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Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and healthcare providers in a rural South African context

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INTERSECTING NARRATIVES OF PMTCT: THE LIVED EXPERIENCES OF HIV POSITIVE WOMEN, GRANDMOTHERS AND HEALTHCARE PROVIDERS IN A RURAL SOUTH AFRICAN CONTEXT

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Submitted in fulfillment of the requirements for the Doctor of Philosophy (PhD) Degree

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Professor Tommaso Milani

DECLARATION

I declare that

Intersecting narratives of PMTCT: The lived experiences of HIV positive women, grandmothers and healthcare providers in a rural South African context

has not been submitted by me for a Degree at this University or any other University and that it is my own work in design and execution. In cases where I used literature sources, all my citations are duly acknowledged by means of complete references.

Signature: ……

Date: ……

ABSTRACT

Although there is extensive coverage of prevention of mother-to-child transmission of HIV (PMTCT) and a decline in new HIV infections of children nationally, challenges still exist with regard to the utilisation and retention of PMTCT services in Mpumalanga Province. The PMTCT research conducted previously in South Africa has been more programme and implementation-focused, therefore, there is a dearth of information on the intersecting narratives of PMTCT lived experiences among HIV positive women (who receive healthcare services), grandmothers (who support those receiving PMTCT services) and healthcare providers (who provide PMTCT services) in a rural context. It is not known how women in the rural communities of Mpumalanga Province make decisions regarding their participation in the PMTCT programme. The impact of family on the early participation in the PMTCT programme and on infant feeding is also not entirely known. Additionally, the cultural and linguistic barriers to PMTCT service provision in a rural setting are not documented. The aim of this study was to explore the intersecting narratives of PMTCT lived experiences among HIV positive women, grandmothers and HCPs in a rural South African context. Such narratives were obtained to assist in describing factors that facilitate and hinder HIV positive women's early participation in the PMTCT programme.

The sample for this study consisted of 66 participants who were divided into three groups: 29 HIV positive women, 32 grandmothers and 5 HCPs. A purposive sampling procedure was used to select study participants. A narrative qualitative research design was used to conduct the study. Data were collected using semi-structured interviews and focus group discussions. Additionally, data were analysed using thematic analysis and small story analysis framework. The social constructionism theory and the phenomenological approach were used to understand participants' lived experiences of the PMTCT programme.

This study provided a unique way of understanding the PMTCT lived experiences by demonstrating multiple perspectives of how PMTCT services are perceived by rural women. The findings revealed intersecting narratives of the lived experiences among the three groups of participants on factors that facilitate and hinder participation in the

PMTCT programme. There were seven key themes that emerged from the study, which include: 1) fear of stigma as a trigger for late antenatal care attendance, 2) HIV testing stgmatisation and fear of HIV burden, 3) fear of stigma and women disempowerment on infant feeding, 4) health services stigmatization and cultural stereo types affecting male involvement, 5) structural violence, tradition and healthcare system as PMTCT blockages, 6) fear as a factor affecting adherence to PMTCT processes and 7) enhancing PMTCT programme through health education, community participation, individual and health system change

This study revealed that PMTCT services non-utilisation stems from negative societal constructions of HIV. Findings revealed a high degree of dependency on "social selves" in relation to health-seeking reality. A pertinent finding of this study was that fear appeared to dominate every aspect of health-seeking behaviour for the HIV positive participants. Hence, factors inhibiting PMTCT utilisation in a rural context included multilevel stigma at the individual, community, and healthcare facility level. Other factors included: structural violence, cultural, traditional, psychosocial, health system and knowledge factors. The facilitators of PMTCT services utilisation were community mobilisation on social and cultural factors; health systems improvement; ongoing PMTCT education (relevant to rural context); HIV disclosure; peer counsellor involvement; family involvement (grandmothers and male partners); individual factors improvement (self-love; self-reliance) and improved language-use in PMTCT. These were suggested to be vital for the PMTCT service improvement. Data for the study generated new category of 'PMTCT shared small stories' and PMTCT affective small stories' which provided a unique way of understanding the context of lived experiences of the three groups of participants. The lack of knowledge, fear and lack of decision-making powers disempower women from adhering to PMTCT cascade processes. The findings of this study have informed implications for the HCPs and the Department of Health, to promote the effectiveness of the PMTCT programme in a rural context.

