask questions that may be beneficial to us.” Irene*

Jane expressed her expectations on this issue:

*“...so, if they can limit the people it will help us.” Jane*

Continuity must be the norm in the PMTCT programme, as opposed to the exception. The benefits of this patient centred approach would have positive impacts in other areas of care.

### 5.2.2.2.3.3 Conducive environment for PMTCT care delivery

The environment in which health services are provided is a measure of quality health service delivery (Reiling, Hughes, & Murphy, 2008). The midwives and CHNs flagged creating a conducive environment for service delivery as an essential consideration to improve patient experience and retention in the PMTCT after review of their transcripts and mothers’ stories. The midwives and CHNs realised that the physical environment and the organization of the space at the ANC was an issue of concern for mothers as this impacted directly on clients’ confidentiality and privacy. Some participants shared this concern about the room at the ANC assigned for PMTCT.

*“If they can change the room where they conduct the test, it will help. You see, it is a room in the corner there. Everybody knows that if you enter that room, you are going to have the HIV test. There is a bench just outside the door where other pregnant women sit waiting for their turns. And you know that the positive result is bad news, so when you come out with your teary face and red eyes, everybody can suspect that you are positive. Even when you keep long inside there, people begin to suspect. So, if they can re-arrange the place for us, it will help.” Mary*

Another challenge reported by participants was the arrangement and protocols in place for accessing treatment refill at the pharmacy was a source of distress for the mothers. Lydia explained that:

*“Collecting drugs at the pharmacy has always been a problem for me because a hospital is a place where many people access healthcare. The problem is that when we get to the pharmacy, there are two windows. There is a separate window where [HIV] infected clients collect our drugs so as soon as you stand there if anybody is aware of the fact they become aware of your status and [the fact that] you are coming to collect our drugs. That becomes a problem anytime you are due for treatment refill. It is a problem.”*

Lydia

The segregation of services made clients self-conscious, worried and shy. The fear of the unintended consequences of the processing procedure for acquiring refills experienced at the pharmacy poses a challenge to retention in the PMTCT programme. Comfort reports that the “problem” contributes to defaulting in the PMTCT programme:

*“I was even telling my husband that I am not comfortable going back to the pharmacy for treatment refill. I remember that I found it very difficult to go back after I delivered.”* Comfort

The women felt that it was unfortunate and reported it was necessary for the midwives, CHNs and other healthcare professionals such as the pharmacists and laboratory technicians, to be conscious of these situations and address them to make service delivery in the programme welcoming and to reduce the hassle associated with accessing care in the PMTCT programme. Mercy stated that this practice needed to stop. The midwives and CHNs also admitted that the mothers’ challenges with the arrangement at the pharmacy needed to be addressed to enhance retention. A reorganisation of the physical space and service delivery strategies could enhance care experience and impact retention.

#### 5.2.2.2.3.4 Engaging the religious leaders

Most of the participants expressed their faith during their narratives. The mothers’ knowledge and health choices concerning HIV was largely influenced by the information they received from the religious leaders. Therefore, religious leaders are

indispensable partners in promoting positive living with HIV, adherence to treatment, and retention in care. Mercy, whose husband died of AIDS shortly after his admission in the hospital was informed her husband's condition was spiritual. That influenced her decision to send him to a prayer garden<sup>14</sup> instead of bringing him to the hospital. She only brought him to the hospital when he was restless and breathless. Esther also reported she had heard that:

*“It [HIV] can be bought and spread by our enemies... You know the witches, so I prayed against it constantly and thought that God would never let that happen to me, that is why I still don't accept it... My pastor confirmed it that the devil was at work, but God is on my side. So, I will receive divine healing.”* Esther

The belief that HIV was a punishment for the morally guilty and also had spiritual connotations was evident in the narratives. Some mothers wholly accepted the advice of the religious leaders and their beliefs thus rejecting PMTCT and ART services. Comfort statement encapsulates this point:

*“So how can my God allow me to go through such things when He knows that I am innocent. I told myself, I would not accept this report... Whose report do you believe? God will never allow this. So, I told her [nurse] I will see her later and left.”* Comfort

The religious messages about HIV affected uptake of PMTCT services as well as the decisions mothers made concerning their health and that of their babies. A midwife shared her challenges:

*“The women listen [more] to the pastors than they listen to us [nurses]. Sometimes, we discuss something, and we agree on the way forward, but they later come back and say that my pastor said this and that...”* Midwife Esi

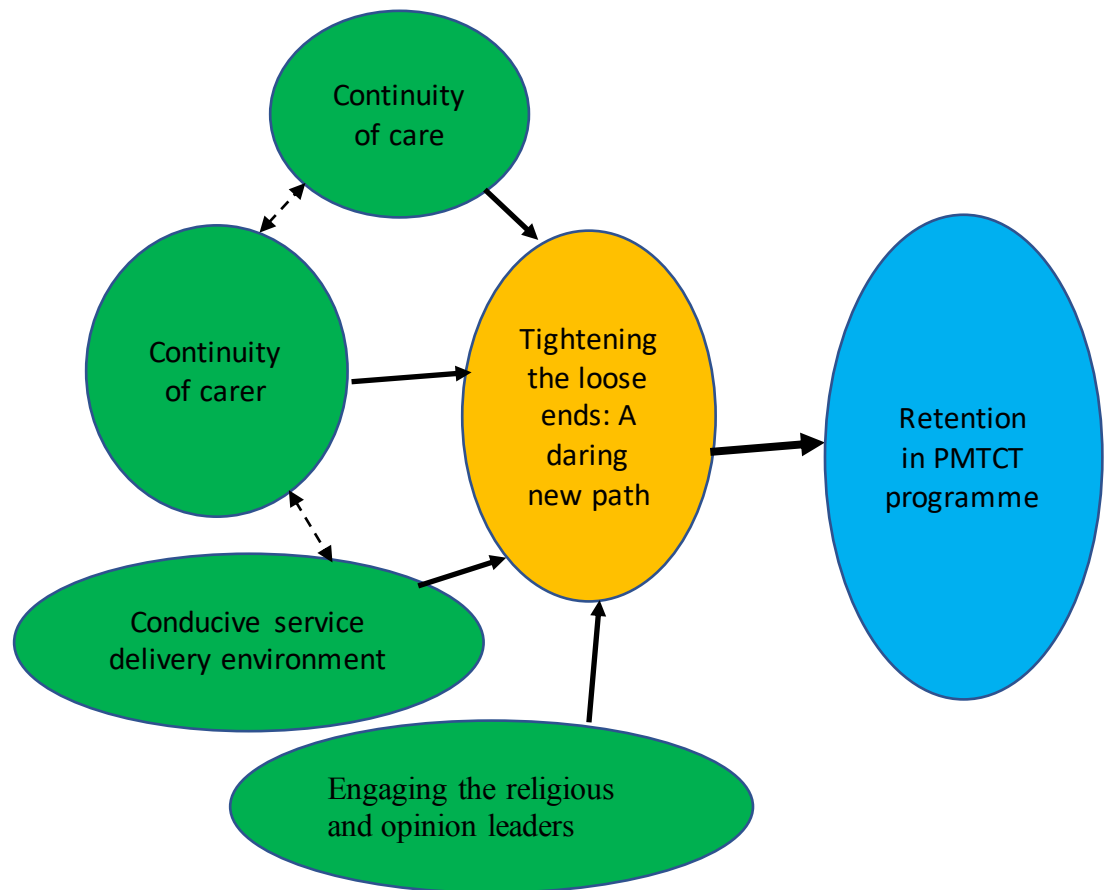
The midwives and CHNs acknowledged that joining forces with the religious and opinion leaders by equipping them with knowledge about HIV and PMTCT tended to influence uptake and retention in the programme positively. Participants believed that restructuring the PMTCT programme in relation to these challenges and

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<sup>14</sup>A faith-based centre where sick people are sent for divine healing through the observation of religious rites such as prayers and fasting.

recommendations will improve care delivery and inevitably enhance retention. Figure 5-8 illustrates the theme clusters that contributed to the emergent theme four.

Figure 5-7 Theme four - Tying up the loose ends: A daring new path



#### 5.2.2.2.4 Conclusion

The stories of the participants and the themes generated reveal that the processes and experiences around testing positive for HIV in pregnancy is extremely challenging. The women found themselves on a journey that began with shock, disbelief, despair, and depression but progressively became more hopeful up until the time of the conversation which ranged up to about seven months post birth. The journey which began with testing positive and enrolment in the PMTCT programme were imbued with stories of positive experiences while giving and receiving care. These

interactions propelled the women to build relationships of trust with the health staff that served as a motivation to remain in care. Although the narratives portray some negative experiences, positive outcomes, including an HIV negative baby and a healthy life, empowered clients, clients remaining in care and rebranding the image of midwifery and nursing. The women found the programme useful and identified strategies/ways of improving the programme to enhance the experiences of other mothers who test positive in pregnancy to improve retention in the PMTCT programme.

### ***5.2.3 Imagine phase***

The aim of the Imagine phase was for participants to create a shared vision of the PMTCT programme that would increase the exceptional experiences of mothers, midwives and CHNs and also improve retention in care. Participants; made up of midwives and CHNs from the ANC, labour ward, PNC discussed the life-giving factors that pertained to their units and collaboratively created a visual image of the PMTCT programme based on their common aspirations for their units. The visual images and their meanings are presented below.

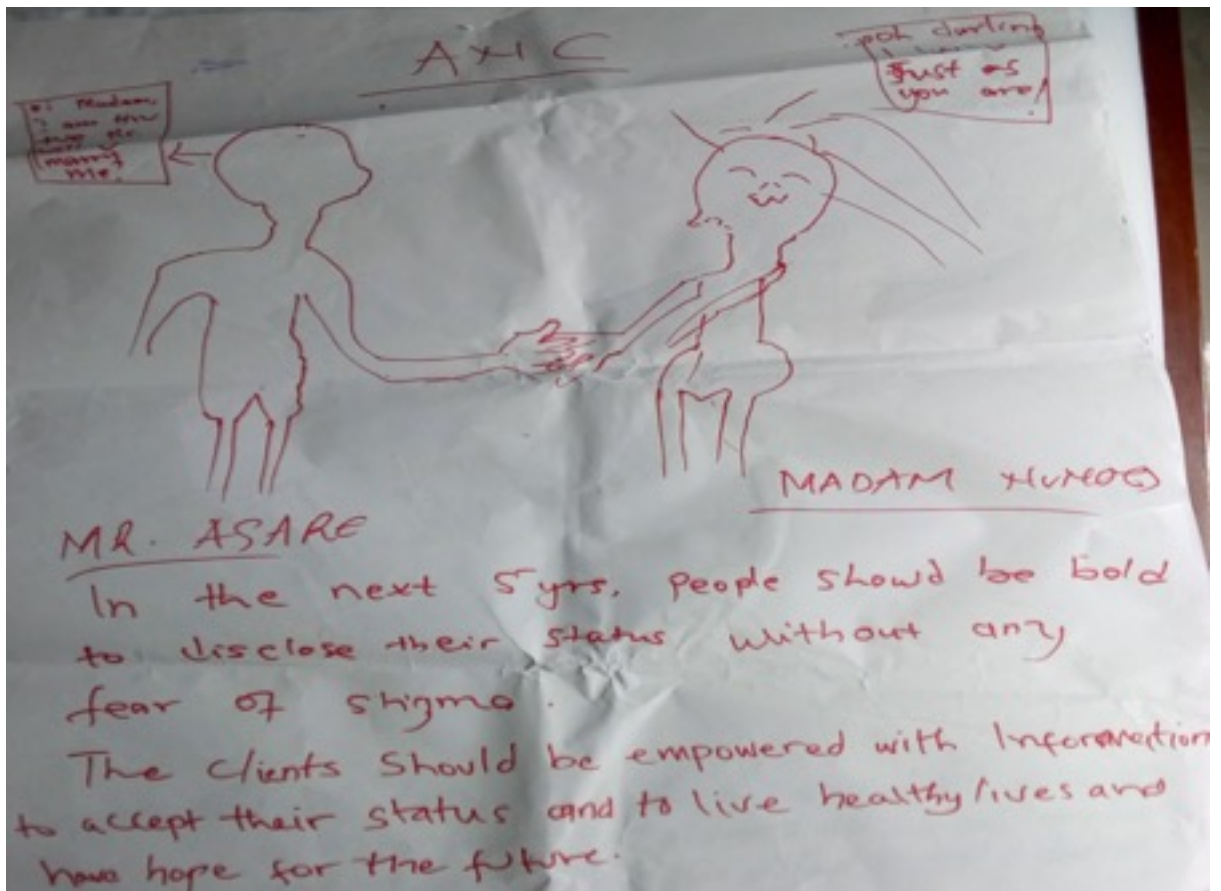
#### **5.2.3.1 Antenatal/Postnatal midwives' group**

Participants in this group explained that the main issue affecting retention in their unit was the fact that an HIV positive diagnosis was usually associated with hopelessness by clients who felt it meant the end of their lives. Fear of discrimination and stigmatization usually underscored their clients' decision to deny the diagnosis, accept help or even disclose to others. The group, therefore, wished for a future PMTCT programme that will empower the clients to make positive choices and enhance the clients' attitude towards life with HIV.

The group presented a drawing of a woman accepting the proposal of a man after he disclosed his HIV status to her.

Meaning assigned: They hoped for a PMTCT programme where clients are empowered with knowledge about HIV through effective counselling, accept their status and are confident enough to disclose their status without fear of stigmatization or discrimination and even have hope for the future (marry).

Figure 5-8 ANC/PNC group vision of the impact of PMTCT programme

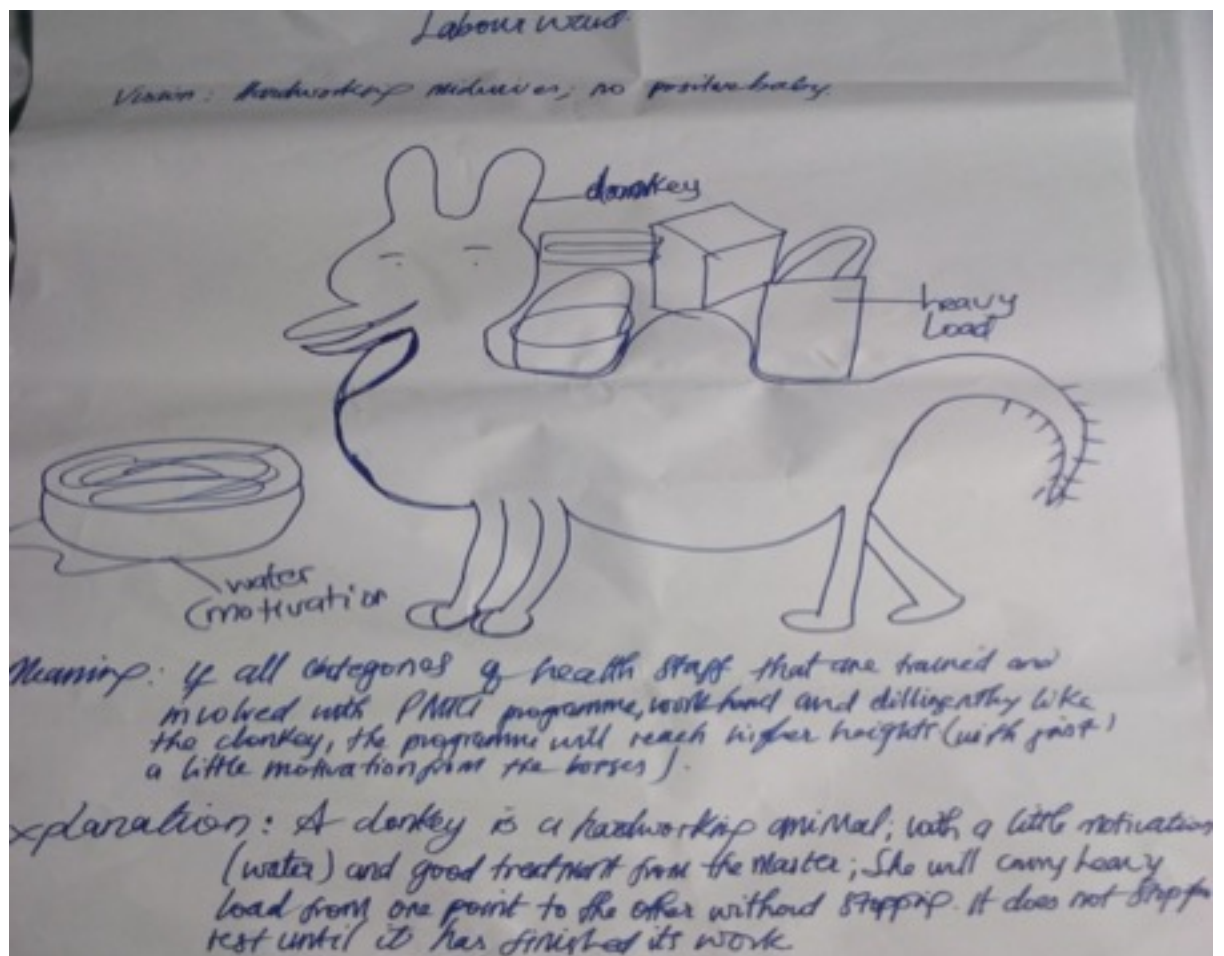


### 5.2.3.2 Labour ward group

The labour ward group explained that their interactions with clients were usually very short however they accepted that the effect of their actions on clients' decision to remain in care was enormous. Their vision was "Hardworking staff, no [HIV] positive babies." They wanted to see all babies born to the HIV positive mothers, to test negative, and in a few years to come, neonatal HIV will be a thing of the past.

The vision of themselves [midwives] serving in the future PMTCT programme is depicted as a hardworking donkey. They seek to be positive contributors to the PMTCT programme but need motivation in the form of time off for training and receiving verbal and written commendation for their efforts in order to be able to undertake the heavy task of providing sensitive and patient-centred care to HIV-infected pregnant women that produce positive outcomes.

Figure 5-9 Labour ward group vision of the PMTCT programme



Meaning assigned: If all categories of health staff that were trained and involved in the PMTCT programme work hard and diligently like the donkey, the programme will reach higher heights with a little motivation from the PMTCT programme managers.

### 5.2.3.3 Public health group

Participants in this group elucidated that they usually interacted with the clients in the communities and explained that the client's beliefs, as well as the influence of community members, influenced their decision to remain in care and live healthy lives. Their vision was: "All hands-on deck for a healthy HIV positive mother and a negative baby." This was illustrated with a drawing of the mother at her home, with the traditional healer, pastor, and nurse all supporting her. Depicting she was not alone but all of them will collaborate to support HIV-infected pregnant women.

Figure 5-10 Public health group vision of the PMTCT programme



Meaning assigned: They explained that if all the stakeholders including pastors, traditional healers and health professionals are trained on PMTCT activities, they can support the woman in their various capacities to live a healthy life and also remain in care so that all positive mothers will have negative babies because of PMTCT in five years' time.

#### **5.2.3.4 Provocative propositions/Possibility statements**

Provocative propositions also known as possibility statements are 'statements that work to "bridge the best of "what is" with the speculation or intuition of what "might be"' (Cooperrider et al., 2003). These statements described the midwives and CHNs' vision of the PMTCT programme that will increase the exceptional experiences of mothers and the health professionals and also improve retention in care. The goals emerged during collaborative discussions on participants' narratives, the drawings and the meanings they assigned to them as significant for achieving retention. The provocative propositions are presented in this subsection in the following order; stigma-free community (5.2.3.4.1), Motivated and committed staff (5.2.3.4.2), Collaborative care (5.2.3.4.3), Relationship between staff and clients (5.2.3.4.4), and Enhanced service delivery (5.2.3.4.5).

##### **5.2.3.4.1 Stigma-free community**

Provocative proposition: We believe that if the community is well informed about HIV/AIDS, and the community members are aware of the availability of services to support the infected person and the successes achieved with treatment, they will be active participants in the care process. That will reduce stigmatization and facilitate acceptance and support of the infected mothers and their (unborn) children.

##### **5.2.3.4.2 Committed and motivated staff**

Provocative proposition: We believe that if the midwives and CHNs who provide care in the PMTCT programme are motivated and committed to the values of the programme and their profession, and supported by managers and system measures, mothers will experience the art of caring in the PMTCT programme. That will promote clients' trust and satisfaction.

#### 5.2.3.4.3 Collaborative care

Provocative proposition: We believe that if religious and opinion leaders are educated on HIV/AIDS and PMTCT services, they will complement the work of the health service by counselling the HIV-infected pregnant women and mothers and support them to remain in care. That will reduce stigma and contradictions as well as improve the health outcomes of mother and child.

#### 5.2.3.4.4 Relationship building between staff and clients

Provocative proposition: We believe that establishing a warm and supportive relationship with the HIV-infected clients will enable them to build trust in the health professionals and confide in us. This will enable them access services freely to improve adherence to treatment and retention.

#### 5.2.3.4.5 Enhanced service delivery

Provocative proposition: We believe that when service delivery in the PMTCT programme is organised to ensure continuity of care and in collaboration with relevant stakeholders, service delivery and uptake in the PMTCT programme will improve. That will enhance clients and health practitioners' experiences in the programme and positively impact retention.

### 5.2.4 *Innovate phase*

The focus of this phase was to engage the participants to brainstorm and identify activities or actions that would result in achieving their visions for the PMTCT programme when implemented. The provocative propositions represent the purpose for which the action plans seek to achieve. The action plans addressed the five provocative propositions; Stigma free community, Committed and motivated staff, Collaboration with religious and opinion leaders, Relationship building between the staff and clients, and Enhanced service delivery. These are presented in tables 5-8 – 5-12 below. The participants believed that acting on these propositions would yield many results with limited resources. Timelines were set for the implementation of the action plans by the units in the PMTCT programme and not for evaluation for the purposes of the study.

## Stigma free community

Provocative proposition: We believe that if the community is well informed about HIV/AIDS, and the community members are aware of the availability of services to support the infected person and the successes achieved with treatment, they will be active participants in the care process. That will reduce stigmatization and facilitate acceptance and support of the infected mothers and their (unborn) children. Table 5-8

Action plan for stigma free community

Table 5-8 Action plans for stigma free community

Vision	Objective	Action steps	Unit responsible for action	Time line (months)
		1.1.1 Organize HIV information outreaches in the communities in the catchment area. 1.1.2 Develop HIV information guidelines that focus on the prevention, testing & treatment and the successes of the PMTCT programme. 1.1.3 Mobilize community members to establish HIV/PMTCT support groups. 1.1.4 Train peer and community outreach groups for HIV/PMTCT activities. 1.1.5 Organize social and mass media campaigns to project the benefits & successes of PMTCT 1.1.6 Offer couple counselling and testing for HIV during PMTCT. 1.1.7 Encourage intimate partner involvement in MNCH/PMTCT activities. 1.1.8 Establish HIV-infected mothers support groups within the facility. 1.1.9 Encourage disclosure of HIV positive status. 1.1.10 Mobilise community members to institute sanctions for those who stigmatize PLWH.		

Committed and motivated staff

Provocative proposition: We believe that if the midwives and CHNs who provide care in the PMTCT programme are motivated and committed to the values of the programme and their profession, and supported by managers and system measures, mothers will experience the art of caring in the PMTCT programme. That will promote clients’ trust and satisfaction.

Table 5-9 Action plan for Committed and motivated staff

Vision	Objective	Action steps	Unit responsible for action	Time line (months)
1. Enhanced professional values and motivation	1.1 To nurture committed and motivated staff to promote effective and supportive care.	<ul style="list-style-type: none"> <li>▪ CHNs and midwives must undergo training on the technical and relational skills required for PMTCT client care before assignment to those units.</li> <li>▪ Rotation of experienced PMTCT nurses and midwives must be within units providing such care to ensure an experienced staff mix.</li> <li>▪ Institute meetings for staff in the programme to ensure positive engagement, team building and information flow.</li> <li>▪ Institute staff support programmes for debriefing.</li> </ul>	All unit providing PMTCT services <sup>15</sup>	6 months

<sup>15</sup>The support of the hospital and nurse/midwife managers of the various units was sought prior to the study implementation.

Table 5-9 continued: Action plan for committed and motivated staff

<b>Vision</b>	<b>Objective</b>	<b>Action steps</b>	<b>Unit responsible for action</b>	<b>Time line (months)</b>
1. Enhanced professional values and motivation	1.1 To nurture committed and motivated staff to promote effective and supportive care.	<ul style="list-style-type: none"> <li>▪ Establish mentoring partnerships between senior nurse/midwives and newly assigned staff into the programme</li> <li>▪ Provide avenues for midwives and CHNs to experience leadership and opportunities for growth such as leading staff meetings and presentations.</li> <li>▪ Establish regular programmes for feedback work through surveys and unit performance reviews to identify areas for quality improvement.</li> <li>▪ Ensure regular staff appraisal and opportunities for staff development.</li> <li>▪ Institute programmes for client feedback and motivate deserving staff e.g. financial, citations or ward plaques etc.</li> </ul>	All unit providing PMTCT services	6 months

### Collaboration with religious and opinion leaders

Provocative proposition: We believe that if religious and opinion leaders are educated on HIV/AIDS and PMTCT services, they will complement the work of the health service by counselling the HIV-infected pregnant women and mothers and support them to remain in care. That will reduce stigma and contradictions as well as improve the health outcomes of mother and child.

Table 5-10 Action plan for Collaboration with religious and opinion leaders

Vision	Objective	Action steps	Unit responsible for action	Time line (months)
1. Collaboration with religious and opinion leaders	1.1 To foster partnership with the various religious and opinion issues to improve uptake in the PMTCT programme and support other health-based interventions.	1.1.1 Engage the chaplain of the hospital in the HIV/PMTCT programme. 1.1.2 Educate religious and opinion leaders on HIV/AIDS and the PMTCT programme. 1.1.3 Involve the Christian council of churches and the Islamic council to establish policies for their membership on counselling about HIV/PMTCT care. 1.1.4 Organize training/health education programmes on HIV/PMTCT for the community leaders, faith-based as well as traditional healers. 1.1.5 Organize outreaches to churches, communities and schools to inform the public about the HIV/PMTCT programme. 1.1.6 Education should include topics such as the successes of the HIV/PMTCT programme in improving maternal health, reducing vertical transmission and reducing mortality. 1.1.7 Develop and distribute pamphlets and leaflets on PMTCT in churches and the community.	Public health unit	6 months

## Relationship building between staff and clients

Provocative statement: Provocative proposition: We believe that establishing a warm and supportive relationship with the HIV-infected clients will enable them to build trust in the health professionals and confide in us. This will enable them access services freely to improve adherence to treatment and retention.

Table 5-11 Action plan for Relationship building between staff and clients

Vision	Objective	Action steps	Unit responsible for action	Time line (Months)
1. Building relationship	2. To nurture a patient friendly staff that will promote uptake and retention	1.1.1 Each unit must adopt a model of care for nursing and midwifery services in the PMTCT programme that enhances continuity of care and carer. Staff member must: 1.1.2 Maintain a roll of their caseload. 1.1.3 Provide the full complements of HIV counselling and testing, and initiate enrolment in the programme for clients who test positive in their care. 1.1.4 Take comprehensive history and contact details (house number and telephone numbers) for clients in their caseload. 1.1.5 Seek patients consent about follow-up and tracking upon defaulting.	All unit	6 months

Table 5-11 continued: Action plan for Relationship building between staff and clients

<b>Vision</b>	<b>Objective</b>	<b>Action steps</b>	<b>Unit responsible for actions</b>	<b>Time line (months)</b>
1. Building relationship	1.1 To nurture a patient friendly staff that will promote uptake and retention	Staff member must: 1.1.6 Establish a therapeutic relationship with the client. 1.1.7 Establish boundaries in the therapeutic relationship while ensuring availability. 1.1.8 Provide adherence counselling at each visit. 1.1.9 Ensure proper documentation of both PMTCT and midwifery/child health care. 1.1.10 Schedule subsequent appointments so that the patient returns to the same staff who tested her for HIV or her team members.	All units	6 months

## Enhanced service delivery

Provocative proposition: We believe that when service delivery in the PMTCT programme is organised to ensure continuity of care and in collaboration with relevant stakeholders, service delivery and uptake in the PMTCT programme will improve. That will enhance clients and health practitioners' experiences in the programme and positively impact retention.

Table 5-12 Action plan for Enhanced service delivery

Vision	Objective	Action steps	Unit responsible for action	Time line (Months)
1. Re-organization of service delivery environment to promote privacy	1.1 To create an enabling environment for service delivery that will promote privacy.	1.1.1 Ensure testing room has privacy; a door that can be closed or sound proof. 1.1.2 Remove chairs from the area in front of the testing room. 1.1.3 If possible use a room that has an exit that does not come back to the waiting room. 1.1.4 Midwives trained in PMTCT should use their own examination rooms for counselling and testing. 1.1.5 No particular room should be assigned for testing. 1.1.6 Place 'door indicators' to indicate when the room is in use.	ANC/PNC	6 months

Table 5-12 continued: Action plan for Enhanced service delivery

<b>Vision</b>	<b>Objective</b>	<b>Action steps</b>	<b>Unit responsible for action</b>	<b>Time line (Months)</b>
2. Team building and collaboration among staffing all units offering PMTCT services	2.1 To facilitate effective communication among PMTCT staff	2.1.1 Build a team with midwives and CHNs from the units 2.1.2 Maintain ongoing communication about patient progression within the various units (patient progress or retention). 2.1.3 Hand over and introduce patients to designated team member when patient is transitioning to a new unit. 2.1.4 Provide feedback on patients' retention status and wellbeing to team members. 2.1.5 Ensure formal orientation to units providing PMTCT care example labour suit 2.1.6 Mentor team members. 2.1.7 Ensure team members are aware of any staff absence (example leave) and a replacement has been established prior to any absence.	ANC/PNC, Labour & Public health	6 months
3. Infection prevention	3.1 To enhance infection prevention practices to promote clients and staff safety.	3.1.1 Ensure the availability of consumables such as gloves essential for the provision of HIV testing, delivery for all mothers and immunization of infants. 3.1.2 Strictly follow the Ghana health service infection prevention guidelines for all mothers. 3.1.3 Change solution for disinfection after soaking instruments used for delivery of HIV positive mothers. 3.1.4 Immediately report any risky exposure to HIV whilst providing care to an infected client. 3.1.5 Organise in-service training on infection prevention for all staff	All units	6 months

## **CHAPTER 6 DISCUSSION OF FINDINGS**

### **6.1 INTRODUCTION**

The chapter presents the discussion of the study findings (6.2), comparison of the study findings with literature (6.3), methodological aspects of study such as the mixed method research approach and the combining of the methods that may have influenced the study such as the strengths, weaknesses (and how they were handled) (6.4), as well as the implications for further research. The researcher's reflexivity report is presented under 6.5. Quantitative and qualitative results are integrated throughout this chapter to give completeness to the discussion (Creswell & Plano Clark, 2007). The discussion is organised according to the specific objectives of the study.

### **6.2 MAIN FINDINGS**

The overarching research question was “what factors will contribute to improved retention in the PMTCT programme?” A client record review was undertaken to contextualize PMTCT retention to the study setting (Section A). The study incorporated the patients' experiences while accessing care in the PMTCT programme and their perspectives on how PMTCT can be improved (Section B, Initiate phase). Midwives and CHNs who provide PMTCT services were engaged in Appreciative Inquiry sessions to brainstorm collectively while incorporating patient ideas to identify strategies to enhance the programme (Section B, Inquire, Imagine and Innovate stages).

The main findings are presented according to the sections of the study.

#### ***6.2.1 Section A: Record review***

The purpose of the record review was to determine the retention of women diagnosed with HIV who started ART during their current pregnancy in the PMTCT programme in the Takoradi Government Hospital until the sixth week postpartum. The review was done for the 12 months period of 2015. Four main findings came out of the review.

1. The uptake of HIV counselling (94.1%) and testing (90.6%) offered under the Opt-out policy in the PMTCT programme was high.
2. Disengagement from the PMTCT programme usually occurred within the antenatal period during which time a total of 30.8% of the women left the programme within this phase.
3. The proportion of women who remained in the PMTCT programme at six weeks postpartum was moderately high, representing 67.3% of all women who tested positive during the study period.

## ***6.2.2 Section B: Appreciative inquiry***

This section presents the major findings in the AI process. The section is organised according to the phases of the AI process: Initiate (6.2.2.1), Inquire (6.2.2.2), Imagine (6.2.2.3) and Innovate (6.2.2.4).

### **6.2.2.1 Initiate Phase**

The objective of this phase was to explore the experiences of HIV mothers in receiving care in the PMTCT programme. One theme was generated under this phase: Transitioning to the ‘new’ woman.

#### **6.2.2.1.1 THEME ONE: Transitioning to the ‘new’ woman**

The HIV counselling, testing and enrolling in PMTCT care represented a phenomenon of transitioning for the newly diagnosed mothers from the state of nonchalance on issues of HIV to women empowered to live healthy lives in spite of their HIV diagnosis. The subsection is organised under four sub themes: Pregnant and healthy (6.2.2.1.1.1), Dealing with disbelief (6.2.2.1.1.2), Shattered dreams (6.2.2.1.1.3), and Journey of hope (6.2.2.1.1.4).

##### ***6.2.2.1.1.1 Pregnant and healthy***

Before testing for HIV in pregnancy, most women perceived that they were at low risk for HIV infection. That was because of the perception of faithfulness in marriage, and beliefs about divine protection gained through religious faith and prayers. An HIV diagnosis brings a rude awakening as the fear of imminent death stares them in the face.

#### *6.2.2.1.1.2 Dealing with disbelief*

Mothers experienced strong emotional reactions such as shock that was expressed with denial and tears after the initial diagnosis of HIV in the PMTCT programme. The need for confirmation of the diagnosis was essential for transitioning towards acceptance.

#### *6.2.2.1.1.3 Shattered dreams*

The dreams of a bright future for women who test positive for HIV in pregnancy usually turn to desolation and hopelessness. The threat of imminent death and the possible risk to others as well as the perceived or experienced stigma usually creates loneliness and social isolation

#### *6.2.2.1.1.4 Journey of hope*

Mothers emphasised the importance of clinging to hope in spite of the initial devastation that the HIV diagnosis brought to them. The findings revealed that generation of hope occurred in four main ways: (1) Gaining knowledge about availability and efficacy of ARTs to prevent vertical transmission. (2) The participants' expression of their religious faith and relationship with God. (3) Re-examining the mothers' outlook on life, the purpose for which they were alive and how best they could live a fulfilled life even with the HIV infection. (4) Staying healthy in spite of the HIV diagnosis. This approach was essential in strengthening the mothers' integrity and stimulating the desire to cling to the hope of a better future. Although implicit in the narratives, spiritual care provided by the midwives and CHNs was a catalyst for renewed hope and the decision to remain in care.

### **6.2.2.2 Inquire phase**

The objective of this phase was for midwives to explore their own stories and the interpretations of the women's composite stories for the factors that enhance retention in the programme. Participants held discussions on aspects of care that needed to be reinforced to enhance retention. Three themes were generated from this phase: Journeying with committed companions (6.2.2.2.1), Glimpses of triumph (6.2.2.2.2) and Tying up the loose ends: A daring new path (6.2.2.2.3).

### 6.2.2.2.1 THEME TWO: Journeying with committed companions

The findings were presented under two sub-themes: Engaged nurse-patient relationship (6.2.2.2.1.1) and Two is a company; more is even better (6.2.2.2.1.2).

#### *6.2.2.2.1.1 Engaged nurse-patient relationship*

From the review of the mothers' stories and their own experience, the midwives and CHNs understood that an important aspect of midwifery and nursing care in the PMTCT programme was establishing and maintaining relationships, which provided a sense of relatedness to the client. This relational aspect was essential because many of the mothers experienced loneliness, depression, and fear of stigmatization that often resulted in social isolation and suicidal thoughts during the initial days after the diagnosis. The midwives and CHNs also realized that being approachable and available to their clients was important in strengthening the relationship. The values appreciated by the participants to sustain the relationship were confidentiality, trust, being approachable, accessible, supportive and caring.

The news of a definite HIV diagnosis to the pregnant woman was a source of stress. In spite of this, the health workers' commitment to duty and empathy for the clients resulted in most midwives and CHNs going the extra mile for the client. Although the mothers appreciated the efforts of the midwives and CHNs, policies on debriefing and emotional time out were not in place to support the health workers emotionally.

All the participants described the various forms of 'counselling'; pre-test, post-test and adherence counselling as pivotal in the mothers' decision to remain in care as they gained knowledge about how to live healthy lives and also it provided the opportunity to for clarifications and questioning pre-test counselling often fell short of what was required. Findings revealed that the counselling process was information giving in nature (See footnote 16). The midwives and CHNs also gathered enough information through the counselling process to tailor care specific to the mothers' needs.

#### *6.2.2.2.1.2 Two is a company; more is even better*

The study revealed that support from the intimate partner and family members to whom the mother chose to disclose was a strong motivation for remaining in the PMTCT programme. The forms of support provided by the family included psychological, emotional and social support that enhanced the mothers' confidence and zeal to remain in the PMTCT programme.

#### **6.2.2.2.2 THEME THREE: Glimpses of triumph**

This theme presents details on the factors that influence expectant mothers diagnosed with HIV in pregnancy to remain in the PMTCT programme. Findings point to the fact that the mothers, midwives and CHNs experienced a sense of elation and accomplishment when they achieved set goals. Three sub-themes were generated under this phase: Celebrating health (6.2.2.2.2.1), Empowered client (6.2.2.2.2.2) and Changing perceptions about midwives and nurses (6.2.2.2.2.3).

##### *6.2.2.2.2.1 Celebrating health*

An HIV negative result for an exposed child, as well as, a 'healthy' HIV infected mother was an accomplishment and a boost for the efforts of the midwives, CHNs and mothers. For the mothers, health was the absence of physical signs of disease. There was a recognition of the feeling of wellbeing and health—maintaining or gaining weight, absence of rashes and other visible skin infections, etc, as a result of the effectiveness of the treatment. Remaining healthy was essential to maintain their power of choice on to whom to disclose or not. Maintaining a semblance of health was a motivation to remain in the programme.

##### *6.2.2.2.2.2 The empowered client*

Participants emphasized that building the self-esteem and confidence of the infected women to make informed choices, about their health and that of their children was a significant achievement of the PMTCT programme. Engaging in the PMTCT programme as an equal partner was an indication of an empowered client, and this positively motivated the mothers' decision to remain in the programme.

### *6.2.2.2.2.3 Changing perceptions about midwives and nurses*

This sub-theme expressed the change in perception of mothers about midwives and CHNs, as well as midwifery and nursing care in the PMTCT programme. Findings revealed that most mothers renewed their negative perception of midwives and nurses. From the midst of the hopelessness, the caring nature of the midwives and CHNs permeated the experiences of the mothers. Findings revealed that some mothers found midwifery services after HIV infection more welcoming and client sensitive than when they were HIV negative. This perception enhanced their decision to continue engaging in the PMTCT programme.

### **6.2.2.2.3 THEME FOUR: Tying up the loose ends: A daring new path**

Four sub-themes emerged within this theme: Continuity of care (6.2.2.2.3.1), Continuity of carer (6.2.2.2.3.2), Conducive service delivery environment (6.2.2.2.3.3) and Engaging the religious and opinion leaders (6.2.2.2.3.4). Findings revealed challenges and gaps in service delivery when accessing care in the PMTCT programme. The participants felt that when the challenges were addressed, the clients' experiences in the PMTCT programme could improve and yield higher retention.

#### *6.2.2.2.3.1 Continuity of care*

The PMTCT programme was 'officially' integrated into the existing maternal, neonatal and child health services. However, at the service delivery level, the integration of the programme into the MNCH service was partial as there were aspects of the care that was fragmented. This fragmentation posed challenges to the clients when they sought to engage in the programme. This could be reorganised to impact patients' experiences and retention in the PMTCT programme.

Ensuring continuity of care across the continuum was identified as a significant solution towards bridging the gaps reported by mothers as they progressed along their journeys. The midwives and CHNs realised that ensuring adequate information flow among staff, standardising patient flow pathways as well as facilitating the mothers' transition from PMTCT to adult care, could enhance service delivery and retention.

#### *6.2.2.2.3.2 Continuity of carer*

Findings portrayed that ensuring the continuity of carer was essential in enhancing retention as it reduced the increasing need to disclose the clients' HIV status and minimised the knowledge about people's status before accessing care whenever the health worker was changed.

#### *6.2.2.2.3.3 Conducive service delivery environment*

The arrangement of the physical environment in the units providing PMTCT services affected the mothers' decision to access or remain care. The allocation of a PMTCT counselling and testing room at the ANC, the waiting room and the organisation at the pharmacy setting affected privacy and confidentiality.

#### *6.2.2.2.3.4 Collaboration with religious and community leaders*

Collaborating with religious and community leaders was a critical factor in ensuring higher rates of retention in the PMTCT programme. The religious and community leaders wielded some power and influence over the community members and followers that could be used to ensure positive health-seeking behaviours of mothers.

### **6.2.2.3 Imagine phase**

The objective of this phase was to explore the aspirations of health staff for improving retention in the programme. The midwives and CHNs had three main aspirations: (1) harness the efforts of all staff trained in the PMTCT programme to reduce the stigma associated with HIV by the society, (2) enhance the quality of service delivery for mothers during labour which ought to be sensitive and compassionate, and (3) to mobilize support for the HIV mothers from the community, religious and traditional leaders.

### **6.2.2.4 Innovate phase**

The objective of the innovate phase was the development of action plans that would guide provision of care in the PMTCT programme to enhance retention. Five action plans were developed under the following headings: stigma-free community, motivated and committed staff, collaboration of religious and community leaders, relationship building between staff and clients, and enhanced service delivery.

## **6.3 COMPARISON OF FINDINGS WITH RELEVANT LITERATURE**

This section discusses the findings of the study with relevant literature. It is presented according to the two sections of the study: Section A record review (6.3.1) and Section B; Appreciative Inquiry (6.3.2).

### ***6.3.1 Phase one: Record review***

This section compares the findings of the client record review in this study with relevant literature. It is organised under the following subsections: uptake of HIV counselling and testing (6.3.1.1), retention in the PMTCT programme (6.3.1.2), the phenomenon of disengagement and re-engagement (6.3.1.3), and the socio-demographic characteristics of participants and retention (6.3.1.4).

#### **6.3.1.1 Uptake of HIV counselling and testing at ANC**

This facility-based review found that women who presented for antenatal care were offered HIV testing and counselling. The uptake of HIV testing in the PMTCT programme by pregnant women was high. Hence 90.6% of the 1 252 pregnant women who reported to the facility and booked for antenatal care became aware of their HIV status. The MNCH department in this facility, therefore, achieved the first 90% in the UNAIDS proposed targets for the AIDS epidemic by 2030 which stipulates that 90% of the people living with HIV should know their status (UNAIDS, 2014). The proportion of pregnant women who knew their HIV status under the opt-out policy of HIV testing in this study was slightly higher than the 82.5% recorded in the same facility in 2012 (Ghana Health Service, 2016) when the policy for testing was voluntary counselling and testing (VCT). This reflects a higher uptake of HCT with the opt-out approach than when the opt-in (VCT) policy was in operation in PMTCT. Similarly, after transitioning to opt-out testing approaches in the PMTCT programme under option B+, high acceptability and uptake of HTC and CD4 testing (98%) in PMTCT at the facility level was recorded in Malawi (Kim, Ahmed, & Abrams, 2015). The rate of uptake was slightly higher in Togo that reported 92% (Tatagan et al., 2011) and 98.5% in five health facilities in Cameroon (Atanga et al., 2017). In spite of this high uptake of HIV testing, in the context of HIV in pregnancy and the PMTCT programme, missed opportunities and opting out

pose a risk for maternal health, vertical transmission and ultimately for paediatric health.

The HIV prevalence among pregnant women at this facility was 3.4%. This rate was higher than the national antenatal prevalence of 2.4% in 2016 (Ghana AIDS Commission, 2016). Similarly, the facility-based antenatal prevalence in a district hospital in Cameroon was 13.1% (Fouedjio, Fouelifack, Fouelifa, & Mbu, 2017) compared with the national prevalence of 3.8% in the national sentinel survey (UNAIDS, 2018). Likewise, a higher rate of antenatal HIV prevalence was also recorded in South Africa (30.8%) (National Department of Health, 2017), while the national prevalence was 12.7% (Statistics South Africa, 2016). Montana, Mishra & Hong (2008) report that antenatal surveillance surveys tend to overestimate HIV prevalence when compared with the national departments of health estimates of HIV prevalence.

In the case of South Africa and Zimbabwe, all women who present for antenatal booking undergo unlinked anonymous testing for HIV as part of a survey to determine the antenatal prevalence. Following the anonymous test, an offer of provider-initiated HIV counselling and testing is made to the clients who may choose to opt-in or -out (Nkomo & Goga, 2015; Wilson et al., 2017). These approaches may account for the high antenatal prevalence of HIV and may be presenting the actual picture.

There have been many debates in support or against the practice of unlinked anonymised HIV testing of pregnant women (Datta & Kessel, 2010; de Zulueta, 2000; Kessel, Datta, Wellings, & Perman, 2012). The arguments against the testing approach has been centred on the ethical principle of autonomy and informed consent in biomedical research (Beauchamp & Childress, 2001; de Zulueta, 2000; Fairchild & Bayer, 2012) while those that support its implementation argue that it is necessary for ensuring the public good as the prevalence information gathered from the unlinked anonymous testing provides an accurate basis for policy planning and health system restructuring for the general population without causing direct harm or invading the privacy of the individuals from whom the samples are taken (Nicoll et al., 2000; WHO, 1989). In the light of these ethical and moral debates, countries like the UK and India have adopted a prior notification system although consent is more implicit than explicit (Bayer, Lumey, & Wan, 1990; Krishnan & Jesani, 2009). WHO

has also provided guidelines for conducting unlinked anonymous testing of HIV that addresses the concerns of those who argue against it (WHO, 2015).

With the introduction of opt-out policy and the missed opportunities for counselling and testing in this study, one wonders if the antenatal HIV prevalence is an accurate reflection of the Ghanaian situation or if another approach to ascertaining a more reliable data should be considered.

### **6.3.1.2 Retention in the PMTCT programme**

Although the definition of outcomes differs between studies (Shargie et al., 2011; Sibanda, Weller, Hakim, & Cowan, 2013), the proportion of women (67.4%) who remained in the PMTCT programme at six weeks postpartum is mostly consistent with a study in Rwanda, which indicated a retention rate of 68% at six weeks postpartum (Woelk et al., 2016). A slightly higher retention rate (73.8%) was recorded in Kwazulu Natal, South Africa (Chetty, Thorne, Tanser, Bärnighausen, & Coutsoodis, 2016). Similarly, in Democratic Republic of Congo, 76.4% of mothers reportedly remained in the programme and accepted all available PMTCT services at the sixth week postpartum period (Yotebieng, Fokong, & Yotebieng, 2017). This rate may, however, be moderately high because of the short postpartum time under review as other studies have reported a decline in the proportion of women who remain in care at six, twelve and 36 months postpartum (Shargie et al., 2011; Sibanda et al., 2013).

Although there was disengagement at all the phases along the PMTCT cascade, the highest proportion of disengagement (30.8%) from the programme occurred during the antenatal period. This finding is consistent with studies in Malawi (Tenthani, Haas, Tweya, Jahn, van Oosterhout, et al., 2014) and Rwanda (Woelk et al., 2016) where disengagement and LTFU of pregnant women who tested positive for HIV in pregnancy occurred immediately after diagnosis and within the first 30 days of diagnosis respectively. This is however contrary to findings by Phillips et al. (2014) in Cape Town, South Africa where disengagement occurred mostly in the postpartum period. The rate of disengagement was two times higher in the postnatal period (6.17 per 100 women-months) compared to the antenatal period (2.41 per 100 women-months) by six months postpartum. The study did not report on the exact timepoints

within the postpartum period when the most attrition occurred. This disparity in findings may be due to the differences in timepoints being investigated.

### **6.3.1.3 The phenomenon of disengagement and re-engagement in PMTCT**

What is marked in this study is the finding that disengagement from a facility after a positive HIV result may not necessarily translate to disengagement from the PMTCT programme. This conclusion is based on the narratives of some women who were classified as ‘retained’ in the programme in the study facility. They reported hospital shopping in two or three other facilities before registering and remaining in the PMTCT programme at the study facility. Literature has recorded similar incidents of hospital shopping in adult HIV care but not as yet in the PMTCT programme. Moshabela, Pronyk, Williams, Schneider, & Lurie (2011) found medical pluralistic patterns of varying levels including orthodox, complementary and alternative health care providers among HIV infected adult clients in South Africa. The newly diagnosed HIV positive clients were also reported to switch between health facilities, providers and sectors prior to initiation of ART and retention in the facility of their choice.

In the current study, findings of the mothers’ narratives also pointed out that the phenomenon of ‘hospital shopping’ was precipitated by the pressing need to confirm the definite HIV diagnosis. The need to confirm the diagnosis stemmed from the mothers’ perceived low risk to HIV although being sexually active, a woman and being of sub-Saharan African descent placed them at elevated risk (Söderström, 2006). As in the case of the study by Moshabela et al.(2011), the sequential patterns of hospital shopping, where different ANC/PMTCT service providers were visited without returning to the previous, were identified in this study. ‘Hospital shopping’ may contribute to multiple registrations, and inflation of the HIV prevalence rate as clients are continuously documented as newly infected in all the facilities they visit.

The phenomenon of re-engagement was also identified in this study as some clients who had sought care outside their facilities without proper transfer, returned to the initiating facility to continue PMTCT programme. Gugsu et al.(2017) purport that the most common reasons for re-engagement in PMTCT programme after defaulting was the mothers’ desire to remain healthy and the counselling health providers give when

they track patients. Health service documentation of re-engagement into PMTCT care has been inconsistent resulting in under-reporting of the phenomenon. Bupamba et al. (2010) recommend that defaulter tracing activities be linked to the client's records to measure return to the programme outcomes.

### **6.3.1.4 Socio-demographic characteristics of participants and retention**

This study could not establish any statistical difference between the socio-demographic characteristics of mothers who remain in the programme throughout the data collection and those who disengaged. This observation could be as a result of the research method employed in this study which was mainly descriptive and did not apply analytic tools. The small sample size did not provide the power to undertake an analytic study. This challenge with sample size is discussed under the limitations (6.4.2). The small sample size is however congruent with the nature of the phase as a baseline study (Hopkin, Hoyle, & Gottfredson, 2015) and the overall study focus on the AI. In spite of this, descriptive analysis indicates unemployed women in the study disengaged. Similar findings were reported in South Africa which reported similar socio-demographic characteristics of the participants who disengaged or remained in the programme although the sample size was large (Phillips et al., 2014). The average age of both the women who disengaged or remained in the programme was 28 years and there was no difference in the educational level and employment status in both groups ( $p = 0.568$  and  $p = 0.155$  respectively).

### **6.3.2 Section B: Appreciative inquiry**

Most studies focus on the factors that promote disengagement and LTFU and report on some negative experiences of clients in the PMTCT/ART programme (Atanga et al., 2017; Bigna, Noubiap, Plottel, Kouanfack, & Koulla-Shiro, 2014; Wang et al., 2017). This study's contribution to knowledge is to explore retention from a philosophically different perspective built around positivity<sup>16</sup>. The study explored the

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<sup>16</sup>Positivity in Appreciative Inquiry philosophy that focuses on identifying the best of what exists in an organisation and seeking to amplify it. This dwells on unconditional positive regard of questioning, analysis and interpretation of data.

experiences of people who chose to engage in the PMTCT programme on their own accord after a positive diagnosis rather than focusing on defaulters because they choose to disengage from the programme. The Appreciative Inquiry approach was used to explore the experiences of the mothers, midwives and CHNs' in the PMTCT programme. Through storytelling and meaning-making, the appreciative inquiry process was applied for the generation of knowledge and consensus (Bushe, 2013) for the transformation of the PMTCT programme into a sustainable patient-centred, positive experience and results-driven PMTCT service delivery that enhanced patients experiences and retention.

From this perspective, therefore, the inquiry uncovered mothers', midwives' and CHNs' exceptional experiences in the PMTCT programme that contributed to the clients' decisions to remain in the programme and the outlook of the midwives and CHNs on providing care in the PMTCT programme. As nurses and midwives are the largest workforce in the Ghanaian health sector, providing quality nursing and midwifery care is essential for attaining better health outcomes at all levels of service delivery including the PMTCT programme (Nursing and Midwifery Council, 2015). This perspective underscores the role of nurses and midwives as prescribed by the American Nurses Association (2010) as protecting, promoting and optimizing health and in this case, optimizing wellness and health of newly diagnosed HIV-infected pregnant women and lactating mothers. In South Africa, the performance of this role by nurses and midwives requires effective application of the knowledge, skills, personal attributes and clinical judgement with the sole purpose of attaining better health outcomes for the clients (Department of Health, 2013)

This section of the discussion of literature is organised according to the themes that were generated and presented in chapter 5 (5.2). It begins with the comparison of findings with literature under the theme: Transitioning into a 'new' woman (6.3.2.1). It is followed by Journeying with committed companions (6.3.2.2) and Glimpses of triumph (6.3.2.3). A write-up on 'Tying up the loose ends: A daring new path' (6.3.2.4) concludes this section.