Key words: PMTCT, HIV, MTCT, healthcare provider, healthcare facility, narratives, small stories, narrative inquiry, women, lived experience, fear, community, thematic analysis, infant feeding, and women disempowrment.

DEDICATION

In Loving Memory of my sister

Sebolashi Virginia Phaswana

1977-2009

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ACRONONYMS

AFASS	Acceptable, feasible, affordable and sustainable
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
AZT	Azidothymidine
BANC	Basic antenatal care
CDC	Centers for Disease Control
CADRE	Centre for AIDS Development, Research and Evaluation
CD4	Cluster of differentiation
CHCs	Community Health Centers
CHWs	Community Health Workers
DPM	Disclosure Process Model
EN	Enrolled Nurse
FFM	Free Formula Milk
FGDs	Focus Group Discussions
GAPA	Grandmothers Against Poverty and AIDS
GIS	Georgraphical Information system
GNP	The Global Network of People Living with HIV
GP	Genal Practitioner
HAART	Highly Active Antiretroviral Therapy
HBCs	Home-based carers
HBHCT	Home-based HIV counselling and Testing
HCPs	Healthcare Providers
HCT	HIV Counselling and Testing
HDI	Human Development Index
HP	Health Promoter
HIV	Human immuno-deficiency virus
HSRC	Human Sciences Research Council
HAST	HIV, Sexually, Transmitted Infections and TB
IDP	Integrated Development Plans
ICW	International Community of Women living with HIV/AIDS

IMAU	Islamic Medical Association of Uganda
IPPF	International Planned Parenthood Federayion
IPV	Intimate Partner Violence
KZN	Kwa-Zulu Natal
LC	Lay Counsellors
MTCT	Mother-to-child transmission
MDG	Millennium Development Goals
MRC	Medical Research Council
NDM	Nkangala District Municipality
NDOH	National Department of Health
NGOs	Non Governmental Organisations
NVP	Nevirapine
PCR	Polymerase chain reaction
PICT	Provider Initiated Counselling and testing
PMTCT	Prevention of mother-to-child transmission for HIV
PN	Professional Nurses
RTHBS	Road to Health Booklets
SdNVP	Singledose Nevirapine
SGs	Support Groups
SRH	Sexual and reproductive health
SSA	Sub-Saharan Africa
STIs	Sexually Transmitted Infections
TB	Tuberculosis
TRC	Truth and Reconciliation Commission
TV	Television
VCT	Voluntary Counselling and Testing
UNAIDS	Joint United Nations Program on AIDS
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
UNFPA	United Nations Population Fund
WHO	World Health Organization

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CHAPTER 1
CONTEXT AND BACKGROUND OF THE STUDY

1.1 Introduction

This thesis focuses on the narratives of PMTCT[1] through the lived experiences of HIV positive women, grandmothers[2] and healthcare providers (HCPs) in a rural South African context. It describes the shared and varying views about aspects that facilitate and hinder the effectiveness of the PMTCT programme in a rural setting. The narratives from the three groups of participants attempt to explain why there is non-adherence to PMTCT cascade processes[3] by the rural women, while the PMTCT programme has been identified as an important intervention in reducing the transmission of HIV from mother to child in South Africa. This thesis thus makes use of rural women's voices regarding their participation in the PMCT programme. The social constructionism theory and the phenomenological approach assist to understand the societal and individual constructions of HIV and PMTCT in a rural setting. It also provides an understanding of the lived experiences which reveal the nature of reality in relation to PMTCT programme.