### **6.3.2.1 THEME ONE: Transitioning into a 'new' woman**

This section compares the experiences of mothers in this study while accessing PMTCT care with relevant literature. The section is organised under the following

subheadings: pregnant and healthy (6.3.2.1.1), dealing with disbelief (6.3.2.1.2), shattered dreams (6.3.2.1.3) and journey of hope (6.3.2.1.4).

### 6.3.2.1.1 Pregnant and healthy

The study findings revealed that most women were nonchalant about HIV before their decision to opt for HIV counselling and testing because of their perceived low risk for HIV infection. It was evidenced from the AI that the perception of low risk to HIV infection was linked to the belief that they were in committed relationships and faithful to their current partners. Eze & Onwasigwe (2017) in a study in Nigeria among antenatal attendees found a significant association between marital status and perceived low risk to HIV infection ( $p < 0.05$ ) even though they engaged in unprotected sex. Darak et al. (2014) also reported a similar finding in a study in India, where only one in five of the pregnant participants in their study perceived themselves to be at risk of an HIV infection. Perceived health-related risk generally informs people's health-seeking behaviour (Sheeran, Harris, & Epton, 2014).

Consequently, in this study, the clients had only tested for HIV during a previous or the current pregnancy only as a fulfilment of a requirement and not of their own volition. Similarly, Bulman, Mathews, Parsons, & O'Byrne (2013) reported from a study in Canada that women agreed to an HIV test in pregnancy out of compulsion.

Gendered power dynamics underscore most married women's decision or attitude in taking the responsibility of ensuring safer sex. This is true for even those women who are aware of their risk of HIV infection. This is as a result of fear of abuse, conflict or even divorce (Mtenga, Geubbels, Tanner, Merten, & Pfeiffer, 2016).

Empowering women through an increased focus on health literacy can therefore not be overstated.

Counselling for HIV testing is an essential aspect of the PMTCT service (Ghana Health Service, 2014). Counselling in PMTCT is geared towards providing the clients with the right information to enable the women make informed choices about HIV testing, maintaining their health after the test for all the clients whether positive or negative and treatment options for those who test positive (Kumar, Singh, & Kusuma, 2015). Solomon, Visnegarwala, Philip, Pappachen, & Alexander (2012) aver that counselling is the backbone of the Prevention of Parent to Child Transmission services and key to the success of the programme in India. Apparent

in this study was the fact that the mothers, midwives and CHNs valued the positive impact of the counselling process in the PMTCT programme. The attitude of both the counsellor and the client were essential to the success of the counselling process. Non-judgmental, receptive and approachable midwives and CHNs were assets to the programme as their demeanour and attitude facilitated acceptance and uptake of services.

Although most of the midwives and counsellors undertook the process with decorum and professionalism, a striking finding was that some midwives and counsellors seem to trivialise counselling in spite of the apparent gaps in mothers' knowledge on HIV infection and prevention. One mother reported, in response to her hesitation to take the test out of fear of the outcome, the midwife told her 'it is not anything.' Similarly, Kelly, Alderdice, Lohan, and Spence (2012) were concerned that midwives do not sensitize the pregnant women about the possibility for a positive result in the pre-test counselling. Pre-test counselling has reportedly been lacking in some PMTCT services and even in instances where counselling was given prior to HIV testing, the approach was service-oriented rather than client-oriented (Buregyeya et al., 2017). In some instances, pre-test counselling was merely information-giving about HIV/AIDS, transmission and prevention, couple testing and implications for the result. Kumar et al. (2015) indicate from a study in India that the pre-test component of HIV counselling was intended for providing information on HIV and PMTCT and motivating the client to opt for testing. Counselling for HIV testing must entail more than information giving as it provides the opportunity for health professionals to address the stigma associated with HIV and the opportunity to gather information about the client that would be useful in planning the individualised care in the PMTCT programme (Theilgaard et al., 2011). The women's perceived low risk, as well as, the gaps in counselling, may have contributed to the intense negative experiences associated with a positive HIV test result.

It was noteworthy that all the participants (mothers, midwives and CHNs) felt that effective counselling was necessary to trigger the process of transitioning of the newly diagnosed HIV positive women from their state of denial towards acceptance and empowerment. Bofill et al. (2015) suggest that adopting motivational interviewing in HIV care is a viable approach to promote engagement and retention

of clients. Motivational interviewing will enable the counsellor to engage with the mother's agenda, focus on the consequences of her choices and stimulate discussions on her options. Hancock, Davidson, Daly, Webber, and Chang (2005) support this assertion and suggest that motivational interviewing will be able to minimise the patients' defences and promote disclosure. That is because the patient-centred nature of the approach fosters active participation and engagement. Since continuous engagement and active client participation are the important aims of PMTCT care, motivational interviewing as a counselling approach especially in the post-test and adherence counselling sessions must be explored.

#### 6.3.2.1.2 Dealing with disbelief

Kubler-Ross' framework on bereavement has been applied in HIV and PMTCT studies to understand the experiences of persons living with HIV including women who test positive during pregnancy (Bain, 2010; Kelly et al., 2012; Lingen-Stallard, Furber, & Lavender, 2016; Zeligman & Wood, 2017). The bereavement and grief of people infected with HIV has typically been associated with the loss of life experienced by family and community members. However, loss can either be abstract or physical (Rando, 1991). With the improvement in the prognosis of HIV as a result of the efficacy of ART, Zeligman & Wood (2017) aver that the conceptualisation of grieving of people living with HIV should not be limited to loss of life but extended to understand the physical, social and emotional loss they experience. In this regard, the application of the Kubler-Ross (1969) framework of grieving to the experiences of women newly diagnosed with HIV in pregnancy revealed the process of disbelief and shock, bargaining, depression and acceptance that culminated in the process of transition and empowerment of the infected mother. Notably, not everyone experienced the same responses in the stages that are described in the framework (Kubler-Ross & Kessler, 2014).

For the newly diagnosed HIV positive pregnant or lactating woman, the sense of loss related to the 'image' of who they were before the test, their ambitions and the future they had anticipated with the birth of their new-borns. The HIV positive diagnoses present a mirror into which they are forced to view the 'actual' people they now were; chronically ill, confronting the bleak reality of their lives, and the future which looks almost non-existent, pointing to imminent death.

Disbelief and denial as initial reactions to a definite HIV diagnosis point to the unexpected nature of the news and the lack of appropriate pre-test counselling. Likewise, Lingen-Stallard et al. (2016) and Kelly et al.(2012) reported similar findings in the United Kingdom. Kubler-Ross and Kessler (2014; p 77) described a person in denial as being “paralysed with shock or blanketed with numbness”. Similar words were used in this study to describe the mothers’ initial feelings. Denial was not a sign of weakness but provided the opportunity for temporary escape to re-gather the needed resources to cope with the diagnosis (Kubler-Ross, 1969) and this was echoed by the women’s actions such as making the decision to re-test or disclose to others. Denial and disbelief sometimes resulted in multiple testing associated with hospital shopping.

But in most instances, the result of the confirmatory test was a catalyst to progress from denial along the process to acceptance and transition. The confirmatory test was a policy and PMTCT programme requirement (Ghana Health Service, 2014; MOH/GHS, 2014). For some of the women, it was critical as it brought closure to the disbelief and aided them in progressing towards acceptance of the diagnosis informed decision making about enrolling in the PMTCT programme. Kelly et al.(2012) also reported a similar need for re-testing by HIV positive pregnant women in the United Kingdom. That was an avenue for bargaining as they wished the results would be negative the second and third times. Negotiating with God for a different result was evidenced in this study. Bargaining is a recognised means of grieving and may even result in making promises to the higher being if only the situation will return to normal (Kubler-Ross & Kessler, 2014). However, in all of the instances when the women sought confirmation, the initial positive results were confirmed which gave the space to get to the point of realisation.

Kubler-Ross (1971) identified anger as a come reaction to loss. Anger was however, not a typical reaction reported by the participants when they were informed of their HIV status. On the contrary, Kelly et al. (2012) reported that women expressed anger at the people whom they felt had infected them. The women in this study may not have reported on anger as the time lapse between their diagnosis and the conversations may have afforded them the opportunity to reflect on the source of the infection and thus modified their reaction. Some mothers who had disclosed their status to their spouses and insisted on testing realized that they were discordant and

needed to reassess their source of infection and their reactions. A significant number of women experienced sadness rather than anger as they accepted the positive results as final. The sadness resulted from their reflections about the loss of hopes about the future, the joys of pregnancy and their image or perception about their health. Kelly et al. (2012) refer to this situation as a disjuncture from the life the mothers knew before their diagnosis.

### 6.3.2.1.3 Shattered dreams

This current study found that even though most of the mothers who tested positive for HIV intrapartum were physically ‘healthy’, they suffered emotional and psychological ill health to the extent of contemplating suicide as a result of the diagnosis. The enormity of a definite HIV diagnosis to the pregnant woman was overtly and covertly revealed in the findings. For most mothers, the unexpected nature of the outcome of the test, feelings of betrayal by their intimate partners and the perceived stigma associated with an HIV diagnosis resulted in internalized stigma. Internalized stigma occurs when affected people emotionally absorb the societal assumptions and stereotyping about an issue such as HIV and applies it to themselves (Drapalski et al., 2013). The internalized stigma resulted in social isolation and emotional instability. Lysaker, Roe, & Yanos (2006) associates the social isolation with decreased hope and self-esteem. These findings corroborate the reported outcomes of a study by da Silva, Moura, and Pereira (2013) who found that the repercussions of emotional distancing and abandonment by intimate partners and other social relations on the newly diagnosed HIV positive woman included emotional instability, suicidal tendencies, and depression. Bezuidenhout et al. (2011) found that a women’s perception of being undesirable because of HIV infection created an emotionally stressful situation.

Depression is a reaction in the process of grieving in the Kubler-Ross framework (Kübler-Ross, 1971). During instances of grief, depression becomes protective as the nervous system naturally shut down so that the individual can adapt to situations they feel they cannot handle (Kubler-Ross & Kessler, 2014). Rottenberg (2005) identifies crying as a typical reaction of people in depressive states. The shock and depression the infected women in this study experienced were characterised by crying, suicidal thoughts, fear of death and stigmatization that often resulted in hopelessness. Similar

emotional reactions were reported in other studies (Lingen-Stallard et al., 2016; Treisman, Jones, & Shaw, 2014).

The role of others in assisting the women to progress through the process of grieving was evident in this study. Soliciting and receiving reassurances and counselling from the midwives and CHNs during the stage of depression were found to be worthwhile in propelling the mothers towards acceptance of the diagnosis. The present findings are consistent with the study by Bezuidenhout et al. (2011) which found that the nurses' role of assisting the client to distinguish between HIV and AIDS was effective in restoring hope and renewing the women's perception of a possible future. That was because AIDS was marked as a state of hopelessness. The distinction reduced the enormity of the HIV diagnosis, albeit not entirely, and allowed the women to assimilate the meaning of the diagnosis. Consequently, in this study, the mothers coped better when they accepted the diagnosis as being similar to other chronic diseases such as diabetes and hypertension which required lifelong medication (Mbuagbaw et al., 2015) and interpreted the diagnosis differently from the societal definition of HIV infection as an indication of promiscuity and unfaithfulness.

In this study, negotiating disclosure of a mother's HIV diagnosis to a trusted person other than a nurse was also seen as an essential step in reducing social isolation and transitioning towards empowerment of the mother process. The negotiation involved deciding whether to disclose or conceal ones' HIV positive diagnosis, choosing to whom to disclose; whether family or friend; the most appropriate time to do so; and the implications of each choice. The mother's peculiar circumstances informed her final decision on disclosure (Linda, 2013). Findings from the record review of this study revealed equal proportions of participants (30.2%) disclosed or concealed their status at the time of review of clients' PMTCT/ART records<sup>17</sup>. This rate of disclosure was lower than the 73.3% reported in Uganda (Naigino et al., 2017). Findings from this study revealed that fear of being blamed for infidelity and being responsible for bringing HIV infection into the family, as well as, concerns about disappointing

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<sup>17</sup>Records of disclosure status were extracted from the mothers' ART folders which are issued when mothers are initiated on treatment. These records are meant to be updated but the researcher could not verify whether the information was updated or represented the initial booking records.

family members were the main reasons for non-disclosure. This finding is consistent with other studies in sub-Saharan Africa (Maeri et al., 2016; Moshi, Helleve, & Gradmann, 2016; Rujumba et al., 2012) where the fear of blame of infecting their partners and placing family members at risk was associated with non-disclosure. The fear, when unresolved, had implications for the transitioning process of the infected woman as the need to conceal competed with other critical positive choices such as returning for a medication refill for fear of being identified. Similar to findings by Mkwanazi, Rochat, & Bland (2015), participants in this study who disclosed their status in spite of the anticipated / potential negative implications reported receiving psychosocial support, and nobody reported any negative consequences. This finding was contrary to the reports of direct abuse, violence, partner rejection and breakdown of families reported by mothers in the study by Kelly et al. (2012). Violence against pregnant women who disclosed their HIV status to their intimate partners was also reported by Hatcher et al. (2014). They found that the intimate partner violence (IPV) of women who were HIV positive was triggered by the perception of infidelity and the allegations that the HIV infection in the family originates from the women. The actual or perceived violence did not only leave physical bruises but emotional and psychological scars of the impact of an HIV diagnosis on the lives of the women who are infected.

#### 6.3.2.1.4 Journey of hope

Although the Kubler-Ross framework of grieving does not specifically dwell on hope as a concept, she purports that “hope persists through all the stages of grieving” and is essential for the individual who suffers a loss to progress through the stages of grieving (Kubler-Ross, 1969, p. 138). Hope and the enhanced desire for hope has been denoted as a defining characteristic of the nursing diagnosis “readiness for enhanced spiritual well-being” by the North American Nursing Diagnosis Association (NANDA) (Anonymous, 2002, p. 68). The feeling of hopelessness therefore is a sign of spiritual ill health that requires nursing attention and care. Taylor (2012) explains that spiritual care should address three needs of humanity; finding meaning and purpose, love and relatedness, and finally forgiveness. With HIV classified as a chronic disease with no cure, Taylor (2012) said that focusing on the spiritual needs of patients with chronic diseases could enhance coping and ignite hope in a seemingly ‘hopeless’ situation. Providing spiritual care to women

confronted with such hopelessness and the fear of imminent death was prioritized by midwives and CHNs especially during the initial phases of knowing their diagnosis in the PMTCT programme. Travelbee (1971) explains that hope enables people to acknowledge their fears, develop confidence in the support offered by others, the desire to complete a task and to have a future orientation to life.

McCormick, Holder, Wetsel, and Cawthon (2001) refers to spirituality as an essential resource of coping for persons infected with HIV, and categorised it as comprising both religious and existential components. These components include understanding the meaning of life, having hope, belief in God and undertaking religious rituals. The Nursing diagnosis for enhanced spirituality identifies activities such as finding meaning and purpose in life, enhancing the clients' connectedness with themselves, others, nature and even a greater power beyond themselves as essential for enhancing spiritual well-being (Diagnosis Review Committee, 2002). A study by Van Wyngaard (2013) reveals that it is appropriate for health practitioners to use faith-based resources to assist HIV positive patients cope when it is acceptable to the client. Crowther, Parker, Achenbaum, Larimore, & Koenig (2002) points to the effectiveness of using spiritual activities such as prayers to improve the patient's sense of control over the illness and also to reduce their sense of hopelessness and isolation. Most participants in this study drew strength from their faith and belief in a God to cope with the diagnosis. Some healthcare providers also used faith-based messages to encourage and stimulate hope in the mothers. The midwives and CHNs provided spiritual care to the mothers by assisting the mothers in exploring their interpretation of, and implication of a definite HIV diagnosis on their health. For most of the mothers, the exercise re-oriented their perceptions about life with HIV enabling them to find hope, positivity, and the opportunity to give and receive forgiveness. These are important characteristics of a person with enhanced spiritual well-being (Diagnosis Review Committee, 2002).

Puchalski et al. (2009) refer to spirituality as the way in which people pursue and express meaning and purpose in their lives, as well as the ways they experience connectedness to the moment, to themselves, people they value, society and what they deem as sacred. The HIV diagnosis forced the women to confront what they valued about life and the purpose for which they existed. Hence, being pregnant can be spiritual as it gives meaning and purpose, and with it, status, approval from in-

laws, and a sense of belonging. For most of these women, the purpose for which they existed shifted from their gratification to protecting and birthing a healthy new life, breeding a sense of selflessness. Providing spiritual care enabled the mothers to effectively cope with their diagnosis (Kremer, Ironson, & Kaplan, 2009). Heidari, Ziaei, Ahmadi, Mohammadi, & Hall (2015), while exploring the spiritual health of the unborn child found that pregnant women consciously undertake or refrain from certain activities in the bid to protect the health of their unborn babies. Consequently, the decision to remain in the PMTCT programme by mothers' in this study, was not out of compulsion but as a result of valuing life above the HIV diagnosis, thus, enhancing their spiritual health. With the renewed perspective of living with HIV, the transition into women empowered to live healthily with HIV was attained. Thus, the women were able to grasp the blessings in their situations in spite of the diagnosis.

The transition process for a woman newly diagnosed as HIV positive involved conquering the emotional, psychosocial and physical demands that the definite HIV diagnosis imposed on the mothers. Kelly et al. (2012) posit that since the focus of these women is mainly on the unborn baby at the expense of the pregnancy and their own health, psychological interventions to aid in the transition and acceptance of their conditions are essential. For those who disclosed or concealed their status, having the midwives and CHNs as a form of support; psychologically, socially and treatment-wise, propelled them through the transition process. The support provides the women with some form of normalcy that motherhood brings in the midst of emotional and psychological 'burden' that the diagnosis brought (Sanders, 2008). The support enabled the emotionally shattered mothers to evolve into empowered women who were able to accept and live healthily with HIV, protect others from getting infected and be optimistic about the future (Lazarus, Struthers, & Violari, 2009). An empowered woman is one who has accepted her HIV status, is well informed about her condition and has made the meaningful decision to engage in the PMTCT programme continuously. In spite of the perceived or actual challenges associated with accessing PMTCT care, the empowered woman engages in the programme as a partner rather than as a passive recipient.

### **6.3.2.2 THEME TWO: Journeying with committed companions**

The findings indicated that although the journey with HIV in pregnancy began with shock and other negative emotions for most clients, it was interspersed with and culminated in positive experiences for clients who remained in the programme and for nurses who provided care in the programme. Sharing experiences in the programme using the storytelling approach was valuable as it provided insights from experiential perspectives to healthcare delivery. Additionally, it inspired resilience in the participants and provided the avenue to celebrate the struggles and achievements of the research participants who had met their goals in spite of their difficulties. This finding is consistent with the findings reported by East, Jackson, O'Brien, & Peters (2010). This section is discussed in the following subsections: Engaged nurse-patient relationship (6.3.2.2.1), Committed to confidentiality (6.3.2.2.2) and Two is a company, more is even better (6.3.2.2.3).

#### **6.3.2.2.1 Engaged nurse-patient relationship**

Health workers with knowledge and skills as well as the availability of infrastructure, resources and/ or logistical support were essential conditions for a successful PMTCT programme. Client-professional interaction is an important component necessary for retention in the IMCHB. The therapeutic content and processes of interaction that occurs between the client and the health provider (Cox, 2002).

Both the mothers and the health workers in this study felt that a relationship of trust based on commitment on the part of both parties was critical for improving the experience of care, achieving programme outcomes and enhancing retention in the PMTCT programme. Dinç and Gastmans (2013, p. 505) describe the process required to build trust as involving various stages which are; understanding each other, individualising, and sharing of one's self. In the case of women in the PMTCT programme, the seeds of trust between the health workers and the mothers were sown when the health worker shared in the profound and life-changing moments in the lives of the mothers in relation to their health - the day when their image of themselves was abruptly changed with an HIV diagnosis. Thorne and Robinson (1988) refer to this initial trust as the naïve trust based on the assumption that the healthcare professional is solely committed to making sure that their health needs are

resolved. They suggest that this trust must evolve along a continuum until it reaches a specific reconstructed trust. Carr (2001) points out that trust built between the nurse and the client is continuously re-negotiated. Conditions identified to strengthen the patients' trust in the health professionals in the PMTCT programme included maintenance of confidentiality, kindness, empathy, respect, availability and easy accessibility of the health staff when needed. This finding is consistent with the factors associated with building trust in nurse-patient relationships identified in other studies (Belcher & Jones, 2009; Eriksson & Nilsson, 2008). Dawson-Rose et al. (2016) found that trust between health workers and PLWH is an outcome of the efforts that the health workers put into the relationships. Consequently, the nurses' efforts to maintain the relationship through telephone calls, follow-ups and home visits ensured that trust was nurtured. Hence, the trust that was finally attained between the parties were usually based on experiential knowledge of commitment between the two participants. Carr (2001) states that the trusting relationship does not only bring support to the client but also provides satisfaction for the health workers in the programme. This mutual satisfaction of the health workers and the clients based on the trusting relationship established during their interaction in the PMTCT programme was evident throughout the study.

This study showed that the development of a positive relationship between the nurses and the patient was valued by both groups of participants as contributing to the exceptional moments in care and underscored the mothers' decision to remain in the programme. Gourlay et al. (2014) stated that the impact of the provider-client relationship on adherence and retention far outweighs the value placed on it. The sense of relatedness associated with the mothers' interactions with the nurses compensated for the feeling of emptiness, loneliness, and isolation that is associated with the HIV infection. Hence, for most of the women who chose not to disclose and even for those who disclosed but did not receive the needed support, the knowledge of having a confidante in the nurse was reassuring and comforting and served as a lifeline to the hope of a possible future. To them, the reality was that establishing a friendship with a health professional while engaging in the programme was important. Thus, one infected mother professed pity for those who had to progress through the programme without such assurance of friendship and support. Most of the mothers expressed the need for friendliness and friendship with the nurses. This

type of relationship extended beyond the provision of clinical care and the technical competence of the nurse/midwives to building an honest, trustworthy, non-judgemental and empathetic relationship with the mothers. This finding is in line with suggestions by Remshardt (2012) who posited that nurses must operate in the 'zone of helpfulness.' That is treat all clients with respect and dignity, being consistent and fair, inspire trust and credibility as well as exemplify professionalism. The patterns of relatedness between the midwives, CHNs and mothers evolved from passivity on the part of the mothers to mutual participation as the relationship evolved. This dynamic interchange was reflected in instances of their interaction such as the first day when the client passively undertook the HIV testing without question because the nurse explained that it was a policy. This is similar to the reported finding by Larsson et al. (2012) where the participants reported that they undertook the test because they felt it was compulsory. Over time, however, the clients required explanations for suggestions made by the health workers while the nurses gently counselled patients to make decisions about their health and choices such as disclosure and infant feeding options. This patterns of relatedness were directed and sustained by both the nurses and the clients, and neither was a passive recipient in the interactive process. Morse (1991) maintains that active participation of the nurse and clients in the interactive process ensures a healthy relationship.

Peplau in her *Interpersonal Relationship in Nursing Theory* believed that the essence of the interaction between the nurses and the patient was to make both of them mature and to become knowledgeable about the situation, the health needs of the patients, and the patients' preferences (Peplau, 1952). The theory has been applied to understand interpersonal relation of patients' in other chronic diseases such as later stages of Alzheimer's disease (Williams & Tappen, 1999), multiple sclerosis (McGuinness & Peters, 1999), schizophrenia (Hewitt & Coffey, 2005) and HIV/AIDS (Carr, 2001; Douglass, Sowell, & Phillips, 2003).

Within the context of the nurse-patient relationship in the PMTCT programme, the nurses and midwives were able to gather pertinent patient information that enabled them to establish an individualized approach to care regarding the needs of the patient (Hewitt & Coffey, 2005). The in-depth knowledge that some nurses and midwives had about patients in this study was found to have ensured holistic care, as illustrated in the case of advocacy and re-engaging in the school system by a teenage

HIV-infected drop-out. This level of relationship is usually not attained in the nurse-patient relationship in most health contexts as there is usually no continuity of the carer who provides the nursing care. Further discussion on continuity of carers is presented in 6.3.2.4.1.2. Gourlay et al. (2014) found similar levels of relatedness in Tanzania but associated it with the cultural setting and the moderate patient volumes. Providing culturally sensitive care to the clients was found to enhance appreciation of the nurses and to strengthen the nurse-patient relationship. Shawa, Omondi, & Mbakaya (2017) state that patients expect the health workers to respect their values while providing healthcare. This expectation makes the midwives and CHNs culture brokers. In this study, the staff was found to understand the cultural norms that touched widowhood rites, early post-partum care that required seclusion and organized care to ensure that their needs were met during those periods.

#### 6.3.2.2.2 Commitment to confidentiality

The study found that mothers' perceptions of the health workers' commitment to maintain confidentiality was a major influence on promoting and sustaining the nurse-patient relationship and, invariably, retention in the PMTCT programme. Perceived or actual breach in confidentiality by health workers is a challenge for retention in the PMTCT and ART programmes. The disclosure of sensitive patient information, as well as visibility of HIV-related services affected retention in the programme (Ferguson, 2013). Dapaah & Senah (2016) also cited the fear of being seen by others when accessing PMTCT services as influencing nurse-patient relationship and retention.

Nurses and midwives in this study placed their commitment to their professional values and the clients above their social relationships and did not disclose clients' status to others. However, in a similar study in Ghana, health practitioners were reported to have breached confidentiality when working with persons living with HIV with the excuse that they sought to prevent the spread of the disease to clients' unsuspecting spouses. The mothers' knowledge of the breach of confidentiality resulted in the loss of trust in the health practitioners (Dapaah & Senah, 2016).

Consistent with findings by Gourlay et al. (2014), this study revealed that the clients' initial perception of health workers' lack of trustworthiness seemed unfounded.

Mothers expressed confidence in the nurses' and midwives' commitment to keeping

their status confidential. Some mothers even relied on them for assistance when they felt accessing PMTCT services might expose them. Although nurses and midwives in the programme had a professional and ethical responsibility to protect the right of the mother not to disclose, they were also expected professionally to prevent the spread of HIV to uninfected persons and to promote behaviour change strategies. Consequently, disclosure to a person of choice was encouraged or enforced prior to the initiation of treatment by the health workers. Dapaah and Senah (2016) report instances of enforced disclosure to an adherence supporter in a similar study in Ghana. They assert that it is a condition for accessing ART services in Ghana although no policy document could be traced to that effect.

Varied levels of the nurse-patient relationship as described by Morse (1991) was identified in this study depending on the phase of the PMTCT programme the interaction occurred. In the labour ward, the relationship bordered at the ‘therapeutic level’ as the clients spent a relatively short period there. Morse (1991) explained that at the therapeutic level of nurse-patient relationship, the nurse might view the pregnant woman initially as a patient but takes into cognizance the fact that the patient has a life outside the ‘patient role.’ Albeit a short experience, the mothers’ experience of care, support, and respect revealed in their stories denotes the value that they placed on the interaction. Ahmadi (2013) denotes that the midwives’ support during labour is considered most valuable for all pregnant women. The support is especially important for the mothers who anticipate discrimination as a result of their positive HIV diagnosis. The positive interaction in the labour ward devoid of discrimination was an important catalyst in the transition process of the mothers’ as they gained respect for themselves and began to see themselves from a different perspective; ‘as a human being and not as an HIV patient’.

The interaction between the midwives and their clients at the antenatal and postnatal units, however, evolved into “connected relationship” (Morse, 1991). The development of this connected relationship could be attributed to the extended period of engagement necessitated by the time spent in these units. Forti (2015) noted that this need for pregnant women seeking constant contact with their midwives may be to gain reassurance, advice, and information. For the pregnant woman who is HIV positive, this need may be greater as a result of their anxieties and fears concerning early parenting and the risk of vertical transmission. For some participants, the nurse-

patient relationship progressed from the professional sphere into the social and family domain where the client was first seen as a person and later as a patient (Morse, 1991). Similarly, Mok and Chiu (2004) found that the nurse-patient relationship evolves into friendship and later the nurses became part of the patients' families and attributed it to the development of trust.

### **6.3.2.2.3 Two is company, more is even better**

Another finding was that, when mothers disclosed to other people other than the nurse, they received the needed support in their engagement in the PMTCT programme. Several studies report disclosure to family members and intimate partners (Kallem et al., 2011; Linda, 2013; Naigino et al., 2017). The concept of family in HIV/AIDS circles was described as a group of individuals who are bound through mutual trust, support and a common goal (Global Programmes on AIDS, 1994). This concept stretches family relations beyond blood ties, marriage, adoption, and sexual partnership as defined by family theorists (Seccombe & Warner, 2004) and extends family roles beyond father and mother, husband and wife, brother and sister, son and daughter as defined by family social science theorists (Burgess & Locke, 1945), to include support groups with people with HIV, religious congregations and work associations (Idolor, 2012). This study found that some newly diagnosed mothers had involved their religious leaders and family in their PMTCT care circle. The facility had no formalised mother support groups for newly infected women in the PMTCT and none of the mothers had reported joining PMTCT mother support groups. Of importance was the observation that one mother, who was contacted by another client, showed an anxious disposition. This finding is contrary to reports of acceptance and engagement in PMTCT mother support groups in Malawi, Nigeria and Zimbabwe (Cataldo et al., 2017; Foster et al., 2017).

Working in the PMTCT programme was found to be emotionally demanding for the health workers. Sheppard (2015) avers that persistent exposure to emotionally demanding situations incapacitates nurses in some instances and may lead to compassion fatigue. The demands of the clients enrolled in PMTCT programme as well as the commitment of the nurses was found to be correspondingly high. A meta-analysis by Nolte, Downing, Temane, and Hastings-Tolsma (2017) identified factors such as becoming overly involved, crossing professional boundaries, limited

opportunity for professional development and lack of support as contributing to compassion fatigue and could result in feelings of being overwhelmed. Although the nurses did not report this in the study, the need to ensure sustainability of the enhanced programme that promotes retention requires that strategies be explored to prevent the occurrence of compassion fatigue.

In the practice of PMTCT and ART programmes, health workers encounter numerous clinical situations that necessitate the delivery of unexpected bad news to clients. Breaking bad news is a significant source of physical and emotional stress for the health worker Shaw, Brown, Heinrich, & Dunn (2013). Hence, nurses and midwives have reportedly experienced excessive workload, stress and burnout while providing care in the PMTCT and ART clinics report on the excessive workload, stress and burnout associated with working with HIV clients (Valjee & Van Dyk, 2014). In this study, informing the pregnant woman of her HIV positive result was described as ‘difficult’ and required clinical skill, emotional and cultural competence. The sense of hopelessness when the clients face the reality of the HIV diagnosis is so profound that they seek to grasp on to anyone that provides the barest of hope. This feeling sometimes resulted in over-dependence on the midwives and CHNs which was expressed as persistent phone calls to the midwives and CHNs late into the night and after working hours, demanding promises from the midwives on the exposed infants testing negative after the DNA PCR test. Baile, Buckman, Schapira, and Parker (2006) point out that the negative emotional and physical reactions patients’ exhibit in response to bad news can elicit anxiety in the health professionals. The focus of the PMTCT programme is solely on the clients and there is no policy or protocol for debriefing or emotional time-out for the health workers to prevent burnout. Staff de-briefing and emotional time out has reportedly been effective in maintaining the professional integrity and effective management of grieving by healthcare professionals such as nurses, physicians and social workers in many stressful situations such as after the death of paediatric patient (Keene, Hutton, Hall, & Rushton, 2010), adverse incidences during surgeries (Clegg & MacKinnon, 2014) and breaking bad news to clients and relatives (McLauchlan, 1990).

### 6.3.2.3 Theme three: Glimpses of triumph

This subsection discusses the factors that promoted retention of mothers in the PMTCT programme. It is organised under the following headings; Celebrating health (6.3.2.3.1) and Changes perceptions about midwives and nurses (6.3.2.3.2).

#### 6.3.2.3.1 Celebrating health

The findings reveal that protecting the unborn child was the initial motivation for remaining in the PMTCT programme for most mothers. Rubin (1975) in her theory of prenatal attachment stated that a pregnant woman develops an attachment to her unborn child. To this point, in this study the need to protect and avoid loss of the unborn child underscored the women's decisions to remain in the programme and to commit to the treatment schedule. Loccoh et al. (2014) reported similar findings from Togo where they found that the mothers' motivation for remaining in care was the knowledge and belief that consistent ART ingestion could protect the unborn child from vertical transmission. Similarly, the need to protect the child overrode the mothers' feelings of unpreparedness to initiate lifelong treatment immediately after diagnosis in Malawi, Tanzania, and Uganda as PMTCT staff adopted approaches to persuade the mothers to start treatment for the sake of the child (Buregyeya et al., 2017; McLean et al., 2017).

The nurses in this study also reported a sense of responsibility to protect the unborn child from getting infected with HIV as the main driving force behind their zeal to ensure mothers remain engaged in the programme. Hence, both pre- and post-test counselling centred on the need to protect the child, placing a burden of responsibility on the infected mother to do 'the right thing'. The focus of counselling showed an obvious lapse in knowledge transfer between the nurses and mothers, as the ingestion of ART during pregnancy has a wide range of benefits including decreasing the maternal viral loads (Chuachoowong et al., 2000), which in turn decreases the incidence of opportunistic infections (Al-Jabri, Balkhair, Al-Balosh, & Hasson, 2011). This finding reveals a deviation in the implementation of WHO's overarching priority in deciding whether to commence ART for a woman during pregnancy or not. WHO recommends that the decision to initiate a woman on ART should be based primarily on the need to improve and protect the health of the woman (World Health Organization, 2006). McLean et al. (2017) therefore warning

that basing the need to test or initiate ART in pregnancy on protecting the child may contribute to the high disengagement in the postpartum period. The need to protect the child is non-existent when the risk for vertical transmission is non-existent after breastfeeding ceases and the mother finds no benefits in remaining in the programme. Focusing counselling on retention and the need to initiate ART solely to protect the child sends the message that the child is most valuable, and the mother only has value as long as she is carrying a child. The woman herself must feel that she has intrinsic value and that maintaining her health is enormously important. The self-worth of women affects how they adjust to various aspects of their lives and this must be emphasised in the PMTCT programme (Jan & Masood, 2008).

In this study, the mothers subsequently found value in continuing their engagement in the programme even after the risk of vertical transmission was over because they recognised the effectiveness of the drugs in maintaining their health. These findings are broadly in harmony with those of researchers such as Katirayi et al. (Katirayi et al., 2016) who found infected women in Malawi remaining in the programme and adhering to treatment because they saw that ART helped them feel healthier and prevented death. The concept of health for these mothers was however limited to the absence of physical signs of disease such as weight loss, skin rashes, and other opportunistic infections. This concept of health is consistent with findings of studies reported from Rwanda and Malawi (Gill et al., 2017; Katirayi et al., 2016) which described living healthily with HIV as the absence of opportunistic infections. Only one mother in this study referred to health as a reduction in the viral load.

Although maintaining physical and physiological health is laudable, the provision of healthcare to HIV positive mothers should be multimodal and focus on touching all aspects of wellbeing; physical, mental and social, as defined by the WHO (World Health Organization, 1948) as well as spiritual (Kremer et al., 2009). Hence to attain maternal health, the nurses counselled infected women at every visit. This promoted psychological and mental wellbeing as well as encouraged disclosure for social support. In instances where social support was unavailable, the nurses provided such support by maintaining an open relationship with the clients. Huber et al. (2011) argue that in the face of increasing chronicity of diseases, the ability to adapt and self-manage in spite of a medical condition should be the focus of health. Therefore a goal of the midwives, CHNs and mothers was to continue treatment, adapt and live

seemingly healthy lives on medication without fear of societal rejection, stigmatization, and abuse, knowing that as long as they were on treatment, there would be no visible signs of their HIV infection.

#### 6.3.2.3.2 Changing perceptions about nurses

A noteworthy finding in this study was the changing perceptions of HIV infected women about the nursing profession and nurses in general as a result of engaging in the PMTCT programme. Some studies have recorded negative attitudes of nurses in general and especially towards persons living with HIV (Anígilájé et al., 2016; Ferguson, 2013). Consistent with these studies and the general rhetoric about the negative attitudes of Ghanaian nurses in the press and social media, most of the mothers had preconceived expectations of discrimination and anticipated being disrespected by the midwives and CHNs while accessing healthcare because of their HIV diagnosis. However, most of the mothers recalled kindness, respect, compassion, trustworthy, supportive and caring attitudes of the midwives and CHNs they encountered in the PMTCT programme. In the same manner, Dapaah (2016) reported positive attitudes of some health workers in adult ART care in Ghana. He said that clients spoke warmly about health workers who showed positive attitudes towards them and selectively mentioned names of staff who were praise-worthy during his study. Armstrong (2006) posits that virtue-based approaches to nursing that focuses on compassion, judgement, moral sensitivity and wisdom is essential in improving nursing practice. Thus, the positive attitudes of some nurses towards clients in Ghana resulted in continuous engagement in the health system. These reports about nurses' and midwives' positive attitudes not only resulted in positive relationships but also changed the clients' perceptions of nursing. Raisler and Cohn (2005) applaud the endurance of African nurses and midwives working in HIV/AIDS care in Africa in the face of increased workloads, crowded facilities and limited resources. Against the backdrop of negative rhetoric about nurses and nursing in general, these findings are striking. Ludema, Cooperrider and Barrett (2006) assert that positive conversations about issues usually yield a transformative dialogue. Hence, to project the positive image of nurses and nursing, it is imperative that the discourse changes from negativity to positivity across the whole spectrum of society.

## **6.3.2.4 THEME FOUR: A daring new path: Tying up the loose ends**

This section focused on the health system challenges that participants felt negatively affected clients' experiences and retention in the programme, the aspirations of the participants towards service improvement and the actions necessary to improve service delivery in the PMTCT programme. An emerging issue from the study was the organization of service delivery for PMTCT clients in the facility. In line with the principles of AI, discussion of this theme focused on finding alternate ways of strengthening the PMTCT programme. The theme is discussed under the following headings; Continuity of care (6.3.2.4.1.1), Continuity of carer (6.3.2.4.1.2), Engaging religious and opinion leaders (6.3.2.4.1.3) and Conducive service delivery environment (6.3.2.4.1.4).

### *6.3.2.4.1.1 Continuity of care*

The general care approach utilized in the study facility is an integrated PMTCT/MNCH programme as recommended in the national policy (Ghana Health Service, 2014). Provision of the PMTCT services occurs across various units in the maternal, neonatal and child health services. Both providers and clients reported positive perceptions of the integrated system. These findings are generally consistent with the findings by An et al. (2015) who reported that health workers and clients had positive perceptions about integration of PMTCT into mainstream services because it increased confidentiality, convenience and efficiency of the service.

In this study, integration of PMTCT programme with existing MNCH services ensured a measure of continuity of care for the mothers accessing care in the programme. Continuity of care refers to the extent to which a series of distinct events are experienced in an integrated manner and is consistent with the client's needs over time (Reid, Haggerty, & McKendry, 2002). Findings of this study revealed that the clients appreciated the instances when continuity of care was ensured especially in instances where the midwife who enrolled them in the programme continued to engage with them throughout the antenatal and postnatal periods in the PMTCT programme. The continuity of care fostered relationship building with the midwives and CHNs, cultivated empathy, building of trust and improved engagement in the

programme. This finding is consistent with Winestone et al. (2012) who reported integration of PMTCT into ANC services also improves patient-provider relationships that resulted in improved patients' satisfaction. Devane et al. (2010) found that continuity of care increase clients' agency, control and increases the mothers' chances of receiving empathetic care. Winestone et al. (2012) found reported integration of PMTCT to ANC services also improves patient-provider relationships that resulted in improved patients' satisfaction. Studies in midwifery have also found increased satisfaction among women who received antenatal, intrapartum and postpartum care under a continuous model of care (Forster et al., 2016; Leap, Sandall, Buckland, & Huber, 2010).

Haggerty et al. (2003) suggest that the focus of continuity of care should include continuity of information, management of the client, and the relationship between the client and the health professionals. In this study, some midwives escorted the clients to the next unit where the client had to continue receiving PMTCT care. This action fostered management continuity which is concerned with coordination of patient care and interaction between service providers. Layer et al. (2014) agree that this finding has the potential to enhance retention in the programme. Although informational continuity was maintained through documentation in patient folders transferred across units, adopting electronic medical records synchronized across units, regular meetings between health staff to keep abreast with the outcomes and challenges of in the PMTCT programme and across the health service could produce efficient and effective outcomes (Psaila, Schmied, Fowler, & Kruske, 2014). Electronic medical records have been shown to enhance efficiencies in flow of work by reducing the required time to retrieve patient folders and charts, improve the efficiency of patient scheduling for appointments and improved communication among primary care givers and their clients (Manca, 2015). When synchronised across health systems, electronic medical records limit the delays in information transfer and rather promote accessibility to patient medical histories, appointment schedules and medical notes (Kern et al., 2013). Disengagement from PMTCT/MNCH was reduced as patient tracking was initiated by health workers within the service prompting the CHNs about missed appointments and defaulting clients. Patient tracking was, however, ad hoc rather than a system sustained process. A system-wide scale-up of patient

tracking would improve re-engagement and retention of mothers in the PMTCT programme. Relational continuity will be discussed in 6.3.2.4.1.2.

Findings from this study revealed some system-related factors that indirectly or directly affected the patients' decision to engage continuously in the programme or otherwise. Clients and healthcare providers in this study expressed concerns about the organization of some services in the PMTCT programme which were structured around the service points and the health system. Segregation or fragmentation of some services at some points in the MNCH/PMTCT contributed to the challenges associated with linkages across the various units in the PMTCT programme. These challenges such as unintended disclosure, the need to establish new relationships at every unit, and disclose their HIV status constantly could have contributed to the mothers' disengagement from the programme. Fear of being identified by other HIV-infected clients accessing PMTCT services at point-of-care has been cited as an underlying care for disengagement (Horwood et al., 2010). Varga & Brookes (2008) report that fear of unintended disclosure as a result of accessing PMTCT services in a fragmented programme could be a factor influencing some mothers' failure to continuously seek care for their HIV-exposed infants. Dapaah and Senah (2016) posit that the debates on integration, fragmentation or segregation of PMTCT/ART services have both advantages and disadvantages and aver that the onus lies on the service providers to decide whether to integrate wholly or partially. Bhuyen, Jorgensen and Sharma (2010) however argue that involving all stakeholders in healthcare decision-making enhances the successful implementation of policies. Hence, incorporating service providers as well as clients' perspectives in restructuring the service delivery approach of the PMTCT programme will improve efficiency, effectiveness and patient experiences and invariably enhance retention (Ford & Fottler, 2000).

Psaila, Schmied, Fowler, & Kruske (2014) state that discontinuity of care between maternity and child health services are real and impacts service delivery and client experiences. They allude to the fact that the professional territoriality in the maternal and child health services is caused by the lack of knowledge and appreciation of the roles and contributions of different health professions in the care continuum. Collaboration between midwives and child health nurses can be improved when organizational barriers that hinder information transfer and communication are

removed as well as make patient care their utmost priority (Psaila, Schmied, Fowler, & Kruske, 2015).

#### *6.3.2.4.1.2 Continuity of carer*

In this study, a group<sup>18</sup> of midwives provided integrated antenatal and PMTCT services. This was contrary to the focused antenatal care (FANC) model that had been adopted by the Ghana Health Service which required individualized care of a pregnant woman provided by one midwife throughout her antenatal period (Nyarko et al., 2006). Lack of infrastructure and human resource constraints underscored the delay in the implementation of this approach of continuity of carer approach. Other studies have also reported similar reasons in the Ghana Health Service that underscored the delays in the implementations of FANC in other facilities (Baffour-Awuah, Mwini-Nyaledzigbor, & Richter, 2015; Nyarko et al., 2006). This delay in the implementation of FANC mainly required the commitment of health service managers and not the midwives who were enthusiastic to implement the policy.

The FANC approach aligns with an aspect of continuity of carer in midwifery where the same midwife attends to a client throughout the peripartum period. The known and trusted midwife provides individualised education and counselling during antenatal, labour and immediate postpartum period to a woman. It also ensures that the midwife identifies and refers a woman in her care who needs obstetric or other specialist care (Sandall, 2014).

The delays in implementing continuity of carer in this study were compensated for by the merging of the ANC/PNC clinics, so that the same group of midwives attended the women during those periods. The approach allowed for relational continuity between the clients and midwives during the periods where the mothers received care in these units. Huber & Sandall (2009) suggest that the continuity of carer allows for relational continuity that ensures 'being known', promotes building of trust, and was an essential indicator of retention in PMTCT care. In this study, however, the changing schedules of the staff and disconnection between the group of

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<sup>18</sup>Midwives assigned to the antenatal / postnatal unit were usually assigned responsibilities by the midwife-in-charge on a daily basis. Thus, although they remained in the unit for a length of time, their assignments changed often, and this detracted from the concept of FANC which required a midwife providing total care to client throughout the antenatal period.

midwives impacted on relational continuity. There was a constant need for clients to disclose their diagnosis to new midwives, community health workers and other healthcare professionals such as the pharmacists and technicians and efforts to establish a trusting relationship with the health workers. Consistently disclosing their status to different people required emotional energy from the clients and negatively affected retention. Gourlay et al.(2014) found that an increase in disengagement from PMTCT care occurred when the established nurse-patient relationship was disrupted by transfers or referrals as it led to anxieties about trust.

In the current study, the midwives felt that it was necessary to ensure the clients knew what to expect concerning the involvement of other health workers in their care so that the clients could adjust their expectations to suit the service delivery approach. Informing the client may not necessarily ease the clients' distress with the situation. It pointed to the power dynamics in the health system and indicated that the client was not the centre of care. Forster et al. (2016) aver that adopting the continuity of carer model of midwifery where a primary midwife attends to the client throughout the peripartum period has high benefits including patient satisfaction. Higher spontaneous birth rates and positive neonatal outcomes have also been reported (Homer, Leap, Edwards, & Sandall, 2017).

The arguments for continuity of care and carer seem to be based on the willingness of the health system managers to commit the efforts and resources required to implement the models of care rather than their potential to enhance the relationship between the health workers and the mothers who access care as well as improve service delivery and retention in the PMTCT programme (Psaila et al., 2014).

#### *6.3.2.4.1.3 Engaging the religious leaders and opinion leaders*

An alternate pathway of care commonly utilized by the HIV positive women in this study was faith healing. Liu et al. (2012) revealed that as many as 20% of HIV patients use alternate remedies in Ghana. Laar et al. (2017) reported that some of the remedies could compromise the effectiveness of ART. In spite of this, the scope of influence of pastors and healers is widened by the firm belief in divine healing through prayers, fasting and herbal treatments that underscored their practice.

For some participants, the first option for seeking support for themselves or assisting their HIV infected relations was seeking help from religious leaders at prayer camps

and gardens. This study revealed different attitudes of religious leaders towards accessing and continuously engaging in the PMTCT programme. Some pastors encouraged and assisted disclosure of HIV status, compliance with treatment and continuous engagement in care. Pharr et al. (2016) suggest that these leaders could leverage their position to influence their congregants and the community at large to understand better and develop positive attitudes towards HIV and persons living with HIV. Other faith leaders only referred their followers to the hospital when it was too late and resulted in death.

Nunn et al. (2012) reported that faith leaders lacked HIV educational information that was appropriate for the faith-based audience and had concerns about the effects of endorsing aspects of HIV prevention strategies which promoted extramarital activities, like condom use, on their congregations. The religious leaders themselves needed to be educated on the basics of HIV and PMTCT care so that they can provide appropriate support for their infected members and also enhance acceptability of the programme among their members.

Layer et al. (2014) pointed out that, although the pastors and healers do not claim to heal HIV, they do not actively motivate the HIV infected clients to utilize the health facility. The health workers in this study realised that they ought to focus on engaging the religious leaders to structure HIV information that is suitable for their audience and to inform them of their role in improving retention in PMTCT and HIV care in general. Although, the study did not explore the role of hospital chaplains, they could be leveraged to use their positions to engage the other faith leaders who have limited knowledge on PMTCT care and enhance better understanding between the faith community and the health system.

The scope of influence of family and community members on the HIV-mothers' decisions to remain in care was covertly depicted in the study findings. The fear of societal discrimination and stigmatization negatively influenced disclosure and retention in PMTCT. This finding is consistent with other studies in sub-Saharan Africa (Gourlay et al., 2013; Kalembo & Zgambo, 2012). Lack of accurate knowledge about HIV prevention (Feyissa, Abebe, Girma, & Woldie, 2012) and doubts about the effectiveness of the preventive measures (Ebied, 2014) contributed to the both perceived and actual HIV-related stigmatization and discrimination. The aforementioned points to the need to review the content of education and counselling

on HIV in the PMTCT programme. Information addressing inaccuracies about HIV to the society must be developed. Training on HIV educational information that addresses prevention, testing, and treatment, as well as stigma, should be directed at addressing inaccuracies about HIV in the society and most importantly project the successes of the PMTCT. Cooperrider & Whitney (2001) suggest that if conversations about issues have a positive focus, people get excited, and interest is stimulated. The conversation about HIV in pregnancy must be re-engineered to project the benefits of testing and treatment such as the proportions of women remaining healthy with low viral loads, decreased risk of HIV positive women infecting their partners and the proportions of exposed children testing HIV negative. The aforementioned may change society's conversations and attitude towards HIV infected people and promote the acceptability of the programme.

#### *6.3.2.4.1.4 Conducive service delivery environment*

Ford and Fottler (2000) refers to the healthcare environment as a "healthscape" and report that the healthcare environment influences the health care experiences of the patients. Patients respond better to treatment when health care is provided in welcoming environment (Lawson, Phiri, & Wells-Thorpe, 2003). Jones (2004) found that good health care environments are therapeutic.

Because of the sensitive nature of PMTCT programme, the physical environment of the health facility is a very significant indicator of acceptability, uptake, and retention in the PMTCT programme. The physical setting in some units along the PMTCT cascade was identified as unsuitable for the kind of sensitive care the women needed. The proximity of the location of the waiting area and the location of the testing and counselling room posed challenges for privacy. Kumar et al.(2015) aver that the need for privacy during counselling and testing was necessary for improved uptake of HIV counselling and testing. Cataldo, Chiwaula et al.(2017) cited breach of privacy as contributing to disengagement from care.

Dapaah and Senah (2016) averred that promoting privacy included ensuring that the reasons for a client's physical presence in the health facility are unknown by other users, as well as keeping the client's data or information away from others. Ford and Fottler (2000) posit that healthcare environments impact clients in various ways including psychologically, socially and physiologically. In this study, the open ward

environments in the labour ward resulted in anxiety for mothers for fear of unintended disclosure of their status to other clients. A study on the impact of different ward designs, bed layouts and privacy on patients and levels of interaction revealed that single rooms were associated with higher levels of nurse-patient interaction than in Nightingale wards (Jones, 2004).

Health system improvement effort requires seeking the patients' perceptions about service delivery and their experiences while accessing care in the PMTCT programme. In this study, for instance, health workers thought that segregation of the dispensing points at the pharmacy for general clients and ART clients was necessary to reduce waiting time and enhance patients' experiences while accessing healthcare. This finding is consistent with Winestone et al. (2012) who reported that health workers perceived that the patients' satisfaction with the integrated PMTCT service is attributable to the decreased time spent at the facility and the increased efficiency of the service delivery. The assertion, however, differed from the perception of the clients in this study. The mothers were uncomfortable with the arrangement at the pharmacy and reported that it exposed them to unintended disclosure of their status. That arrangement was cited as the primary factor that could have caused mothers to disengage from care. To the patients, the need to protect their HIV status superseded their concerns about the time spent at the facility, although both could have been addressed if the mothers had been engaged in the system improvement. Adams, Maben, and Robert (2013) revealed that including patients in the evaluation and redesign of health care services leads to the identification and implementation of several improvement projects across health services. Hence, the decision to integrate or segregate health service delivery should incorporate patient perceptions and focus on the need to conveniently provide services to the clients to promote easy access and also provide clients the privacy they need to access the care without fear of unintended disclosure. In this regard, various revisions were made to the action plans as the process unfolded in response to participants' inputs.

Reorganizing the healthcare environment with the improvement of patient care experience as the focus, will invariably increase clients' satisfaction and improve retention.

### **6.3.2.5 Summary**

This discussion focused on the objectives of the two sections of the study which sought to determine the rate of retention in the PMTCT programme and to apply the AI as a process to determine the factors that contribute to retention in the PMTCT programme. The rate of retention is moderately high. Retention is made possible by a successful transition of the woman who is newly diagnosed HIV positive into an empowered woman, a positive-nurse-patient relationship, achievement of the goals of the PMTCT programme, and enhancement in service delivery that focused on improving patient experiences and care outcomes. There were similarities in some of the study findings with other studies in sub-Saharan Africa. These included the retention rates at six weeks postpartum period, the factors that enhanced retention such as the health of the babies and mothers, social support as well as positive nurse-patient relationship and semi-integrated service delivery approaches. There were however certain findings that were different across studies. The perception that health workers knew better and could unilaterally take decisions on mothers' welfare were found to contradict the findings of this study. The process of disengagement as well as re-engagement and hospital shopping were also found in this study.