The researcher's interest in conducting this study was informed by the lack of existing literature on narratives from rural HIV positive women, grandmothers and HCPs about the PMTCT programme in the Mpumalanga Province. This realization stemmed from the researcher's prior experience of implementing PMTCT interventions in Mpumalanga Province from the year 2009 to 2013. Having conducted research in this area of study, I noted the limitations of quantitative approaches, especially as a means of attempting to understand the lived experiences of the PMTCT programme in a rural context. The researcher's publications as well as other studies attest to this point as demonstrated in section 1.3 of this Chapter. The silence and disregard of key individuals who participate in child affairs (such as grandmothers/ older generation women with grandchildren), as well as the lack of narratives regarding interactions between the HCPs and the HIV positive women on PMTCT programme issues prompted the researcher to gain further insight into their

[1] PMTCT stands for Prevention of Mother to Child Transmission of HIV. The abbreviation of PMTCT will be used throughout the document as it is being used widely by the South African Department of Health (2008; 2009; 2010; 2011) and globally (WHO, 2010)
[2] 'Grandmother' in this study context refers to older generation women in the community who either have grandchildren or look after grandchildren.. The grandmothers were not not related to HIV positive women in the study
[3] PMTCT cascade processes are outlined in Chapter two of this thesis in figure 2.1.

experiences. The lived experience is central to this study because it provides the participants' personal experiences of the phenomenon and the meanings they attach to it (Creswell, 1998). Furthermore, it assists to unpack participants' "perceptions, attitudes, beliefs, emotions and feelings" (Denscombe, 2003, p.97) of being on the PMTCT programme, supporting those on the PMTCT programme and providing PMTCT services. Therefore, this means that the lived experience provides an opportunity of "seeing things through the eyes of those who have experienced the phenomenon" (Denscombe, 2003, p.98). The lived experiences in this study context also provide insight about antenatal care and postnatal care utilisation, PMTCT services provision and older women generation views of PMTCT programme.

The uniqueness of this study is brought by the use of the methodological triangulation principle (Creswell, 1998) which involved obtaining PMTCT lived experiences from HIV positive women, grandmothers and HCPs. This provided multiple perspectives of how PMTCT is viewed in a rural South African context. At the end, such triangulation shows intersecting and varying narratives of PMTCT. Obtaining HIV positive womens' narratives at different points of the PMTCT programme also gave a unique understanding of the lived experience at each level. The insider knowledge in terms of the cultural and linguistic advantage that the researcher possesses also played an important role in acquiring credible data. The researcher is a fluent speaker of Setswana and Sepedi languages and being born in a rural disadvantaged area, she is better positioned to understand the issues pertaining to health seeking behaviour in a rural setting.

1.2 Overview of HIV/AIDS epidemic in South Africa

South Africa continues to experience one of the worst AIDS epidemics in the world (National Department of Health, South Africa, 2011a). AIDS has become one of the leading causes of illness and death among women of reproductive age (WHO, 2007) and therefore, despite progress made in scaling up the response towards HIV over the last decade, it remains the most serious infectious disease, requiring multiple interventions. According to the National Department of Health, South Africa (2013), there were an estimated 6.1million people living with HIV in South Africa with an estimated generalized epidemic prevalence of 17.9%. The HIV prevalence amongst antenatal women in South Africa is estimated to be 29.5%. Mpumalanga (the current study area) is one of the provinces in the country with a high HIV prevalence due to mother to child transmission (MTCT) of HIV. The HIV prevalence in

Mpumalanga was 35.6% overall, whilst the Nkangala district's (area of study) prevalence was estimated at 32.1% in 2012 (National Department of Health, South Africa, 2013). The estimated number of new HIV infections in 0-14 year old children in the Mpumalanga Province was 2846 in 2011 (National Department of Health, South Africa, 2011a). This suggests that mother to child transmission (MTCT), whereby the HIV positive woman vertically transmits HIV to the child contributes to high spread of HIV (WHO, 2010). The advent of programmes such as PMTCT allows for the provision of a continuum of care services that assists with the reduction of the high HIV spread in the country (National Department of Health, South Africa, 2011a). The following section provides an overview of PMTCT in South Africa, in order to facilitate an understanding of interventions that have been carried out to curb the vast spread of HIV across the country.