## **6.4 STRENGTHS AND LIMITATIONS**

This section presents the strengths and limitations of this study and the strategies that were employed to minimise any weaknesses.

### ***6.4.1 The strengths***

This is an original study. A strength of the study lies in the choice of topic that sought to explore retention rather than attrition or loss to follow-up. Although, some studies have also studied facilitators for retention in PMTCT (Iroezi et al., 2013; Kim et al., 2016), they usually focused on factors that contribute to loss to follow-up (Gouveia, da Silva, & de Albuquerque Mde, 2014; Rawizza et al., 2015). Focusing on facilitators of retention and exploring the aspirations of the participants for improving service delivery and strategies to enhance retention provided a basis for service improvement that is absent in similar studies (Clouse et al., 2013; Tomori et al., 2014) that just focused on facilitators of retention or risk factors for attrition.

The mixed methods research design employed in this study lends strength to the study. The designed lean strength to the study as recruitment of participants for the qualitative section of the study was informed by the baseline quantitative study, hence ensuring a focused recruitment. Tracking a specific group of people rather than looking at global percentages for recruitment ensured that the findings of the study was context specific. Given the nature of the research question, the design allowed for a clearer and in-depth understanding of retention in PMTCT programme in Takoradi Hospital. The study allowed for the establishment of a baseline of retention throughout the PMTCT cascade in the study facility that had earlier on not been explored or established.

The guiding propositions that underscore AI; viz appreciation, applicable inquiry that leads to knowledge generation, collaborative and capable of initiating change (Cooperrider & Srivastava, 1987) lends strength to the study. The use of Appreciative Inquiry as a research method (see 4.7.9) in the study of facilitators for retention in PMTCT is novel. AI provided a different lens through which the sensitive topic of testing HIV positive in pregnancy, as well as people's personal choices could be studied in a more empowering and celebratory way, while identifying opportunities for improved practice. Maintaining a positive outlook required redirecting the participants' focus towards reflecting on the positive experiences and identified opportunities in a seemingly distressing situation. Paraphrasing and clarifying statements were useful in achieving the mind shift to positivity. The process stimulated a sense of accomplishment and enhanced self-expression that influenced participation and engagement. The positive outlook of AI and the participatory nature ensured that despite the sensitivity of the topic, in-depth data was generated and also promoted a sense of ownership of the process and its outcomes.

The strength of this study lies in the fact that despite the sensitivity surrounding disclosure and identity especially for women who are diagnosed HIV positive in pregnancy, the use of the AI approach provided a way to have the women's voice and experiences heard fairly directly by the nurses and midwives who participated in the study through the use of storytelling and reconstruction of the mothers' stories. This approach was possible because of the poetic principle underlying the AI methodology that allows for the experiences of participants to be shared in original

stories and the synergogenesis approach that allowed for the reconstructed stories to be introduced as data. The principles of free will and enactment underscoring the AI methodology provided the basis for applying AI as an intervention to enhance service delivery and retention that resulted in concurrent changes to some aspects of PMTCT care while the session was ongoing. This was a major strength of the study as the participants were able to choose areas of improvement and implement them. Since a successful AI required commitment on the part of the all participants and those in position of authority (principle of wholeness), immediate changes occurred as a result of the synergogenesis and consensus building process in response to the mothers' concerns about unintended disclosure. The location of the waiting area away from the room assigned for HIV counselling and testing was immediately changed. Also, the confirmatory test, patient registration into the PMTCT programme, as well as the refill of ARTs for the infected pregnant women were relocated from the laboratory and pharmacy respectively to the ANC unit. Thus, the impact of AI was immediately felt by the service providers and provided further motivation for enhanced engagement in the study and improved service delivery.

Another strength of the study was the collaborative nature of the study that improved ownership of the action plans and outcomes among the participants.

#### ***6.4.2 The limitations***

The choice of setting posed a limitation for the study. Although, it was a district hospital and well patronised by expectant mothers, the number of women who tested positive to HIV in pregnancy was limited. The sample for the phase one was small; 43 pregnant women newly diagnosed HIV positive in the current pregnancy. That prevented any predictive statistical calculations. A larger sample may have allowed for making inferences and generalisation. This sample was, however, the whole population of women who tested positive for HIV and enrolled in the PMTCT programme in the facility.

The record review was limited to one year, hence limiting the power of the study. Although a multiple year record review could have addressed the power and sample size limitations, the review was conducted for one year because of the rationale for the phase was to enlighten the staff involved in the AI sessions the outcomes of their services within the period for which eligibility for participation was required. The

findings were useful as it provided a description of the prevailing state of retention in the PMTCT programme which was context specific and will provide the basis for further health service research. This was useful in stimulating discussion about the PMTCT retention in the facility among the nurses and midwives.

The researcher recognized the limitations associated with data obtained from routinely collected records in relation to the data quality. For instance, records of disclosure status extracted from the mothers' ART folders which are issued when mothers are initiated on treatment are meant to be updated, but the researcher could not verify whether the information was updated or represented the initial booking records. In spite of this limitation, various patients' records are collected on the mothers in different units such as the ANC, Labour ward, PNC and the pharmacy while accessing care in the PMTCT programme. This study required that the researcher access all these records, hence, the opportunity to verify the entries was available to ensure data quality.

The sixth week postpartum timeline for assessing the retention rate in section A of this study could be regarded as a limitation in relation to Rollins et al (2014) position regarding the post breastfeeding cessation coverage versus 12 months. Albeit, the sixth week postpartum time line may limit the scope of the study, the retention rate calculated in this section was to serve as a baseline to gain a general picture of the state of retention in the PMTCT programme in the facility and to stimulate discussions in the Appreciative Inquiry sessions. The sixth-week postpartum time line is essential as it indicates an important milestone in the PMTCT cascade for both mother and exposed infant. It aligns with the initial DNA PCR testing of the exposed infant and appropriate counselling after the test will inform the mothers' decision to continue to engage in care for her own sake and for that of her child. The discussions and subsequent development of action plans for improving patients' experiences and invariably retention in the PMTCT programme in section B, however covered the whole PMTCT programme until such time when the mother and infant were transferred to the adult and paediatric ART programme or the infant is discharged.

The researcher recognized that gaining access to the mothers could present a breach in the health services' code of confidentiality (Ghana Health Service, 2002) promised to the women when they engaged in the PMTCT programme. A methodological approach to involve the gatekeepers to inform eligible mothers about the study was

employed. The implication for data analysis was that the researcher could not ascertain the accuracy of the aggregated number of mothers invited into the study provided by the midwives as it exceeded the number who were eligible according to the record review. Also, the midwives were unable to report on the number of mothers who had declined to participate in the study. The researcher recognized this limitation, but the circumstances were such that nothing could be done about it. The researcher believed that its impact on the study would be minimal as the record review revealed that only 29 mothers were eligible and 12 were recruited into the study. Data saturation also achieved at the tenth conversation with the mothers.

Concerning the recruitment of participants described in 4.7.8, the researcher recognized the tendency to reveal the mothers' HIV status to other participants if they were required to participate in the study, hence breaching their right to decide to whom to disclose. She felt that the mothers could not be required to disclose their status which could occur if they participated in the group sessions with other mothers and healthcare providers. Individual in-depth qualitative conversations were organized for the mothers to ensure participation without compromising confidentiality. This approach was necessary to ensure that their perspectives could be included in the study. The researcher protected the mothers' identities by reconstructing the individual mother's narratives into two composite stories and the use of pseudonyms throughout the text to eliminate that limitation. The researcher ensured that the voices of the mothers were not inadvertently overlooked in the AI process. The mothers' stories were embedded in the "Inquire" phase and contributed to the initial outcomes from which all the decisions in the subsequent phases evolved. The researcher also ensured that the nurses and midwives consistently referred to the stories and the composite story summary sheets during all the phases of the AI process. Hence, the mothers' voices actively influenced the outcomes of the study.

In spite of efforts to protect the identity of the mothers, some midwives and community health workers who were privy to the individual journeys of some mothers were able to recognise their stories in portions of the composite stories. The researcher consistently reminded the health workers of the commitment they had made by signing the confidentiality agreement and the fact that the stories were reconstructed and did not represent the perspective of any single individual. They

were advised to keep the identities of the mothers they recognised in the stories to themselves. Hence, safeguarded the privacy of the women.

The researcher recognised the limitations of paired conversations as a data gathering technique. A demonstration of the activities to be undertaken in the AI session as described in 4.7.8 was held to equip the participants with interviewing skills. In spite of this, the researcher realized two conversations were superficial. An approach consistent with AI methodology was applied to minimise the weakness; the participants shared their stories again in the inquire group where clarifications and meaning-making occurred. The data that emerged from that group was therefore detailed and complemented what had been collected during the paired interview.

## **6.5 REFLEXIVITY REPORT**

Reflexivity is an approach to critically evaluate the research procedures and practices from more than one perspective (Jones, 2001). Reflexivity reveals a depth of complex ethical, emotional and epistemological aspects of the research that may otherwise remain hidden (Blaisdell, 2015). Through reflexivity, the researcher attempts to acknowledge the limitations of the research, hence, becomes honest and ethically matured in the research process. The researcher deliberately reveals to the reader the underlying epistemological assumptions that underscored the design of this study, framing of the questions and strategies to collect the data and the particular way to present the findings (Ruby, 1980). Reflexivity therefore, serves as a means of quality control for qualitative research (Berger, 2015) and accounting for a person's values, beliefs, knowledge and biases as a researcher (Buckner, 2005).

Finlay (2002) in a synthesis of literature on the various approaches to reflexivity identified five types; introspection, intersubjective reflection, social critique, mutual collaboration and conscientious reflection. Finlay admits that although the types focus on different aspects of the research process, their borders overlap, with each having its strengths and weaknesses. This reflexive report seeks to tap the strength of all the various types of reflexivity and adopts the Finlay's typology to serve as a guide. This report is presented under the following subheadings: Reflexivity as Introspection (6.5.1), Intersubjective reflection (6.5.2), Social critique (6.5.3), Mutual collaboration (6.5.4) and Conscientious reflection (6.5.5)

### *6.5.1 Reflexivity as Introspection*

Bryman & Cassell (2006) assert that the significance of the researcher in any research process is implicated in the data that is generated by virtue of his or her involvement in the data collection and the interpretation. Through introspection, researchers continuously undertake an internal dialogue and critical self-evaluation of their positionality as well as acknowledge that this position may affect the research process and outcomes (Bradbury-Jones, 2007). I became aware of the challenges faced by the District Health Administration as a result of my position as a trained HIV/PMTCT counsellor, public health practitioner as well as an intern at the District Health Directorate after undertaking studies in health policy. Awareness of the high incidence of HIV recorded in pregnancy, increased reports of patient attrition and the policy implementation challenges, consequently kindled my desire to investigate the phenomenon. Given this prior experience and exposure to the PMTCT programme, I had a prior understanding of the phenomenon as a clinician and educator.

Kacen and Chaitin (2006) aver that being a part of the context has both advantages and disadvantages that may influence the research process. They said an advantage of being an insider was that the researcher possesses information such as language and knowledge of the context which external researchers may lack. On the other hand, they felt that prior knowledge of the context may prevent the researcher from looking at issues through a fresh lens, thus losing out in gaining new insights that were unexplored as yet. In this instance, the knowledge of the context was an advantage as it afforded me the insight necessary to effectively design the study. At the start of the programme, the desire was to understand why pregnant women who had tested HIV positive in pregnancy do not access the PMTCT programme with all the potential benefits it had for their babies and their health. I planned to trace lost mothers to inquire about the reasons why they left and find ways to get them to re-engage in the programme. However, after consulting with the health care providers and managers, it became apparent that it was a problematic venture because of the inconsistent residential address system in Ghana at the time, the incorrect telephone numbers, and inaccurate addresses given by the mothers, and the financial implications of trying to find those who are lost in follow-up. Engaging with the

issue through the research lens, the insight I gained shaped the focus and design of the study from attrition to retention.

Being a part of 'the system' also afforded me the opportunity to gain access to the research setting and participants albeit not without following due process and ethical review. As in the study by Marshall, Fraser, & Baker (2010), my position as a lecturer known to the staff and who had taught some of the midwives may not have only contributed to their willingness to participate but also to recruit for the study.

### *6.5.2 Reflexivity as inter-subjective reflection*

Bryant (2016) refers to inter-subjective reflection as reflexive thinking about meaning-making that takes place mutually between the participant and researcher, with the focus on understanding the thoughts, emotions, attitudes, the researcher's values, meaning making, and the body language of both participants and researchers. Reflections on the emotional investments that the researcher makes into the research process must be monitored for its impact (Marshall et al., 2010). I was aware that some participants might experience emotional (outbursts) when they shared their personal experiences. Thus, I made arrangements for counselling in case any of them might need it. However, I underestimated the emotional impact listening to some of the stories would have on me. As reported by Pellatt (2003), I experienced mixed feelings; worry when women shared stories about suicidal thoughts' sadness when they shared experiences of the death of a spouse or child, and anger when a mother shared how the mortician disclosed her status to relatives. There was also joy when they shared the news of positive outcomes and experiences of the programme when they accessed the PMTCT programme. Hedican (2006) explained that researchers sometimes detach their emotions from the research process in an attempt to eliminate bias but suggested that exploring the emotions elicited in the researcher has the potential to generate knowledge. Thus like Marshall et al. (2010), I made notes of the emotions and thoughts I experienced during the study in an attempt to acknowledge their influence on the research process and also reduced this impact albeit not bracket it, as suggested by van Manen (Van Manen, 1990).

### *6.5.3 Reflexivity as social critique*

Allan and Arber (2017) argue that social critique concerns managing the power dynamics between the researcher and the participants collaboratively. I was not

oblivious to the power dynamics that were at play between the participants and I, during the research process. Hesse-Biber & Johnson (2015) say that researchers typically have more power than the participants and stresses the need for this power to be balanced as it may impact the informed consent and the data collection processes. Karnieli-Miller, Strier, and Pessach (2009) however argue that the ownership of power occurs in a continuum and shifts with each stage of the study as participants tend to wield much power during data collection when they assume the position to determine the quality and quantity of information they share. Karnieli-Miller et al. (2009) suggest early negotiation of power in the relationship, beginning when the participants are approached about the study. Sivell et al. (2015) point out the manner in which participants are approached and recruited into studies may contribute to widening the power gap between the researcher and the participants as the credentials of the researcher when presented creates the impression of an expert and a superior member of the relationship. As part of the strategies to manage the power dynamics at play, I introduced myself as a nurse who was currently a PhD student who needed to collect the data for a PhD thesis in the information sheet which invited them for participation. This was necessary to ensure that my position as a student soliciting for information inundate

Richards and Schwartz (2002) posit that it is ethical to disclose the professional background of the researcher. However, the participant should be informed that the focus of the relationship is research and not therapeutic. In this study, the gatekeepers (CHNs and midwives) were aware of the position of the researcher as a nursing lecturer, PMTCT counsellor, a senior nurse as well as public health practitioner in the district where the study was conducted. They might have divulged this to the participants during the process of informing them of the study. Although, I might have had power as a result of my professional background, I also minimized the power by ensuring that the women had the autonomy to decide to approach me to become participants. An important consideration that needed to be addressed in drawing conclusions from the data concerned whether or not and to what extent knowing my professional background, as well as nurses providing initial information about the study to their clients, could have impacted their' willingness to participate or talk openly about experiences.

As suggested by Blackstone (2012), I ensured that the mothers were aware of their right to agree or refuse to participate without any implications for their access to healthcare or assistance received from the midwives (Appendix H).

Hesse-Biber and Johnson (2015) argue that relinquishing the choice of venue for the conversation to the mothers is an avenue to balance the power in the researcher-participant relationship. As in Blackstone (2012), the conversations with the mothers occurred in various locations selected by the participants including church compounds, offices, and homes. Sivell et al. (2015) aver that conducting an interview in the home of the mother allowed the participant to be in charge but also admitted that it had specific challenges including 'unexpected guests.' In this study, two participants whose conversations were held in their home requested the presence of the introducing nurse or family relative to be present during their conversations. A significant concern that nagged me during data collection and analysis was, could the presence of others influence the responses of the participants? Sivell et al (2015) maintain that the presence of companions during an interview with a participant can influence the interview process and also the information shared as they may even dominate the conversation. However, they also admitted that it could not be avoided in certain circumstances. Dell'Aglio and Koller (2017) also suggested that allowing the presence of others upon the request of the participants shows the respects of the participants' autonomy, wishes and daily routines, as well as, gives a better understanding of the context of the participants. Following these suggestions, the nurse and relatives were allowed to be in the location of the research however they were requested not to make interjections or contributions in the conversation before the start of the conversation. I observed that the presence of others in the vicinity close to where the conversation was held provided some confidence in the participants who had been withdrawn during the initial meeting for information and consent. I could however not ascertain its impact on their responses.

Furthermore, Parahoo (2014) avers that nurses have to balance their gate keeping role of patients entrusted to their care with the potential to influence the outcomes of the research. For instance, Stevens, Lord, Proctor, Nagy, and O'Riordan (2010) report that clinical staff did not inform certain eligible families about their study as they felt their participation in the study would cause distress to their clients. As in the study by Stevens et al. (2010), the midwives were unable to report on the number of

eligible clients they had contacted or how many had declined to be contacted by the researcher or participate.

Karnieli-Miller et al. (2009) maintain that researchers have recourse to many strategies to address power imbalances in the researcher-participant relationship. In this study, a potential power imbalance occurred when the labour ward manager enrolled as a participant. Although, her participation gave credence to the study, her presence might have covertly affected the participation of the midwives in the study. A strategy to break down the existing boundaries of power and authority created by her position was adopted during the paired interviews when she was paired with an experienced midwife who was not intimidated by her institutional position (4.3.4.7.2.1).

The midwives and CHNs were also assured that they could opt not to participate or withdraw from the study at any time without fear that the decision will affect their jobs before, and, during the study (Appendices I and J). Additionally, the researcher ensured that the participants were aware at all times that it was a research study and had its ethical boundaries.

#### ***6.5.4 Reflexivity as mutual collaboration***

Riskin and Bamberger (2014) say that ‘team’ reflexivity is a collective activity in which members of a team undertake a review of their previous work and generate strategies to modify their work behaviour in order to achieve better future results.

Finlay (2002) explains that research participants can be involved in the reflexive process if they are co-opted into the study as co-researchers and engage in data analysis and evaluation. As in the study by Zuniga, Lopez, and Ford (2016), I was aware that my perspective and facilitation style could influence the AI sessions, and the data generation and analysis process. Information gathered from undertaking the individual conversations and becoming immersed in the data during analysis revealed the heterogeneity in the factors influencing retention. This awareness shaped my perspective before the AI sessions with the nurses and midwives. Therefore, I had a methodological obligation to negotiate my status so as not to influence the discussion. Collaborative reflection was a strategy that ensured the analysis included perspectives from other stakeholders. The midwives and CHNs were engaged in discussing and collaboratively analysing the composite stories as

well as their narratives to develop ideas to improve service delivery and retention during AI sessions. Stepping out of their roles as health providers and assuming the role as co-researchers, they were able to reflect on the PMTCT service delivery from the different perspectives; viz CHNs, midwives, and mothers (Alvesson & Skoldberg, 2009).

I recognised the constraints that conducting the AI sessions with the midwives and CHNs within a week could pose (see 4.3.4.7.1.2). I was unable to personally listen, transcribe or analyse the paired conversations apart from the analyses done by the group. Although the participatory analysis is consistent with the AI process, the researcher later referred to the transcripts during the writing-up to ensure that all the relevant data were captured. In retrospect, facilitation of the data unravelling process would have been simpler and expedited if the researcher had transcribed earlier and immersed herself in the data from the paired conversations. In spite of this, the close scheduling of the sessions was in fact a strength, as it kept the momentum going. It allowed for the freshness of the material to the researcher and the participants which ensured ease of recap of previous data. That allowed for clarifications and smooth transition through the various stages of the AI process.

By not presenting your analysis the participants had greater freedom to influence how the data was understood and this enhanced the participatory nature at the analysis stage.

As in the study by Marshall et al. (2010), I also engaged in reflexive discussions with the supervisor regularly. Queries raised in these meetings enhanced the reflexivity processes and challenged decisions concerning methodology.

### ***6.5.5 Reflexivity as Conscientious reflection***

Researchers are required to gain ethical approval to conduct studies involving human participants based on the submission to protect the patient by ensuring confidentiality in addition to other ethical requirements. Saunders, Kitzinger, and Kitzinger (2015) argue that complete anonymity is unachievable in qualitative studies when data collection involves face-to-face conversations. Thus, like Wiles, Crow, Heath, and Charles (2008), the need to protect the identity of the participants created uncertainties especially concerning the inclusion of specific information in the reconstructions of the mothers' stories introduced to the nurses in the AI process.

Peter (2015) emphasizes that in instances where the study population is small and they are being studied because of a unique phenomenon, anonymity may not be enough in protecting their identities as participants could easily be linked to specific information such as events that occurred and employment details. Wiles et al. (2008) admit that this can result in the difficult decision of omitting crucial interview data from the final report or publications. Saunders et al. (2015) however felt it was problematic to eliminate the entire narrative of a participant when it was essential to contextualize the study. In this instance, a participant who provided information on breach of trust and patients' rights by health professionals in the labour ward and theatre was the only patient who had undergone caesarean section among the study population. As done by Wright, Waters, and Nicholls (2004) in their study with clients with mental illness, I used pseudonyms and tried to de-identify the participants as much as possible without distorting the information. This was consistent with honouring the obligation to privacy of the participants. The reconstructed portion of her story was also sent to her to seek her permission before including in the final reconstructed story. It was however unclear whether full anonymity was achieved.

As in other studies, I had concerns about disclosing information revealed by participants under research conditions that have ethical and legal implications on health service delivery and patients' health to persons outside the research team (Corden & Sainsbury, 2006; Wiles et al., 2008; Wright et al., 2004). Melville and Hincks (2016) report that many researchers become uncomfortable when faced with the situation where they have to decide whether to breach the promise of confidentiality or to leave a participant at risk of harm in order to protect a participant's identity. In this study, a participant disclosed that a healthcare worker was convincing her to purchase herbal treatment that could cure HIV. Knowing the falsehood of this information and the fact that the health worker was taking advantage of the client's desperation to be cured and abusing the client's trust, I was faced with the dilemma of keeping the information as data, educating the participant about the falsehood or reporting to the hospital management.

My position as an 'insider' in the PMTCT programme and a senior nurse who knew the implications of any decisions made about the issues heightened my indecision. Wiles et al. (2008) report that they felt compelled to break confidentiality when they

perceived that participants were at risk of harm but not when there were issues of illegality. As in the case of Wiles et al. (2008), the participant did not agree to disclosure as she claimed she had not bought the drug and had also established a relationship with the health worker that could be affected. Hence, the researcher was duty bound not to report the incident but educated the client after the conversation session. Booth and Booth (1994), suggest that in such circumstances, the interviewer does not carry the moral burden of the information gathered alone. They recommend using a reference group of experienced outsiders with whom the researcher can discuss anonymised material that poses ethical dilemmas. Hence, the researcher shared with her supervisor during supervision. Issues on empowering clients with knowledge about HIV infection and treatment options as well as discussing issues with their counsellors were deliberated as part of the midwives and CHNs' collaborative discussions to improve clients' experiences and retention in PMTCT.

### ***6.5.6 Summary***

The impact of the experiences of the researcher and participants interactions as well as the positionality of the researcher on the research process cannot be overemphasized. Reflexivity offered the opportunity to acknowledge the subjectivity of the output of the study and allowed for the researcher to examine her motives and prejudices and also allowed for growth in the process.

### ***6.6 Conclusion***

The findings of this study contribute to the knowledge base of PMTCT retention by highlighting the positive outcomes of PMTCT service delivery, the factors that enhances retention and the aspirations of the midwives and CHNs towards enhancing PMTCT services delivery. The study reveals positive midwifery and nursing care that positively influenced the care experience and retention in the PMTCT programme. The study adopted measures that were contextually sensitive and ensured inclusion of the HIV-infected mothers without breaking their confidence.

## **CHAPTER 7 RECOMMENDATIONS AND CONCLUSION**

### **7.1 INTRODUCTION**

This chapter presents a summary of the study. It presents a reflection on the purpose of the study, the objectives of the study and the chosen methods that were employed in the research process. The contribution of this research and the implications of the study to the field of nursing and midwifery and the health system as a whole are also discussed. Recommendations for research and strengthening the service delivery and the health system are presented. A section on the conclusion follows this.

### **7.2 SUMMARY OF THE STUDY**

This Mixed Method Sequential Explanatory with Appreciative Inquiry as its dominant method was conducted among HIV positive mothers who were diagnosed in their current pregnancy, and nurses and midwives who work in the PMTCT programme in a district hospital of a low-middle-income country.

The purpose of the study was to apply Appreciative Inquiry as a process to determine what factors will contribute to improved retention of women who are newly diagnosed HIV positive in the PMTCT programme. The study explored the experiences of the mothers while accessing care in the PMTCT programme and the reasons why they decided to remain in the programme. The aspirations of midwives and CHNs providing PMTCT services to enhance retention in the programme were also explored.

A two-section approach was adopted. Section A was a descriptive retrospective study that involved a record review of a cohort of HIV positive mothers who were diagnosed in the current pregnancy. This data provided baseline data regarding the rate of uptake of PMTCT services; the socio-demographic, obstetric and clinical characteristics of mothers; and the retention rate at the various points in the PMTCT cascade. Section B explored the experiences of the mothers while engaged in the PMTCT programme and the factors that had underscored their decision to remain in the programme using the generative conversation approach of the AI method. After

that, the AI sessions was undertaken with nurses and midwives providing PMTCT services to explore their aspirations, review the PMTCT services through the experiences of the mothers and to identify strategies that would enhance retention collaboratively. The researcher who had undertaken training in Appreciative Inquiry facilitated the process.

The study found a high uptake of HIV testing and counselling by the women who booked for healthcare in the integrated MNCH/PMTCT service, 94.1%, and 90.6% of respectively. However, there was a gradual decline in retention at various points along the PMTCT cascade. The highest disengagement (30.8%) occurred in the antenatal period. The mothers' socio-demographic characteristics were not associated with disengagement or retention in the programme. The study identified the phenomenon of hospital shopping and re-engagement at a later stage by some expectant mothers who tested positive in the current pregnancy but defaulted or disengaged from the programme antenatally. The rate of retention was 67.4% at six weeks postpartum.

Data unravelling in Section B generated four main themes: Transitioning into a 'new' woman, journeying with committed companions, glimpses of triumph, and tying up the loose ends: a daring new path. The study found that confronting the HIV diagnosis was enormous and carried with it multiple implications for the women, their unborn children, families, society, and the health system. A successful transitioning from the vulnerable and emotionally shaken woman to an empowered HIV infected woman who lived a healthy life was found to require the personal commitment of the infected mother and the commitment of the midwives, nurses and other people to whom the mothers chose to disclose. The women's faith, accepting HIV as a chronic disease, the decision to disclose or otherwise, and the spiritual care received while they engaged in the programme, aided the transition process.

Relationships established between the women and the midwives/CHNs were found to aid the transition process and also supported the newly diagnosed HIV infected mothers' decision to remain in the programme. These relationships were built on trust, confidentiality, accessibility, encouragement, and commitment. The study identified varying levels of relationships;

therapeutic relationships<sup>19</sup> at the labour ward and connected relationships<sup>20</sup> at the ANC, PNC, and public health units. The mothers' perceptions about midwives and nurses also changed as the women developed personal relationships with them and received support and care. Friendliness of the staff in addition to their technical expertise was found to foster the development of this relationship and enhance the mothers' decisions to remain or re-engage in the programme.

For both the mothers and the health care workers, positive experiences while engaging in the programme was found to be an essential consideration underpinning the mothers' decision to remain in the programme. These included a healthy mother who did not experience or exhibit the signs and symptoms of HIV as a result of the effectiveness of the drugs, an HIV negative result for an exposed baby and establishing positive relationships with the health workers. The women developed resilience over time through knowledge sharing and active participation in decision making concerning their care. This resilience strengthened their resolve to remain in the programme in spite of the challenges they encountered or perceived to be associated with an HIV diagnosis or accessing care.

In spite of these positive experiences in the PMTCT programme, the study identified some aspects of the health system and service delivery that needed strengthening or redesign to improve the care experience. The action plans developed included enhancing the integrated MNCH/PMTCT by ensuring continuity of care and carer, delivering sensitive care in a conducive environment and engaging religious leaders to enhance retention in the programme. Strategies to enhance care were collaboratively developed and implemented based on these service delivery shortfalls.

### **7.3 THE CONTRIBUTION OF THIS STUDY TO THE FIELD**

This was a novel study that used the AI approach to explore retention in the PMTCT programme. Studies focusing on the HIV infected women diagnosed in pregnancy who had remained in the PMTCT programme using the AI approach were not found.

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<sup>19</sup> A nurse-patient relationship where the nurse views the mother as a patient but takes cognizance of mothers' life outside the patient role (Morse, 1991).

<sup>20</sup> The nurse-patient relationship where the nurse views the mother first as a person who has a health need and requires assistance (Morse, 1991).

The approach was successful as it resulted in the development of context-specific strategies to enhance service delivery and improve retention in the PMTCT programme.

Unlike other studies which have focussed on attrition, the study was the first to review retention of women across the whole PMTCT cascade in the study setting and to engage the service providers in discussing the outcomes of retention, disengagement, and LTFU in their facility. Due to the minimal integration of the MNCH/PMTCT programme, the nurses and midwives were unaware of the whole picture of retention in the PMTCT programme. This exposure enlightened them about their contribution to service delivery from a broader perspective.

The literature on interventions to promote retention in the PMTCT programme indicates that interventions have usually been developed by researchers and implemented in research settings. These have not produced a high effect of change as indicated in the literature review. The inclusion of the mothers', midwives and CHNs' perspectives in developing the action plans that aimed to improve the care experience of the mothers and to enhance retention was novel. Advocating for continuity of care and carer and the development of teams across the PMTCT cascade to enhance information flow was feasible within the existing practices of the programme.

## **7.4 RESEARCH AND CLINICAL IMPLICATIONS**

Several implications for research and PMTCT clinical care have been drawn from the study findings and conclusions.

### ***7.4.1 Research implications***

Most studies on retention in the PMTCT programme focus on reporting trends of testing, disengagement, and LTFU. The evidence from this study reveals that the emotional and psychological instability created in the woman who is newly diagnosed HIV positive in pregnancy contributes to the increased levels of disengagement in the programme before treatment initiation in the ANC period. The option B+ policy to initiate treatment immediately without recourse to the mother's WHO staging or CD4 count points to the essential question of how to manage the newly diagnosed woman in PMTCT in the first few days of testing to prevent

disengagement and LTFU. Research to strengthen counselling approaches that will be successful in the immediate period following testing is needed.

The study findings revealed that the phenomenon of re-engagement after defaulting exists in the PMTCT. Evidence from the study points to two reasons why re-engagement occurs; a personal reflection of the mother on the benefits of the PMTCT programme, and ad hoc patient tracking efforts by CHNs. There is however limited documentation on patients who re-engage after disengaging from the programme. Research to explore the trends of re-engagement and the factors that underscore the decision will be worthwhile in informing policy on retention in PMTCT care.

### ***7.4.2 PMTCT service delivery implications***

This sub-section presents intra-service issues (7.4.2.1) as well as partnerships outside the services (7.4.2.2 &7.4.2.3) that would enhance the functioning of the services.

#### **7.4.2.1 Providing relational PMTCT services**

In the case of PMTCT care, the needs of the newly diagnosed mothers are enormous. Engagement between the midwives, CHNs and the clients extend over a period of several months to over a year. The practitioner-client relationship was an essential factor in the newly diagnosed PMTCT mothers' decisions to remain in the programme. Nursing and midwifery are relational professions. Hence, professionals ought to be taught how to establish and maintain the practitioner-patient relationship within the necessary boundaries of the professions. Training of nurses and midwives who render PMTCT services must include the dynamics of establishing and maintain effective practitioner-patient relationships in addition to training on the specific skills and competencies required for effective service delivery in the programme.

A friendly yet effective and efficient healthcare worker might facilitate the development of the relationship and enable open communication about service related and client related challenges that must be addressed to enhance retention.

### **7.4.2.2 Involvement of faith leadership in PMTCT programme**

Narratives in Chapter 5 revealed a high level of religiosity of women in the programme. The religious leaders' beliefs about divine healing and orthodox medicines as well as the causes of HIV infection influenced their advice to their memberships on accepting treatment or otherwise. Faith in God and the confidence the newly diagnosed HIV positive women had in their religious leaders, was found to influence their decision to initiate care or continuously engage in the programme. The religious leaders should be educated about HIV and PMTCT services. Involving religious leaders of the various faith groups in PMTCT activities such as health education campaigns and liaising with the leaders to use their platforms to inform their members about the benefits and positive outcomes of PMTCT could yield positive results in promoting retention. The education should address the fact that accessing healthcare does not mean that one does not believe in divine healing. That could have the additional benefit of improving the health literacy of both male and female members and the community as a whole on the issues of HIV and PMTCT. It could also help change the narrative about HIV and PMTCT, reduce stigmatisation and judgmental attitudes, and promote support.

### **7.4.2.3 Continuous community mobilisation related to PMTCT services**

Although the findings showed a high level of acceptability of HIV testing in pregnancy, the narratives also indicated that stigma and discrimination persist in the community. This often resulted in self-stigmatisation by the infected mothers and resulted in social isolation. This perceived or experienced stigma negatively impacts retention. The study suggests that a vibrant community mobilisation towards enhancing health literacy on HIV and PMTCT will enhance community-wide acceptability, and support for the programme. The health literacy strategy should focus on changing the narratives about HIV towards the benefits of the PMTCT programme and the successes attained. Involvement of the community leaders can also enhance male involvement in the programme and reduce the fear of disclosure,

abandonment, abuse, and blame that most women perceive they would suffer if they disclosed their positive status to their spouses.

### ***7.4.3 Implications for nursing and midwifery professions***

This subsection focused on the implications of the study findings on the nursing and midwifery professions and organised as follows: Supportive strategies for nurses and midwives in the programme (7.4.3.1), Training of staff rendering services in PMTCT (7.4.3.2), Motivation for health staff in the PMTCT programme (7.4.3.3), and Empowerment of health workers to programmatic change (7.4.3.4)

#### **7.4.3.1 Supportive strategies for nurses and midwives in the programme**

At the time that this study was conducted, there was no protocol for emotional care and debriefing of midwives, community health professionals and other healthcare professionals who provided care in the PMTCT programme. It appeared that policymakers and administrators were unaware of the emotional demands providing care to HIV positive pregnant women had on the nurses and midwives. It was apparent that much of the PMTCT training that had been organised sought to ensure technical competence without attending to the emotional needs of the healthcare providers. Hence, the health workers used individual resources and strategies to manage the stresses associated with the provision of care. Ineffective handling of stressful situations could result in health worker burnout that could affect the relational aspect of service delivery and consequently affect retention of newly diagnosed HIV positive mothers in the PMTCT programme.

#### **7.4.3.2 Training of staff rendering services in PMTCT**

The study found that most of the nurses and midwives rendering services within the MNCH/PMTCT integrated programme started working without formal training in PMTCT care. The study identified many instances of missed opportunities (5.1.1) for engaging pregnant women in care and instances of unsatisfactory experiences of the mothers while accessing care. These could have resulted in disengagement from the programme, and indeed the women indicated that their friendship with the nurses and

midwives influenced their decision to remain in care. PMTCT care had technical and ethical components that require formal training to provide the best care. In-service training of staff who are rotated to units offering PMTCT services before the onset of their rotation may have curtailed some of these disappointing experiences and have enhanced retention.

### **7.4.3.3 Motivation for health staff in the PMTCT programme**

The integration of the PMTCT programme into the existing MNCH services increased the workload of midwives and CHNs providing services in those units without allocation of additional staff and resources. The programme demanded commitment and engagement from the health workers far beyond the demands of providing care to pregnant women without the HIV infection. Although these commitments maybe covert, they were necessary for ensuring retention of the mothers and positive outcomes of the programme. The availability of staff trained in PMTCT, 24-hours is necessary for sustaining the staff efforts and relationship built between the health staff and the mothers. However, it may not be feasible or reasonable to expect that the healthcare professionals are on call all the time. Thus, the sustainability of this enhanced programme may be affected when measures to increase the staff strength, technical skills and motivation are not in place. Patient tracking, for instance, required patience and persistence, providing reminders of appointments and encouragement of the mothers ensured through telephone calls and text message that had financial implications for the midwives and CHNs. These were however not covered by the health system. The study also found that there was lack of recognition or motivation from the health managers. That could have resulted in the midwives and CHNs resigning their efforts and indifference.

### **7.4.3.4 Empowerment of health workers to programmatic change**

As the main implementers of health policy, nurses and midwives are privy to many challenges issues and challenges that impact the outcomes of health policy. It is evidenced in this study that midwives and CHNs, when giving the opportunity to organisational improvement projects are a resource as a result of the experience they

garner during the course of their work. It is recommended that health professionals should be included in future health improvement projects at the planning, implementation, and monitoring and evaluation stages. This would not only improve project outcomes but empower the health workers. Acknowledgement of ones' abilities is a viable source of empowerment and knowledge creation.

#### ***7.4.4 Implications for the Health System***

This subsection presents the implications of the study findings for the health system under the following headings; facility-based Health improvement (7.4.4.1), organisation and Structure of the Health System (7.4.4.2) and accommodation for nursing activities on PMTCT folder (7.4.4.3).

##### **7.4.4.1 Facility-based Health Improvement**

Theme four covered participants' concerns about the organisation of the PMTCT programme in the facility. The observation implies that the hospital managers need to restructure service delivery focusing on improving clients' experiences. The open environment of the waiting area, location of the testing room and allocating one room for PMTCT activities were found to discourage uptake of the service. The data also showed that segregating HIV services at the pharmacy exposed the clients to unintended disclosure that resulted in clients' discomfort and, invariably, disengagement. Frequent changing of health care providers at the various units providing PMTCT services especially at the pharmacy required patients to disclose to multiple health professionals on multiple occasions. This was emotionally stressful for the clients. The narratives showed the need to address these at the facility level as they could discourage people from remaining in the programme.

##### **7.4.4.2 The Organisation and Structure of the Health System**

The District Health Directorate has demarcated the catchment areas of the health facility under its administration. However, these demarcations are not enforced in relation to clients accessing health care. There is no clear access point and the lack of coordination of records on client enrolment and testing in the PMTCT programme across facilities enabled duplication of registration and potential inflation of LTFU. HIV testing and enrolment of infected mothers in care are localised in each health

facility. The study identified the phenomenon of ‘hospital shopping’ of newly diagnosed pregnant women, and re-engagement in the initiating facilities later on in the pregnancy. With the lack of coordination of patient records and an individualised registration number that was centralised across all facilities providing PMTCT services in the district or the country, the opportunity for multiple testing and enrolment of individuals could have resulted in inflation or over-estimation of the national PMTCT incidence rate, the rate of disengagement and LTFU. Multiple registration could however not be detected as the study was limited to one health facility.

With the introduction of opt-out policy and the missed opportunities for counselling and testing in this study, one wonders if the antenatal prevalence of HIV is an accurate reflection of the Ghanaian situation or if another approach to ascertaining a more reliable data should be considered.

#### **7.4.4.3 Accommodation for nursing activities on PMTCT folder**

The lack of documentation of certain nursing activities that were later found in the AI to have contributed to retention. The design of the PMTCT patient folder did not accommodate continuous documentation of certain important PMTCT activities such as counselling, patient tracking and health education. Although, the patient and nurses’ narratives revealed that these activities especially patient tracking was done, no records were available to this effect. Hence, the assumption that patients who were lost from the PMTCT programme were not tracked. At the time of the study, although nurse-or midwife-led care models had been rolled out, the patients’ folders had not been modified to accommodate such nursing and midwifery care activities but were only limited to the medical components of PMTCT care. This indicates that nurses and midwives are not involved in policy and design of patient records.

### **7.5 RECOMMENDATIONS**

The recommendations from this study are geared towards research in PMTCT (7.5.1), strengthening the capacity of nurses and midwives (7.5.2) and health system strengthening (7.5.3).

### ***7.5.1 Research in PMTCT***

This section presents the recommendations for further research in the PMTCT programme. It is as follows; Design of intervention studies (7.5.1.1) and Collaborative research (7.5.1.2).

#### **7.5.1.1 Design of intervention studies**

This study has implications for selecting research designs to study retention. Research studies on retention are mostly retrospective in nature and also report on disengagement rather than retention. Continuous engagement at the various service delivery points in the PMTCT programme is influenced by different factors. The study findings reveal that the decision to remain in the PMTCT programme solely lie with the mother, although certain factors may influence her choice. It is recommended that intervention studies designed to improve retention will seek to amplify context specific factors that are already accounting for retention. The involvement of stakeholders, clinical midwives, nurses' and patients in the designing of intervention studies to improve retention could improve the effect of such interventions in the PMTCT programme

#### **7.5.1.2 Collaborative research**

The health facility should collaborate with academics to research the patterns of service delivery and outcomes in the PMTCT programme that will yield positive outcomes and retention. The outcomes of the collaboration will enhance the development of context-specific strategies to enhance service delivery and also promote ownership of the strategies. Involvement of the PMTCT staff in such studies as researchers will not only promote ownership but will enhance their research skills and the ability to identify challenges that needs to be addressed or successes that needs to be amplified. The health system should also involve clients in research in a more meaningful way not only as subjects but as stakeholders who actually contribute to the project design and implementation.

Following findings from this study, further research studies are necessary to understand and clarify aspects of PMTCT service delivery.

- i. A study to explore the factors influencing pregnant women's decision to opt-out from HIV testing and the gaps in service delivery that creates missed opportunities in the antenatal period is required
- ii. A follow-up study to explore the transitioning experiences of mothers from PMTCT into adult ART care and its impact on long-term retention.
- iii. A study to explore the effect of continuity of carer model on retention in the PMTCT programme and for maternity care in general.
- iv. A study to evaluate the implementation of health policy on MNCH/PMTCT integration in health facilities and its impact on retention in the programme.
- v. A feasibility study on the implementation of a comprehensive electronic registration system across facilities providing PMTCT services.
- vi. A case study to explore the relational engagement between nurses/midwives and newly diagnosed HIV positive pregnant women under the PMTCT programme.
- vii. A study to examine the midwives' role as gatekeepers for HIV-infected women enrolled in the PMTCT programme and its implications for service delivery and retention.
- viii. A study to explore the spiritual care experiences of mothers and nurses in the PMTCT programme and its implications for retention in care.
- ix. A study to investigate the emotional engagement of nurses and midwives and how they are managed while rendering care in the PMTCT programme.
- x. Explore the role of hospital chaplains and faith leaders in enhancing uptake and engagement in the PMTCT programme.

### ***7.5.2 Strengthening nursing and midwifery capacity***

The study findings revealed implications for improving the capacity of nurses and midwives providing services in the PMTCT programme. Recommendations for the capacity building is organised under the following headings: Continuous professional development and mentorship (7.5.2.1), Clinical support for nurses and midwives (7.5.2.2), and Evidence-based practice initiatives (7.5.2.3).

### **7.5.2.1 Continuous professional development and mentorship**

Training and continuous professional development (CPD) of all nurses and midwives working in the MNCH/PMTCT programme should be mandatory before working in the units. These training and CPDs should not only focus on equipping the staff with technical skills but with relational skills and the necessary capacities and strategies to manage both the clients and their own emotional experiences while providing care in the PMTCT context.

Giving the shortfalls in the nurses' and midwives' efforts at counselling revealed in this study, establishing a system of regular training and assessment on their competence on HIV counselling is imperative. These training programmes should be regular and carry CPD points as well as certifications for Professional Identification Number (PIN) renewal to ensure commitment and active participation.

There is the need to establish a facility based-clinical facilitation and mentorship programme for all nurses and midwives who are assigned duty in units along the PMTCT cascade. The programme would improve standards of care and patients' experiences. Nurses and midwives who have undergone formal training in PMTCT service delivery and clinical expertise must be assigned the clinical facilitation and mentorship roles. This programme will be effective if the responsibilities are recognised as additional responsibility and applicable for appraisal of the nurses and midwives.

### **7.5.2.2 Clinical support for nurses and midwives**

It is recommended that a programme for emotional care and debriefing of nurses and midwives providing care in the PMTCT programme should be established. This programme should be scheduled at regular intervals to ensure that the nurses and midwives working in the programme have an opportunity to share their concerns and have the necessary emotional support to augment their efforts and prevent burnout and compassion fatigue. Motivational packages that can enhance commitment in the staff should be included in programme improvement strategies. Opportunities for the staff to develop themselves experientially and theoretically should be considered.

### **7.5.2.3 Evidence-based practice initiatives**

Much research is being conducted on PMTCT across the globe, and this is evidence that ensures that the PMTCT service delivery keeps evolving. In the wake of the implementation of the nurse- or midwife-led PMTCT care, access to evidence to improve practice should be made available to the nurse/midwife practitioners.

### ***7.5.3 Strengthening the health system for PMTCT care***

The research findings had implications for strengthening the health system to improve the PMTCT programme. Recommendations to ensure service delivery improvement through health system strengthening is presented under the following subheadings: Establishment of active patient engagement strategies (7.5.3.1), Clinical practice (7.5.3.2), Registration and enrolling of clients (7.5.3.3), Redesigning Patient folder suitable for Nurse- or Midwife-led PMTCT care (7.5.3.4), Human resource management (7.5.3.5), Developing local capacity for sustaining HIV/PMTCT programme (7.5.3.6).

#### **7.5.3.1 Establishment of active patient engagement strategies**

The HIV infected mothers are important stakeholders in the PMTCT programme. The availability of prospects for participation in the programme as active partners, opportunities to contribute to decision making, availability of avenues for reporting challenges while accessing care and the need for quick actions to assuage or solve patients' complaints will enhance patient experiences and improve retention. These strategies should be communicated to the clients through leaflets, posters and during engagements with the health workers. This will also help enhance staff patient relationships as the channel of communication will be clearly stated

#### **7.5.3.2 Clinical practice**

Practice guidelines that standardise the care of women who test positive in the PMTCT programme should be developed and tested. The practice guidelines should be context-specific and should be based on scientific evidence and national policies. It is essential to ensure all nursing and midwifery professionals providing care within

the PMTCT programme follow the guideline when providing care to infected mothers.

Monitoring of service delivery through report reading, exit interviews and managing of patients' complaints should be instituted to enhance PMTCT service delivery.

Clinical teams across the various units providing PMTCT services should be established to enhance patient flow and information transfer between the nurses and midwives. This strategy is essential to ensure a smooth transition of patients across the care continuum. It will also reduce the emotional burden associated with the need to disclose their status to new staff continuously. It also has the benefit of ensuring that patients' progression through the PMTCT programme is monitored so that missed visit and disengagements are immediately identified and managed.

### **7.5.3.3 Registration and enrolling of clients**

As part of the health system improvement plan, the study points to the need for an integrated, centralised electronic PMTCT data capturing system that has a unique identification for each client. This could be linked to the national health insurance since the free maternal health policy being run in the country provides free health insurance under the National Health Insurance scheme for all pregnant women.

Linking this system district-wide or nationwide can reduce multiple registrations and promote a clearer picture of the incidence of HIV in pregnancy as well as the rate of retention.

It is recommended that records regarding the opt-out choice of women and potential missed opportunities for PMTCT counselling and testing are maintained. These records must be reviewed regularly, and strategies drawn from the knowledge gathered from the review of these records to improve service delivery and policy development on PMTCT programme.

### **7.5.3.4 Redesigning Patient folder suitable for Nurse- or Midwife-led PMTCT care**

A comprehensive patient clinical document that accommodates nursing, midwifery and medical components of PMTCT care is required. This will guide nursing practice within the PMTCT programme and serve as evidence of quality care. It would enhance monitoring and evaluation and flow of patient information across the

continuum without the patient having to explain themselves or disclose their status continuously. Clinical audits of all records and PMTCT clinical management decisions should regularly be undertaken. The delivery of care in the PMTCT programme must be regularly monitored to ensure that practice guidelines and protocols are being followed.

### **7.5.3.5 Human resource management**

Adequate number of staff who have received training in PMTCT care must be assigned to the PMTCT/MNCH units to provide the required care. Because of the specialised nature of the interaction between mothers and the nurses and midwives in these units, rotation of staff should be reduced to a minimum. Rotation of the staff should be between ANC, intrapartum and PNC, but not out of the MNCH department. This will ensure that with a long engagement, the patients' can establish and maintain trusting relationships with the staff. It will also allow for the development of nurses and midwives who will attain proficiency in PMTCT service delivery.

In-service training, continuous professional development and further education in PMTCT and MNCH specialties should be supported and sponsored. They should be prioritised and seen as an integral aspect of quality improvement that is essential to achieving the goals of the health service and not as an add-on.

### **7.5.3.6 Engaging faith leaders in the PMTCT programme**

Most of the population in Ghana identify with a religious organisation (Ghana Statistical Service, 2015, p. 31). The health service should partner with the faith leaders to enhance the uptake of PMTCT programme. Leadership of the main religious organisations should be co-opted into committees constituted to improve the knowledge of the populace on HIV/PMTCT services. The hospital chaplain should be engaged on providing support for clients and staff in the PMTCT programme who agree to be referred to the chaplaincy office.

### **7.5.3.7 Developing local capacity for sustaining HIV/PMTCT programme**

Accessing care in the PMTCT is free under the free maternal and child health programme. Although the infants ARV prophylaxes are not covered, the mothers are promised life-long treatment. The limited access to DNA PCR testing equipment and reagents also affects service delivery and increases the mothers' anxiety as the waiting time to determine the HIV status of the exposed mother is extended. These services require financial commitments from the government. In light of the heavy dependence of the National AIDS Control programme on foreign aid and the changing commitments of foreign donors, there is a need for government to build local capacity to deliver the services under HIV/PMTCT programme. This would assuage the fears of the mothers about possible non-availability of ART and other services in the future. Instituting a fund under the National Health Insurance Scheme to as an alternative for the unpredictable foreign aid concerning HIV is critical.

## **7.6 DISSEMINATION OF FINDINGS**

Copies of the research report will be presented to the National AIDS Control Programme, Ghana, the Sekondi-Takoradi District Health Directorate and the Takoradi hospital. Feedback will also be given to the nurse manager, the nurses, the HIV/PMTCT coordinators in the district, the training coordinators and the participants. The study findings will also be disseminated through publications in peer-reviewed journals and presented at relevant national and international conferences.

## **7.7 CONCLUSION**

This study speaks to the subject of retention of newly diagnosed HIV positive mothers in pregnancy enrolled in the PMTCT programme. It was conducted in a district hospital that provides services to a broad category of people with various socio-demographic, economic and religious characteristics in a cosmopolitan yet under-resourced context.

The study showed that acceptability of HIV counselling and testing was high, but attrition occurred along all the points of the PMTCT cascade with no association with any of the maternal socio-demographic indicators. The retention rate was

moderately high. The mothers who are diagnosed HIV positive in pregnancy undergo the phenomenon of transition from the once-indifferent woman on issues of HIV to women empowered and living healthily with HIV. The decision to remain in the programme in spite of the many challenges is a personal choice of the mothers that are influenced by the relationships they establish with the nurses and midwives, the positive outcomes of care and the positive experiences they gain in the PMTCT programme.

The study recommends that PMTCT training should include developing relational skills for nursing and midwifery practitioners. The factors that enhance the positive experiences of the mothers in care should be amplified, and health system challenges that contribute to disengagement should be addressed. The study also proposes the establishment of nursing support programmes to assist the nurse and midwife practitioners manage the emotional stresses that providing care in PMTCT brings through debriefing.

The Appreciative Inquiry process was useful in identifying the qualities of the nurses and midwives in the PMTCT programme and the aspects of the services they rendered that have contributed to retention of mothers in the programme from both the practitioners and the clients' perspectives. The method allowed for the development of a plan of action to amplify these attributes and practices across the programme. The Appreciative Inquiry was useful and valuable in identifying strategies to enhance the health workers efforts in improving retention in the PMTCT programme.

The benefits of PMTCT to the mother, family, the community and the country are enormous. To attain the UNAIDS/WHO goal of eliminating paediatric new infection and ensuring mothers remain healthy by 2030 can be attained if service delivery in the PMTCT programme is client-centred. Understanding and incorporating patient perspectives into health system planning can achieve the goal. This study contributes to this important venture by sharing the patients and providers' perspectives.

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## APPENDICES

### *APPENDIX A: Ethical Approval from UCT Faculty of Health Sciences Human Research Ethics Committee.*



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E53-46 Old Main Building  
Grootte Schuur Hospital  
Observatory 7925  
Telephone [021] 405 6492  
Email: [sumayah.ariel@uct.ac.za](mailto:samayah.ariel@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

30 January 2017

**HREC REF: 917/2015**

**A/Prof S Clow**  
Department of Health & Rehab Sciences  
F-45  
OMB

Dear A/Prof Clow

**PROJECT TITLE: "WHY I STAYED WHEN OTHERS LEFT": AN APPRECIATIVE INQUIRY OF RETENTION IN THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV PROGRAMME IN SEKONDI-TAKORADI METROPOLIS, GHANA (PhD Nursing Candidate - Ms S Abraham)**

Thank you for your response letter dated 14 January 2017, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30 January 2018.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.  
(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

**We acknowledge that the student, S Abraham will also be involved in this study.**

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.

HREC:917/2015

## *Appendix B: Ethical Approval from Ghana Health Service Ethics Review Committee*

### GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

*In case of reply the  
number and date of this  
Letter should be quoted.*



Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra  
Tel: +233-302-681109  
Fax + 233-302-685424  
Email: ghserc@gmail.com  
18<sup>th</sup> August, 2016

*MyRef. GHS/RDD/ERC/Admin/App  
Your Ref. No.*

Susanna Aba Abraham  
University of Cape Coast  
School of Nursing and Midwifery  
Cape Coast

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	<b>GHS-ERC011/05/16</b>
Project Title	Why I Stayed When Others Left: An Appreciative Inquire of Retention in the Prevention of Mother-to-Child Transmission of HIV Programme in Takoradi, Ghana
Approval Date	18 <sup>th</sup> August, 2016
Expiry Date	17 <sup>th</sup> August, 2017
GHS-ERC Decision	<b>Approved</b>

**This approval requires the following from the Principal Investigator**

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report **after completion** of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED:   
PROFESSOR MOSES AIKINS  
(GHS-ERC VICE-CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

*Appendix C: Approval letter from the Regional health Directorate*

In case of the reply the number and the date of this letter should be quoted.

My Ref. No WR/GHS/PH/SL4  
Your Ref. No.....



REGIONAL PUBLIC HEALTH DIVISION  
P. O. BOX 221  
TAKORADI  
22<sup>ND</sup> February 2016

**THE MEDICAL DIRECTOR - E N R H**  
**THE MEDICAL SUPT - TAKORADI HOSPITAL**  
**THE MEDICAL DIRECTOR - GHAPOHA HOSPITAL**  
**THE DIRECTOR - JEMIMA CRENSIL HOSPITAL**

**APPROVAL FOR RESEARCH IN PMTCT OF HIV IN SEKONDI TAKORADI METROPOLIS**

The Regional Director of Health Services has granted approval to the bearer of this letter Susanna Aba Abraham to conduct the above research in the Sekondi Takoradi Metropolis.

Kindly accord her the necessary courtesies since the Regional Health Directorate is very much interested in the research findings.

Thank you.



**DR. KOFI ASEMANI-MENSAH (PH)**  
**DEPUTY DIRECTOR (PH)**  
Ghana Health Service  
Western Region

cc: The Metro Director  
Metro Health Directorate  
Sekondi Takoradi

*Appendix D: Letter from Sekondi-Takoradi Metropolitan Health Directorate*

In case of any reply the number  
And date of this letter should be  
quoted



SEKONDI-TAKORADI METROPOLIS  
POST OFFICE BOX 187  
SEKONDI

**OUR CORE VALUES**

- Team work
- Professionalism
- Innovation
- Integrity
- Client centeredness
- Discipline

TEL NO: 0206663467

22<sup>ND</sup> FEBRUARY, 2016

Our Ref: GHS/WR/MHD/11/14

**THE DIRECTOR  
HUMAN ETHICS BOARD  
GHANA HEALTH SERVICE  
ACCRA**

**APPROVAL TO CONDUCT RESEARCH IN PMTCH ON HIV IN THE METROPOLIS  
MS. SUSANNA ABA ABRAHIM – PHD IN NURSING**

The above-named officer is a second-year PHD in Nursing student at University of Cape Town, South Africa.

The Regional/Metropolitan Health Directorates have granted her the approval to conduct research in PMTCT of HIV in the underlisted facilities in the metropolis.

- Effia Nkwanta Regional Hospital
- Takoradi Hospital
- GPHA Hospital
- Jemima Crentsil Hospital

You are kindly requested to offer her all the necessary assistance she may need.

Thank you.

**JOYCE K. BAGINA  
METRO DIR. OF HEALTH SERVICE**

**Director  
Metro Health Directorate  
S.T.M.A  
Sekondi**



*Appendix E: Letter from Takoradi Hospital*

In case of the reply the number and the date of this letter should be quoted.

**TEL No: +233-031-22501/2**  
My Ref. No. GHS/TH/  
Your Ref. No.  
.....  
E-mail:  
[takoradihospital@yahoo.com](mailto:takoradihospital@yahoo.com)  
Fax No. 03122503



GHANA HEALTH SERVICE  
TAKORADI HOSPITAL  
P. O. BOX 7  
TAKORADI

21<sup>ST</sup> APRIL, 2016

**TO WHOM IT MAY CONCERN**

Dear Sir/madam,

**RE: APPROVAL FOR RESEARCH IN PMTCT OF HIV IN  
SEKONDI/TAKORAD METROPOLIS**

With reference to your letter number WR/GHS/PH/ R4 dated 22<sup>nd</sup> February, 2016 signed by Dr. Kofi Asemani-Mensah - Deputy Director Public Health please.

The hospital management has agreed to your request as stated above to conduct research in PMTCT on the above named hospital.

You are by a copy of this letter assured of the necessary assistance.

Thank you.

  
**FRANK OWUSU ASARE**  
**(PRIN. ADMININSTRATOR)**  
**FOR: MEDICAL SUPERINTENDENT**

## Appendix F: Maternal records form

### Data Extraction Form A

**Date:** \_\_\_\_\_

Demographic characteristics									
PMTCT Folder number:									
Age (years):	(1) <20 (2) 20-24 (3) 25-29 (4) 30-34 (5) 35-39 (6) 40-45 (7) >45 (9) NR	Employment Status:	(1) Self employed (2) Formal (3) Not employed (4) Part time (4) Student (9) NR						
Educational level:	(1) No education (2) Primary (3) Secondary (4) Tertiary (9) NR	Marital Status:	(1) Married (2) Single (3) Divorced (4) Widowed (9) NR						
Baseline HIV screening & ART initiation									
Date of HIV 1 <sup>st</sup> Diagnosis:	___/___/___ DD MM YYYY		Gestational age (at ARV initiation)	_____ (In weeks)					
Date of 1 <sup>st</sup> CD4 (booking):	___/___/___ DD MM YYYY		Date of ARV screening:	___/___/___ DD MM YYYY					
Adherence counselling (date)	1 <sup>st</sup> ___/___/___ DD MM YYYY		2 <sup>nd</sup> ___/___/___ DD MM YYYY	3 <sup>rd</sup> ___/___/___ DD MM YYYY					
Type of ARV initiated:	(1) Prophylaxis (2) HAART		Disclosure status:	(1) Yes (2) No (9) NR					
When was treatment initiated?	(1) Antenatal (2) Labour (3) Postnatal (5) NR		Disclosed to whom:	(1) Partner (2) Other family member (3) Friend (4) Other (9) NR					
Obstetric history									
Site of delivery	NO. of ANC visits	Exclusive breast feeding	No of PNC visits DD/MM/YY			Date of delivery	Weight (kg)	Sex	Mode of delivery
			1st	2nd	3rd				
		(1) Yes  (2) No						(1) M  (2) F	(1) SVD  (2) C/S
Outcome of pregnancy:	(1) Alive (2) Still birth (3) Spontaneous Abortion (4) NR		Outcome of PMTCT care:			(1) Discharged (2) Dead (3) Defaulted (4) Transferred to long term			

## Appendix G: Maternal Clinic Retention form

### Data Extraction Form B

**Instructions:** List all PMTCT visits from the time of diagnosis. Note any changes in treatment and health professional's comments about the clients' participation in care.

<b>MATERNAL PMTCT RECORDS</b>					
<b>ANTENATAL PMTCT CARE/ARV REFILL HISTORY</b>					
Visits	Gestation Age (weeks)	Date DD/MM/YY	Next Appointment DD/MM/YY	Number of pills dispensed	Comments (1) Missed (2) TFO (3) Dead (4) Defaulted (5) NR
1 <sup>st</sup> (Initiation of ARV)					
2 <sup>nd</sup>					
3 <sup>rd</sup>					
OTHER					
<b>POSTNATAL/PMTCT CARE</b>					
Visits	Date DD/MM/YY	Drug & Dosage	CD4 Results	Viral Load	Comments Missed/TFO/ Dead/Defaulted
1 <sup>st</sup>					
2 <sup>nd</sup>					
3 <sup>rd</sup>					
Outcome:	(1) Discharged (2) Defaulted (3) Dead (4) Transferred to long term care				
<b>NEONATAL/INFANT PMTCT CARE</b>					
Nevirapine at birth:		(1) Yes (2) No (9) NR	PCR at 6 months	(1) Yes (2) No (9) NR	
Nevirapine for infants supplied:		(1) Yes (2) No (9) NR	Results of PCR at 6 weeks-18 months:	(1) Positive (2) Negative (9) NR	
Feeding choice		(1) Exclusive BF (2) Mixed feeding (3) Formula (9) NR	Outcome of care:	(1) Discharged (2) Defaulted (3) Dead (4) Transferred to paediatric care	
PCR @ 6 weeks:		(1) Yes (2) No (9) NR	Gender:	(1) Male (2) Female	
Results of PCR at 6 weeks:		(1) Positive (2) Negative (9) NR	Weight at birth (in Kg):		

## *Appendix H: Information Letter for Mothers*

Dear Potential Participant,

My name is Susanna Aba Abraham. I am a Ghanaian registered nurse and a doctoral student in the University of Cape Town, in South Africa. I am researching what makes mothers stay in the PMTCT programme in the Sekondi-Takoradi Metropolis.

### **What is the Purpose of this research project?**

Ensuring that pregnant mothers registered into the PMTCT programme remain and receive proper care is important stop new HIV infection in babies born to HIV infected mothers and the mothers also remain alive. However, some pregnant women who test positive in pregnancy do not stay in the programme until they complete the treatment required to prevent transmission of the virus to their babies. The researcher understands that many factors contribute to a pregnant woman's decision to stay in care throughout the period of pregnancy, labour and postnatal. Therefore, the study aims to learn about the experiences expectant mothers diagnosed with HIV have while receiving care in the PMTCT programme and to understand the reasons that influence their decision to remain in the PMTCT programme. The research also seeks to find out if an approach called 'appreciative inquiry' can be applied to ensure that more expectant mothers who test positive in pregnancy remain in the PMTCT programme.

### **Why have you been asked to take part?**

I have asked the midwives who know you are eligible for this study, to inform you about it and to ask you to leave your contact details so that I can meet with you to see if you are willing to participate. I am asking women who have tested positive to HIV in pregnancy, enrolled and remained in the PMTCT programme to tell me their experience and why they stayed in the PMTCT programme. Your experience in receiving care in the PMTCT programme will provide valuable information and insight for the purpose of the study and deep understanding of the experiences you have had since your enrolment in the PMTCT programme. The findings of the study

will also add to current literature on improving the PMTCT care. I will be grateful if you could accept to be a participant in this research.

**What will participation in the study involve?**

Once you have read the information sheet and agree to consider being a participant in the study then I will contact you by phone to decide the time and location for the conversation. This will provide you with the opportunity to ask questions prior to agreeing to participate. Your participation in the study will involve an in-depth conversation on your experiences since your diagnosis and enrolment in the PMTCT programme. The whole conversation is expected to last for one hour that will be undertaken by the researcher when you attend your usual appointment at the PMTCT unit, or at a time that is convenient for you and place of your choice. I would like to audiotape the conversation to help me to capture your ideas accurately. You may however, choose not to have the conversation audio-taped but you can still participate in the study. After the initial conversation there will be two follow-up meetings the time and location to be decided with you. The first meeting will be to give you to read and agree that the content has been recorded accurately. After that conversation will be analysed and a story-type record made. At the second meeting (time and location to be decided by you) this story will be brought back for you again to check for accurate interpretation and correction if needed. This process will be spread over about two weeks. The story will not include any information that can identify that it is your story. This story will be used as an example for the health service providers when they participate in a group discussion to make plans to try and encourage women to stay on the PMCT programme. The information will only be used for the purpose of this study.

**What will be the risks involved?**

There are no expected harms or discomforts associated with the study. If you become distressed talking about your experiences, the conversation session can be postponed, and you may be referred to your PMTCT counsellor with your consent.

**What benefits, if any, will there be for those taking part in the study?**

There will be no financial reimbursement for your contribution in this study as the discussion will be done during your usual appointment at the PMTCT unit. However,

by participating in this research, you will have the opportunity to share your experience with a woman who is passionate about PMTCT care. You will also have had opportunity to improve the care for women just like yourself and their families who enrol in care in the future. In addition, by going through this process, you may feel that you have been heard and supported.

### **Voluntary participation**

You have an option to participate or not in this study. If you do agree, you will be asked to indicate this by signing an informed consent form. During the conversation you may choose to answer only questions with which you feel comfortable or decline audio recording of such sessions. You may withdraw from this study at any time without providing detailed explanation for your decision. You will not suffer any consequences for such a decision, nor will there be any difference in the health care that you receive currently or in the future. With your permission, the conversation will be audio-recorded to ensure that the information is accurately documented.

### **Confidentiality and Privacy**

Your identity and the information you provide during the conversation will be treated as confidential and will not be reported in any manner that may be linked to or identifies you with the information. Once the transcription (written record) has been made and finalised, all audio recordings will be encrypted and stored on CD or USB Flash Drive for the period of the study (one year). The audio recordings will be deleted from the recording device once analysed and finalised at the end of the year. Your identity will not be disclosed even in the thesis or any publication that may be produced from the study. Access to audio recordings of the conversation will be restricted to only the researcher and the supervisor. You may choose any name that will not expose your identity during the course of the conversation.

### **Who to contact for further information.**

The researcher highly appreciates your participation in this study.

If you have any questions or concerns regarding this study, you may contact following:

#### ***Researcher:***

Susanna Abraham

P. O. Box LG 949  
Legon  
Tel: 0200747222  
Email: [sabraham@ucc.edu.gh](mailto:sabraham@ucc.edu.gh)

***The supervisor:***

Professor Sheila Clow  
Division of Nursing and Midwifery,  
University of Cape Town  
Tel: +27836595266  
Email: [Sheila.Clow@uct.ac.za](mailto:Sheila.Clow@uct.ac.za)

The University of Cape Town Faculty of Health Science (UCT FHS) Human Research Ethics Committee can be contacted in case participants have any questions regarding their rights and welfare as research subjects on the study on this address:

Prof. Marc Blockman  
Human Research Ethics Committee  
Old Main Building, Groote Schuur Hospital  
Floor E52 Room 23  
Observatory, 7925  
Tel: +27214066338  
Email: [Marc.Blockman@uct.ac.za](mailto:Marc.Blockman@uct.ac.za)

The Ghana Health Service Ethics Review Committee can also be contacted on this address:

The Chairperson,  
GHS Ethics Review Committee  
Research and Development Division,  
Ghana Health Service,  
P. O. Box MB 190  
Accra  
Tel: +233-0302681109/0302679323  
Email: [ghserc@gmail.com](mailto:ghserc@gmail.com)

**Thank you.**

## *Appendix I: Informed Consent Form for Participants*

### Informed Consent

By signing this form, you agree that Susanna Aba Abraham has explained the purpose of the research and that you understand the nature of the study and the means by which your identity will be protected. Your signature indicates that you grant permission to voluntarily participate in this study and also for the interview to be recorded.

I \_\_\_\_\_ have read (or had read to me by \_\_\_\_\_) the information sheet. I understand what the research requires of me and all my questions have been duly answered. I do not feel that I have been forced to take part in this study and I am doing so of my own free will. I know I can withdraw at any time if I so wish and that this will have no negative consequences for me.

### **Please circle as appropriate:**

I ACCEPT /DECLINE to be audio recorded during the interview session.

Signed:

_____	_____
Participant	Date and place
_____	_____
Researcher	Date and place
_____	_____
Witness	Date and place

**Thank you.**

## *Appendix J: Information Letter for Midwives and Community Health Nurses*

Dear Potential Participant,

My name is Susanna Aba Abraham. I am a registered nurse and a doctoral student at the University of Cape Town, South Africa. I am conducting a research into how to improve retention in the PMTCT programme.

### **The Purpose of this research project:**

Retention of expectant mothers registered into the PMTCT programme is important to ensure the goal of eliminating new paediatric HIV and keeping the mothers alive. However, in many instances some expectant mothers leave care before they complete the treatment required to prevent transmission of the virus to their babies. The researcher understands that many issues contribute to the expectant mother's decision to stay in care throughout the period of pregnancy, labour and postnatal. As such, the study aims to find out the experiences of health staff in giving care in the PMTCT programme and the health-care related factors that influence expectant mothers diagnosed with HIV in pregnancy to remain in the PMTCT programme. The research also seeks to find out if an approach called 'appreciative inquiry' can be applied to improve retention in the PMTCT programme.

### **Why has the participant been asked to take part?**

I am asking nurses or midwives who have been trained and worked in the PMTCT programme for at least one year to tell me their experience and what measures they think can be put in place to ensure more expectant mothers stay in the programme. You have been contacted because of your training, experience and involvement in the provision of care to expectant mothers diagnosed with HIV in pregnancy and enrolled in the PMTCT programme. Your experience in PMTCT care would provide valuable information and insight for the purpose of the study. To be eligible to participate in this study, you should be a registered nurse and / or midwife have received training in PMTCT care and also worked in any of the units that provide PMTCT care for at least a year. It will also seek to find out your aspirations and those of other health care professionals for improving retention in the programme so

that appropriate strategies and protocols can be developed to improve retention in the programme. The findings of the study will also add to current literature on improving the PMTCT care.

### **What will participation in the study involve?**

Your participation in the study will first require you to attend an information session on appreciative inquiry so that the approach to be used in collecting the data and the conversation guide will be explained to you. This will provide you with the opportunity to ask questions prior to agreeing to participate. Approval has been sought from the health services managers and programme coordinator to contact you for this study and arrangement has done to organise all the sessions as part of your facility's In-service training activities.

You will also be required to attend and complete three group sessions. The Appreciative Inquiry process involves paired conversations and small group activities. You will also be expected to share your thoughts with the whole group. At the end of the sessions, the researcher will collect all the documents you create as individuals and groups because the information constitutes an important part of the data for the study. The researcher will also need to audiotape each session with the purpose of aiding the researcher to analyse the data and report writing. The conversations will be transcribed from the audio and hand delivered to you to read and agree that the content has been recorded accurately. The information will only be used for the purpose of this study. The interactive process is expected to last for three sessions that is spread across six weeks.

### **Compensation or reimbursement for participation**

There will be no financial reimbursement for your contribution in the study, but refreshments will be provided. However, findings of the study will inform improvement of the PMTCT programme for all women and their families who enrol in care.

### **What will be the risks involved?**

There are no anticipated harms or discomforts associated with the study. All participants in the appreciative inquiry sessions will also be asked to respect the

confidentiality of other participants to prevent breach of trust and loss of your privacy.

**What benefits, if any, will there be for those taking part in the study?**

There may or may not be immediate benefit(s) to you by taking part in the study. By participating in this research, however, you will have the opportunity to share your experience with other health workers in the PMTCT programme. You will also have the opportunity to improve care for expectant mothers who test positive to HIV. In addition, as you examine your work, strength and values, you may develop more insight into what will help to improve retention in the PMTCT programme.

**Voluntary participation**

You have an option to participate or not in this study. Your decision to participate or otherwise in this study will not influence your employment in the health facility or your work in the PMTCT programme. You will also be required to sign an informed consent form indicating your willingness to participate in the study. You may withdraw from this study at any time without providing detailed explanation for your decision. You will not suffer any consequences for such a decision.

**Confidentiality and Privacy**

Your identity and all the information you provide during the conversation and appreciative inquiry sessions will be treated as confidential and will not be reported in any manner that may be linked to or identify you with the information. Hard copies of information sheet and group activities will be kept safe in a locked filing cabinet. Once transcriptions have been made and finalised, all audio recordings will be encrypted and stored on CD or USB Flash Drive. The audio recordings will be deleted from the recording device once transcribed and finalised. No raw information containing identifying information or otherwise will be made available to any person other than the researcher named in this document. Access to the audio recordings and documents produced in the group sessions will be limited to only the researcher and the supervisor. You may choose another name during the period of interaction and this name will be used in the thesis and any publication that may ensue from the study to protect your privacy. It is expected that you will also respect the privacy and trust of other participants in the appreciative inquiry session.

**Who to contact for further information:**

If you have any questions or concerns regarding this study, you may contact following:

*Researcher:*

Susanna Abraham  
P.O. Box LG 949  
Legon  
Tel: 0200747222  
Email: [sabraham@ucc.edu.gh](mailto:sabraham@ucc.edu.gh)

*The supervisor:*

Professor Sheila Clow,  
Division of Nursing and Midwifery,  
University of Cape Town  
Tel: +27836595266  
Email: [Sheila.Clow@uct.ac.za](mailto:Sheila.Clow@uct.ac.za)

The University of Cape Town Faculty of Health Science (UCT FHS) Human Research Ethics Committee can be contacted in case participants have any questions regarding their rights and welfare as research subjects on the study on this address:

Prof. Marc Blockman  
Human Research Ethics Committee  
Old Main Building, Groote Schuur Hospital  
Floor E52 Room 23  
Observatory, 7925  
**Tel: +27 21 406 6338**  
Email: [Marc.Blockman@uct.ac.za](mailto:Marc.Blockman@uct.ac.za)

The Ghana Health Service Ethics Review Committee can also be contacted on this address:

The Chairperson,  
GHS Ethics Review Committee  
Research and Development Division,  
Ghana Health Service,  
P. O. Box MB 190  
Accra  
Tel: +233-0302681109/0302679323  
Email: [ghserc@gmail.com](mailto:ghserc@gmail.com)

**Thank you.**

## *Appendix K: Generative Conversation Guide for Mothers*

Date & time of interview:

### ***Introduction***

Thank you for taking time out of your busy schedule to take part in this interview. My name is Susanna Aba Abraham. Before we start, I would like to explain the focus of this interview. You were contacted because in spite of the many challenges people face in the PMTCT programme, you have kept all your appointments. I acknowledge that you may have had some negative experiences since your diagnosis. However, because you stayed, I would like to gain insight into what motivated you and the positive experiences you have had so that we can find ways to enhance the experiences of others enrolled in the programme to ensure they also stay. Please remember that your feedback is confidential.

1. Let's begin by thinking back to the day you found out you were pregnant. How did you feel? What were your expectations for the pregnancy?
2. Tell me your experience during HIV testing and counselling. What was it like for you? How did you receive the news of your diagnosis?
3. Looking back since your diagnosis and enrollment in the PMTCT programme, think about an experience you have had with the programme – a time when you felt cared for and had a sense of satisfaction. Tell me a story of that experience.

*Probe:*

- a. Can you please tell me what you value most about that experience?
- b. What role did others play?
- c. What are the key factors that made this experience special?

4. Please tell me about the reasons that made you stay in the PMTCT programme?

*Probe:* Consider family support, disclosure, resources, health provider role, benefits of the programme.

5. Imagine a good friend has been diagnosed with HIV in pregnancy, what three things will you ask the staff to do to provide the best care that is possible for her?

***Thank you for participating in this study.***

*Appendix L: Generative Conversation Guide for Midwives and  
Community Health Nurses*

Date of interview:

***Introduction:***

The Appreciative inquiry process involves paired interviews and small group activities. You will also be expected to share your thought with the whole group. At the end of the sessions, I will collect all the documents you created as individuals and groups because the information constitutes an important part of the data for the study. Please do not write your name on any documents (Write the interviewee's name as written on the name tag).

- a. *Working in pairs, take turns to interview each other. Participant A interviews Participant B and vice versa.*
- b. *Use the interview schedule as your script and ask the questions as they are written on the interview schedule.*
- c. *Let the interviewee tell his or her story and PLEASE do not interrupt.*
- d. *Take notes of high points and quotable quotes.*
- e. *Check with the interviewee if you captured the highlights of the story that mattered most.*

Initiate phase

1. Reflect for a moment and remember an exceptional experience you had working in the PMTCT programme - a time when you felt you were really contributing to the lives of the women (and the babies) that you have served, a time when you felt you were really making a difference. Tell me a story about that experience.

2. What made that experience exceptional?

*Probe:*

- a. What role did you play?
- b. What role did others play?
- c. What are the key factors that made this experience exceptional?

3. What are the things you value deeply? Specifically, the things that you value about your work.

4. What do you think is the unique contribution of the PMTCT programme to the society and in the field of health care as a whole?

*Probe:*

- a. What sets it apart from other programmes in this hospital?

5. If you have three wishes that would ensure that more of these exceptional experiences would be possible more of the time, what would they be?

***Thank you for participating***

*Appendix M: Confidentiality Agreement for Group Sessions*  
*Form*

**Confidentiality Agreement**

I agree to participate in the Appreciative Inquiry group session along with other nurses and midwives

I understand that my voice may be recorded during the sessions for follow-up analysis.

I understand that the recordings of my voice will not be publicly broadcast.

I understand that the information discussed in the group sessions that I will participate is confidential and that I will not divulge this information to any other party.

I acknowledge and agree that I will keep confidential all information discussed during this session


*Signed:*

\_\_\_\_\_  
*Participant*

\_\_\_\_\_  
*Date and place*

\_\_\_\_\_  
*Researcher*

\_\_\_\_\_  
*Date and place*

\_\_\_\_\_  
*Witness*

\_\_\_\_\_  
*Date and place*

**Thank you.**

## *Appendix N: Composite stories*

### **Akosua's story**

Akosua woke up with a start and tried to orient herself with her environment. She had dozed off on the couch as she watched the television. The cry of her three months old Ama pierced the space 'aah the little terror has woken up so soon'. Looking up to the clock on the wall, she might have slept for less than fifteen minutes. She smiled and went to the room where Ama lay on the bed throwing her fist and punching the air in anger for having been left alone. Laughing, Akosua threw herself on the bed beside Ama and this made her bounce off the mattress making her squeal with laughter; she was so easy to love and please.

Akosua felt blessed, she had received the good news of her baby's results from the midwife at the hospital; Ama was HIV negative! She was free from the HIV virus, sickness, stigma and discrimination and free from the clutches of death. Joy bubbled in her chest as she caught Ama to herself.

Incidence of the past twelve months rushed into her memory. Akosua had gotten married about three years ago and had struggled getting pregnant. Living with her in-laws in the same compound had not made the situation any easier. She recalled her mother in-law, Awo Yaa calling out to her early one morning 'I hope it has not come' referring to her menses. The pain and anguish she felt drove her to church to seek for God's assistance and to the traditional healer for herbs to get pregnant. After three years of waiting, Akosua missed her menses for the first time since she had gotten married. Anxiously she bought the pregnancy test kit and rushed to her mother's house to do the test in private. 'It is positive!' she exclaimed as the two lines appeared on the kit. As Akosua went home, there was a new sprint in her steps which was evident to all who knew her. She did not tell anybody, including her husband, Elvis, about her pregnancy. She decided to wait until she had had it confirmed at the hospital.

Early the next morning, she arrived at the antenatal clinic at the European hospital. Pregnant women with various sizes of bulge protruding under their dresses filled the seats while others stood behind the benches; she joined the women who stood behind the benches. She felt a sense of belongingness; she was a complete woman. She looked around with a smile on her face and listened with rapt attention as the midwives educated them on malaria prevention in pregnancy. Soon it was her turn to see the midwife alone in the cubicle after her booking. After her examinations, she was asked to do laboratory investigations and collect some drugs. Her pregnancy was confirmed, and she was scheduled to come back the next month.

Soon the long wait ended, and she had to return for the second ANC visit. After the usual physical examination, the midwife informed Akosua “You have to do an HIV test. It is now a national policy that all pregnant women must do it to protect their babies so let us go to the other room for the test”. Akosua felt hesitant and it was obvious to the midwife, so she reassured her “it is nothing, you have to do it. It is for your own good, let’s go”. Akosua followed her through the corridor lined with other pregnant women to the last room in the corner. The door was closed, the midwife asked her about her knowledge on HIV and any risk behaviours she might have engaged in. Akosua scanned her mind and found none. The blood was drawn, and the test was done. After a few minutes, the midwife looked at her sadly and said “Madam, you are HIV positive”. The silence that followed was deafening. As the words sunk into mind and heart, the questions, how, when, I mean how, kept on ringing in her mind. This cannot be possible! The midwife kept on talking but Akosua paid no attention. All she heard was “you have to do a confirmatory test at the lab before you can start treatment.” The confirmatory test was also positive. Akosua recalled the shock and devastation she experienced, the tears she had shed. It was like her life had ended and the joy of pregnancy was insignificant. She followed the midwife like a zombie to the pharmacy. The lady pharmacist was so kind and understanding; she enrolled Akosua into the PMTCT programme and also counselled her about the drugs and the need for adherence, the dose and the side effects. The lady also gave Akosua her personal phone number and appointment card. Akosua collected her drugs and went home with the sense of gloom all over her.

The first few days after the test, Akosua kept the drugs in a wardrobe away from her husband's view but did not take them. She thought so much and could not even eat; this resulted in weight loss. Elvis noticed this and asked if she was ill. That was what drew her attention to the fact that she had not even told her husband about her pregnancy. She informed him of the pregnancy but kept silent about the HIV; she was afraid he would abuse her and also tell his mother since he tended to discuss all their issues with her.

On her next visit to the hospital, she met with the midwife who noticed she had lost weight. She was not doing well at all. The midwife held her hands, comforted and counselled her "you are not alone in this situation, Akosua, even a nurse who tested positive in pregnancy decided to take her treatment and now her child is 20 years and still negative. So, you have to take the drugs, please." She explained that Akosua needed to take the drugs for her own health and to protect the innocent child. That was what made her resolve to take the drugs; for the baby's sake. She decided not to tell anyone about it but take the necessary measures to ensure her baby was negative.

Lying back on the bed, she smiled as she remembered how the midwife and the pharmacist had made the journey with HIV in pregnancy bearable. A special experience that easily came to mind was the assistance and support she received from the midwife and the pharmacist when the pharmacists went on a two months nationwide strike: to demand for more salary and improved work conditions. She had needed a refill for treatment but knew the pharmacy was closed because of the strike. She had spoken to the midwife who asked her to contact the pharmacist which she had done when Akosua met her outside the hospital. She had reassured her and asked Akosua to follow her to the pharmacy where she had spent time looking for her PMTCT folder and supplied the drugs. In truth Akosua appreciated her support and encouragement.

Although the journey had been bearable, it had not been totally devoid of situations that nearly made her quit. Akosua groaned when she recalled her experience during her admission for caesarean section. Her mother, Mamaa and her sister, Akua had followed her to the theatre. The theatre nurse had not asked Akosua if she had disclosed her status to them or not. She had given the septrin to them and explained how it was to be administered. Akua being a nurse had become suspicious and asked

why the baby needed septrin, to which Akosua had not answered. Her discomfort had not ended there but followed her to the ward. During ward rounds, the doctor had mentioned her diagnosis in his booming voice, not mindful of the fact that there were other patients on admission too. The midwives also used to refer to 380-1 when they came for handing over. Akosua felt so self-conscious and could not wait to be discharged.

Akosua's resolve to remain in care was reinforced when she held her baby in her hands: she was so beautiful when she looked in her eyes. Every visit to the hospital had brought her encouragement: her CD4 count had improved and her viral load was also dropping. She looked good and no one could even suspect that she had HIV. The midwives were always motivating her when she came for visits. Her midwife-friend had visited her at home on one occasion when she had complained to her about her husband giving the baby water although she was to exclusively breastfeed. The midwife had resolved the issue easily by informing the husband on the advantages of exclusive breastfeeding.

Akosua's anxiety increased again when she came for the second week postnatal visit; the midwife informed her on the need to bring the baby during the sixth week postnatal visit for the DNA PCR test. At home, she intensified her prayers and ensured both mother and child kept strictly to the treatment schedule. On the sixth week PNC visit, the midwife took Ama in her arms and commended Akosua for taking good care of her. In the same room where, mother had done her test, Ama's foot was pricked and her blood was dropped onto the sample sheet. She was told the results will be ready in a month's time.

The wait for the results was the longest Akosua could remember having since her diagnosis. The anxiety and the fear that accompanied the wait were almost unbearable. Soon the much awaited call from the midwife came: the results were ready. Akosua rushed to the hospital immediately and was told "congratulations, your baby is negative!" The tears were uncontrollable, this was her greatest achievement. The midwife told her there was a need for a repeat test when the child was one year and six months because she was still breastfeeding. But the negative result was enough motivation that it was possible."

Ama's cry pierced her thoughts and ended Akosua's daydreaming. Rocking Ama in her bosom, she whispered in her ears, "We will make it together! We have won the first battle against HIV and we will win the war!"

## Yaa's Story

Yaa sat dejectedly in front of the midwife at the antenatal clinic, she held her hands in front of her eyes and cried uncontrollably as the import of the news she had just received sank in. She was pregnant and HIV positive. The dread and shock she felt, rose like bile in her throat and made her nauseous; "HIV?" she asked herself "am I going to die? This could not be true; she couldn't accept this. As for the pregnancy, well she can accept it because she had engaged in sex with Kofi, her boyfriend. But HIV, how? She had always thought they were faithful to each other and had no reason to suspect that he was cheating on her. As these thoughts run through her mind, tears rolled down her cheeks and her shoulders shook in obvious anguish.

It was as if the midwife read her mind, she informed Yaa at the precise moment of the need to do a confirmatory test and directed her to the laboratory. After a few minutes of waiting, the report was positive again. Yaa did not send the results of the confirmatory test to the midwife at the antenatal clinic but she boarded a taxi home. Yaa alighted from the taxi in front of Kofi's house and called him outside for a discussion. She decided to disclose only the pregnancy to him to see his reaction. Kofi's response was unexpected; she had thought he will be supportive, but he had told her he was not responsible for the pregnancy, ended the relationship and walked away without a backward glance towards her. She walked home dejected and hid in room with the excuse of preparing for the school's end of term examination.

The subsequent days were trying for Yaa as she tried to hide the episodes of morning sickness from her grandmother. Many thoughts went through her mind as she sat behind her writing desk in her room, "How could I have allowed this to happen to me? How can I stay in school with this pregnancy? Tears rolled down her cheeks as she recalled her vision to become a lawyer when she completed her schooling. "I must abort it. I am just 17 years old and have my life ahead of me, "Eeeei", she exclaimed, "but what if someone found out about the HIV? That will be my end. I

must take my life. I must end it all.” Her dreams and prospect were meaningless as death was imminent with this HIV diagnosis. After a long period in thought, “I can’t do it” she spoke out loud.

Yaa decided to inform her pastor, who she felt would know what to do. Pastor Nkansah, listened quietly as Yaa explained her story. “Aah Yaa you have greatly disappointed me. I thought you were obedient to the teachings of this church. How could you allow the devil to lead you astray? But thank God you have accepted your sins.” He reassured her of God’s forgiveness and the possibility for divine healing of the HIV. He led her to pray for forgiveness and declared a one week fast and prayer for mercy and divine healing. God will do a miracle.” Yaa left the church comforted and with her faith renewed. Pastor Nkansah also insisted on the need to disclose to her grandmother and offered to assist her in that regard.

He visited Yaa’s home that evening and counselled Aunt Aso, Yaa’s grandmother with the word of God and called Yaa in to speak for herself. Although his presence was reassuring, it was a difficult task. Aunt Aso cried and voiced her disappointment but promised to support Yaa through her pregnancy.

The very next day, Aunt Aso went with Yaa to the hospital to see the midwife who counselled her as a treatment supporter. Aunt Afia, the midwife who had performed the pre-test counselling was the first person they met on their arrival. “eei Madam, where have you been? I looked around for you the whole time when you left for the lab, but you never returned.” Tears flowed down Yaa’s face prompting the midwife to comfort and encourage her. “I know this is difficult news for you, but it is not the end of the world. Many people have HIV and are doing well on treatment.” The midwife thanked Aunt Aso for her support and explained her responsibilities as the treatment supporter for Yaa.

Yaa and Aunt Aso were escorted by the midwife to see the pharmacist, who counselled them on the need for adherence and initiated her on ART. Aunt Aso told the Pharmacist and midwife that they wanted to pray and fast for divine healing but Aunt Afia counselled her to keep on praying but to act fast by taking the treatment which is free to maintain her own health and that of the unborn child.” Aunt Aso and Yaa listened intently and asked for clarification on some of the things Aunt Afia

said. They made the decision to try the treatment until Yaa gave birth and then decide on further action. Yaa was enrolled into the PMTCT programme and they were escorted to the pharmacy to be giving the treatment and the next appointment date. Three adherence counselling sessions were organized for them to ensure that she remained in care. They took the drugs to the pastor who prayed over it and encouraged her to diligently take them even as God was working spiritually on her behalf.

During one of the adherence counselling, Yaa shared her concerns concerning her education with the midwife who encouraged her to discuss with the headmaster of her school to defer her course for a year. With the assistance of her grandmother, they met the headmaster who permitted that she sat for the end of term examination at the school and defer the course for the next academic year.

On her fourth day of treatment, Yaa had a drug reaction and was admitted to the ward. The pharmacist changed Yaa's drugs and observed her throughout her admission. To Yaa's dismay, one of the nurses on duty in the ward, Ekuba was a member of the church and stayed in her neighbour. Yaa became anxious that the nurse would find out about her status and disclose it to someone at church or her neighbours. She confided in Aunt Afia [midwife/counsellor] who immediately stepped in and talked to the Ekuba about Yaa's concerns. She came to Yaa's bed side and reassured her that her status was safe with her and that she had a professional responsibility to be confidential about her patients' diagnosis. Yaa found a friend in Ekuba and her assistance was invaluable; she was very helpful during the admission and subsequently after her discharge. Ekuba assisted her whenever she came for ANC and she was also on hand during her labour and delivery.

Just before her seventh ANC visit, Yaa had to come for a treatment refill at the pharmacy. At the hospital, she met her neighbour who was also going to the pharmacy and suggested they walk together. Yaa became anxious that her neighbour will know her status as there were two windows where patients were expected to place their folders. She had been informed by the pharmacist earlier to place her folder in the second window which she later learnt was for patient coming for ART refill. Yaa excused herself and went to look for her counsellor for assistance. She waited on the bench outside the room where counselling was done because Aunt

Afia was busy with another client. Shortly after, the client came out with tears in her eyes and Aunt Afia holding onto her. Yaa immediately suspected that the client was also HIV positive as the room had been designated for HIV counselling and testing. She felt pity for the woman and said a silent prayer for her. It reminded Yaa of the day she had come for her test, there were other women sitting outside the door. Yaa, contemplating on what had just happened asked herself, “did they also suspect or guess my HIV status from my demeanour when I come out?”

When Aunt Afia came back from seeing the patient off, Yaa confided in her about her friend and the challenge she had with collecting her drugs at the pharmacy. Aunt Afia, went with her to see Mr. Agyei, the pharmacist and to find a solution to that problem. He agreed to allow her to enter the pharmacy for her refill. But that was short lived as he was transferred to another hospital and the new pharmacist was not comfortable with that arrangement.

Yaa’s fears were confirmed when she met a woman in the market who said she knew her from the hospital. During their interaction, the woman had explained that she was also an HIV patient and had gotten to know her at the pharmacy. Although, they had become friends later on, Yaa’s concerns about other people knowing her status increased. In spite of her concerns, Yaa continued to receive care and gave birth to a baby girl. Aunt Aso was supportive and ensured that both baby and mother took their medicines every day.

During the second postnatal visit, the midwife informed Yaa on the need to bring the baby for the DNA PCR test during the sixth week postnatal visit. At home, Aunt Aso was a great source of support and encouragement. Yaa also informed Pastor Nkansah and prayers were said on the baby’s behalf. On the sixth week PNC visit, the midwife pricked the sole of the baby’s feet with a needle and smeared it onto the sample sheet whilst Yaa held her. She was informed the results will be ready in a month’s time.

When the results were ready, Aunt Afia, called Yaa to inform her that her baby test was negative. Yaa’s joy knew no bounds. She went to see Pastor Nkansah, who advised her on the need to inform her boyfriend’s family about the baby. With the help of the pastor and grandma, Yaa informed her them. His parents were

disappointed and shocked but accepted responsibility and promised their support and care for both mother and child.

Aunt Aso took responsibility for the baby when school reopened and Yaa continued her education.

*Appendix O: Excerpt of Colaizzi thematic tracking map*

Significant statement	Transcript no.	Page no.	Line no.	Formulated meaning	Categories	Theme
<u>No. I did not accept the news at that instance. I did not believe it. Even when I went home, I was very disturbed. I thought so much about it and could not sleep. I was really disturbed... So, the next month, when I went for antenatal, I had lost weight.</u>	5	2	2-3	The result of the test is usually not accepted immediately although it becomes a source of concern.	Dealing with disbelief	Transitioning into a “ new” woman
<u>I decided not to accept the result in Jesus name... I didn’ t say anything, but I knew I did not accept the results.”</u>	2	2	7-8	The result is not accepted initially, and confirmation of the results is needed to facilitate acceptance	Denial	
<u>I did a confirmatory test the same day. She directed me to the lab. I had to wait for a while before the results was returned to me.</u>	6	2	1-3	A laboratory confirmation of the test results was accepted as final by the women. A definite result from the lab brought some finality to some mothers’ doubts.	Double sure: the confirmatory test	
<u>“ When she told me that I had the HIV virus; I cried so much, I was devastated. I couldn’ t even answer the questions she asked, I just kept on crying...”</u>	3	2	4-5	Pregnant women do not expect a positive diagnosis and are usually shock.	Devastation and tears	

## *Appendix P: Participants' life stories*

### **Introduction of Mothers**

#### **“Jane”- Conversation 1**

Jane was born and raised in the northern region of Ghana. She has no formal education. At the age of 20 she migrated to Takoradi in the western region of Ghana with the help of uncle. She started work as a domestic worker and had a child with a colleague in the house which led to Jane losing her job. She started her small business roasting plantain and groundnuts and has been doing this for the last three years. She met her partner about a year ago and cohabited without marriage. Her antenatal diagnosis was in October 2016 and at the time of the conversation, five months had elapsed. When she found out she was pregnant, her partner deserted her, and she classes herself as single and unsupported as she lives alone. At the time of her diagnosis, she had one living child. Her HIV diagnosis occurred in her second pregnancy at the age of 36 years. She had a normal spontaneous vaginal delivery at term. She was recruited into the study at the postnatal clinic when she returned to collect the results of her daughter's DNA PCR test, which tested negative. She was motivated to tell her story because she maintained that it gave her an opportunity to express her appreciation to the staff who assisted her through her journey. She remains on the antiretroviral medication for life. She requested for the conversation to be held at her church premises where she believed had a lot of privacy and she felt comfortable.

#### **“Mary”- Conversation 2**

Mary was born in the northern part of the western region of Ghana and remained there for her formative years and primary education. At the age of 21, she migrated to Takoradi with her first husband, with whom she had a daughter. She owns a small shop at the hospital. She separated from her husband as a result of family interference. She met her second partner, cohabited with him without marriage and fell pregnant. She claims she was abandoned by her partner when she informed him she was pregnant. She met her third partner and got pregnant. She got pregnant

because he promised to perform the traditional marriage rites when she gave birth. She asserts that he was transferred to another region and she has since not heard from him for about six months. Mary found out about her HIV status in June 2016 when her first child was admitted to the hospital. She claims the source of her infection was spiritual as she had been cursed by the father and grandmother of her second child. She did not accept her status initially but went to another hospital for antenatal care where she tested positive again and was enrolled in the PMTCT programme in July 2016. She was 34 years old at the time of the conversation. She was contacted for this study by the CHN when she brought her child to the child welfare clinic for growth monitoring and immunization. The conversation was held at the hospital. She remains on treatment.

### **“Rejoice”- Conversation 3**

Rejoice was born and raised in Takoradi. She had her primary and vocational education, achieving a National Vocational Technical Institute Certificate in Catering in Takoradi. She is a Christian. Prior to her marriage, Rejoice lived with her parents. She got pregnant with her boyfriend in 2012 but the baby died a few days after birth. She was not informed of the cause of death. Thereafter, she sold fruit by the roadside to raise funds to start her catering business and in the process met and married her husband. Her pregnancy after the marriage was delayed for two years which brought anxiety and also resulted in a strained relationship with her in-laws. Her HIV diagnosis was in March 2016 when she attended antenatal clinic. She has not disclosed her status to her spouse for fear of being divorced. Her baby was tested HIV negative at six weeks but since she was still breastfeeding she is required to repeat the test three months after complete cessation of breastfeeding. Rejoice requested for the conversation to be conducted at her home in the presence of the community health nurse whom she said she trusted.

### **“Vera”- Conversation 4**

Vera is an 18year old student who hails from the central region of Ghana. She is a Christian. She was raised in Takoradi by her mother who is a single parent, and her grandmother. She completed her basic education in Takoradi and enrolled in the senior secondary school but dropped out in the second year because she got pregnant.

The boyfriend who impregnated her travelled out of the country before she realized she was pregnant, but his parents accepted responsibility for the pregnancy. Her HIV diagnosis was made at the antenatal clinic when she was six months pregnant, but she was transferred to Takoradi hospital at her request. She was seventeen years old at the time of diagnosis. Ten months had elapsed since her diagnosis at the time of the conversation. She disclosed her HIV status to her grandmother and her mother who have been supportive as her treatment supporters. Her daughter tested negative to the DNA PCR at six weeks but is still breastfeeding and expected to have a second test three months after complete cessation. Vera is on life-long treatment and has plans of learning a trade when her child is enrolled in school. She was recruited into the study by the CHN and the conversation was conducted at home during a home visit.

#### **“Irene” –Conversation 5**

Irene from the western region of Ghana. She was raised in her hometown where she also had her basic education. She migrated to Takoradi to learn a trade in dressmaking. She was married and had a child prior to her diagnosis during her second pregnancy at the age of 35. Ten months had elapsed from the time of her diagnosis at the time of the conversation. Irene is on lifelong ART. She had disclosed her status to her aunt whom she trusted and who serves as a treatment supporter but has not disclosed to her husband for personal reasons. Irene was recruited into the study with the assistance of the midwives. At her request, the conversation was held at the Star of the Sea Catholic church for reasons of privacy.

#### **“Felicia”- Conversation 6**

Felicia hails from the Central region of Ghana where she spent her formative years. She moved to Takoradi with her family when her father was transferred to the harbour as an accountant. Shortly after the transfer her father died and, since he was the breadwinner, the family experienced economic hardship, which led her to marry at the age of 20. She was enrolled into school by her husband and currently is a student at a polytechnic where she is pursuing a BSc degree in Banking and Finance. Felicia was diagnosed HIV positive at the antenatal clinic at the age of 24 during her second pregnancy. She disclosed her status to her husband who was initially

supportive but then withdrew when he tested negative. Her baby was born by elective caesarean section due to pre-eclampsia and large baby. She is still on antiretroviral medication. Both babies are negative. She was referred by the midwives from the postnatal clinic. The conversation was held at the Catholic Church premises where she felt comfortable.

#### **“Lydia”- Conversation 7**

Lydia hails from the Western region of Ghana. She started basic education there but dropped out due to financial constraints. She migrated to Takoradi to seek greener pastures and has traded in fruits until now. She met her first partner with whom she had two children. The relationship ended when he did not show commitment by performing the traditional marriage rites. Lydia met and married her husband, a soldier about three years ago, with whom she has a daughter who is two years old. Her husband travelled to South Sudan on a peace-keeping mission and returned a year later. She became pregnant again and was diagnosed HIV positive at the antenatal clinic at the age of 37. She suspects she was infected by her husband. Lydia said she had earlier seen her husband taking some medications she now identifies as antiretrovirals when she enrolled in the PMTCT programme. She had a spontaneous vaginal birth and eight months had elapsed from the time of her diagnosis to the time of the conversation. Both of the children she has with her current husband had tested negative at the time of the conversation. Lydia was still on life-long treatment. She was recruited into the study with the assistance of the CHN during an outreach programme. She chose her home for the session.

#### **“Blessing”- Conversation 8**

Blessing is a 20 year old lady who hails from the central region of Ghana. She resides in Takoradi with her paternal grandmother. She has no relationship with her mother as Blessing was abandoned with her paternal grandmother when she was a year old. She became pregnant at the age of 18 by her teacher who fled the town and has not been seen since. She tested positive for HIV at antenatal clinic at the age of 19 when she was three months pregnant. She was assisted to disclose her status to her grandmother who served as her treatment supporter. Her father and paternal uncle were also informed of her diagnosis and have been very supportive. Blessing

dropped out of school due to her pregnancy. She had a spontaneous vaginal birth and breastfed her baby exclusively for six months. She is on life-long ART treatment. She was encouraged by her father and headmaster to continue her education and at the time of the study she was in secondary school form two in the same school. Her paternal grandmother has responsibility of the baby. The baby tested negative after complete cessation of breastfeeding. She was recruited into the study by the community health nurse with the assistance of her grandmother. Upon her request her session was held at home in the presence of her grandmother and the community health nurse.

#### **“Comfort” – Conversation 9**

Comfort is a 27 year old lady who hails from the Upper East region of Ghana. She was born and raised in Takoradi as her parents worked there. She was a Muslim but converted to Christianity out of love for her husband. She has since been disowned by her family. Comfort completed her polytechnic education and earned a Higher National Diploma in Catering and Hospitality. She is self-employed and supplies pastries to restaurants in the metropolis. She tested positive for HIV at the antenatal clinic during her second pregnancy. She reports her husband “cheated” on her and thus infected her. He refuses to test but has been supportive in acquiring the drugs for her baby. Comfort reports a strong faith in keeping well but is worried of increasing the risk to her baby as her husband refuses to use condoms. She has since stopped breastfeeding her baby although she is just four months old. Her baby tested negative at six weeks to the DNA PCR and is currently awaiting testing at six months.

Comfort was recruited into the study by the midwives at the PNC when she went back to inform them she had stopped breastfeeding. Her conversation was organised at her office where she felt comfortable.

#### **“Grace” – Conversation10**

Grace is a 26 year old woman who hails from the Central region of Ghana. She had her formative years and basic education in her home town. She moved to Takoradi to stay with her father and step mother when she was 15 years old, when her biological mother, who was her primary care giver, died. She trained as a dressmaker and currently owns her own shop. Grace met and married a tailor in 2016 and

immediately got pregnant. She admits they did not court for a long time. She fell ill frequently during her pregnancy and she recalls her husband buying drugs for her. She recalls being tested for HIV at the ward when she was admitted during one of her sick episodes, but her results were not communicated to her. She was referred to the midwives at the antenatal clinic prior to her discharge where she was tested again and informed she was HIV positive. But she went to a private laboratory to retest for a final confirmation before she initiated treatment. She was enrolled into the PMTCT programme at the age of 25 during her first pregnancy. She later found out that the husband was a known HIV patient who had been on treatment for the seven years but had defaulted. She had a spontaneous vaginal birth and opted to exclusively breastfeed her daughter. Her baby had recently tested negative to the DNA PCR. She was referred to the study by the midwives at the PNC. Her shop was the setting of the conversation.

#### **“Mercy”- Conversation 11**

Mercy hails from the western region of Ghana. She had a basic education but dropped out of school as a result of financial constraints and a teenage pregnancy. She married the father of her first child at age 20 and he set her up selling pure water at the main lorry station. She has subsequently had four other children with another man. Mercy was diagnosed when she was five months pregnant with her fifth child after her husband had died following a diagnosis of AIDS. The family initially attributed her husband’s illness to a curse and he was sent to a prayer garden for a while before he was brought to the hospital moribund. Mercy was 31 years at the time of the conversation. She had to undergo widowhood rites following her husband’s burial and has subsequently completed the rites. Mercy is currently enrolled on treatment for life. Her baby tested negative for the six weeks DNA PCR test and is anxious for the final test results at 18 months as her baby is still breastfeeding. She reports facing financial challenges and suggests that the drugs for the babies should also be made free. She was enrolled into the programme by the community health nurse during a home visit and the conversation was held at her home where she felt there was privacy.

### **“Esther”- Conversation 12**

Esther hails from the Northern region of Ghana but was born and raised in Takoradi. She has no formal education. She is a Christian. Esther cohabited with her first boyfriend with whom she has three children. She reported the relationship ended due to disagreements concerning religious beliefs. She is currently cohabiting with her second boyfriend who is the father of her last born. Esther tested positive to HIV during the antenatal booking visit when she reported during her most recent pregnancy. She believes the disease has a spiritual connotation as the church teaches that and organizes prayers against that. She however agreed to treatment as a precautionary measure as she waits divine healing. Her current boyfriend had been admitted to hospital at the time of the conversation as a result of prolonged coughing and very high temperature at night. She has currently been enrolled onto lifelong treatment. She has disclosed her status to her boyfriend who supports her in prayers and with treatment. Her baby tested negative to DNA PCR test at six weeks and is required to repeat the test at 18 months. She was enrolled into the study by the community health nurse during a home visit. The meeting was held at her home.