1.3 Overview of PMTCT in South Africa

The PMTCT programme is one of numerous interventions that are used in the country to decrease the high transmission of HIV from mother to child (National Department of Health South Africa, 2010; 2011a). It has also been identified as one of the leading global HIV prevention strategies (WHO, 2010). PMTCT programme aims to decrease the number of HIV infected babies born to HIV positive mothers. According to the National Department of Health, South Africa (2011a), approximately 95% of the South African HIV positive women went through the PMTCT programme in 2011. The UNAIDS (2012) shows that the PMTCT programme has contributed to the decline in newly diagnosed HIV infections since 2009. Mpumalanga Province (area of study) has been noted as one of the provinces with the lowest levels of PMTCT roll-out, although the level of performance regarding PMTCT roll-out has progressed considerably (58.2%) (National Department of Health, 2008). It is suggested that without receiving PMTCT services, around 90,000 babies will be born infected with HIV every year in South Africa (Department of Health Operational Plan, 2009). It has also been suggested that a comprehensive PMTCT intervention has the capacity to reduce the newborn HIV infection rate to less than 5%, meaning that 75,000 babies' lives will be saved annually (Department of Health Operational Plan, 2009).

In South Africa, numerous studies have been conducted on the social and bio-medical impact of HIV on individuals, their families and their communities (Bond, Chase, & Aggleton, 2002). In addition to this, there have been studies conducted on PMTCT that are programme

and implementation-focused, highlighting the challenges of staff shortages and training (Tint, Doherty, Nkonki, Witten & Chopra, 2003; Doherty, Besser, Donohue, Kamoga, Williamson & Visser, 2003a), space challenges (Doherty, Besser, Donohue, Kamoga, Stoops & Williamson, 2003b) and challenges related to the supply of consumables, such as Nevirapine, test kits and formula milk (Beresford, 2004). Furthermore, there has been a relatively large volume of PMTCT quantitative research which has mainly relied on surveys to understand some of the factors affecting the PMTCT programme. Such quantitative studies have focused on PMTCT treatment adherence factors (Peltzer, Mlambo, Phaswana-Mafuya & Ladzani, 2010); infant feeding practices (Sibeko, Dhansay, Charlon, Johns & Gray-Donald, 2005); and infant and prenatal HIV testing issues (Peltzer & Mlambo, 2010; Peltzer, Mlambo & Phaweni, 2010).

Over and above these studies, there are few studies conducted in South Africa that have used qualitative narrative methods as a tool to explore the lived experiences of women participating in the PMTCT programme. For example, Varga and Brookes (2008a) used a narrative method to explore barriers to adolescents' enrollment and participation in the PMTCT programme in Limpopo Province. Other qualitative studies in South Africa have focused on pregnant women's perceptions of HIV testing consent (Groves, Maman, Msomi, Makhanya & Moodley, 2010); household experiences of HIV and AIDS (Hosegood, Preston-Whyte, Busza, Moitse-Sindile & Timaeus (2007); women's perceptions and experiences of HIV prevention trials (Stadler, Delany & Mntambo, 2008); stories of women living with HIV (de Souza, 2010); infant feeding practices (Doherty, Chopra, Nkonki, Jackson & Persson, 2006); illness and treatment use (Gilbert & Walker, 2009) and the support of HIV positive people (Squire, 2007).

1.4 Statement of the problem

South Africa has made significant progress with regard to the roll-out of PMTCT services nationally. Such progress has been shown by a successful integration of PMTCT services within basic antenatal care (BANC) services, sexual and reproductive health (SRH) and child and adolescent health (National Department of Health, 2010). Significant improvements have also been noted with regard to the reduction of MTCT rate from 8% to 3.5% in 2011 (Goga, Dinh, Jackson & SAPMTCTE study group, 2012). However, despite the above mentioned successes, the implementation of PMTCT services continues to be a challenge

especially in a rural context. Late antenatal care utilisation care is an ongoing challenge in Nkangala district with only less that 45% of pregnant women reported to be attending antenatal care before 20 weeks (Massyn et al., 2013). The inappropriate infant feeding practices such as mixed feeding have also been noted (South African Department of Health, 2013). HIV testing and male non-involvement also continues to hamper the effectiveness of the PMTCT programme. Furthermore, despite the PMTCT research that has been conducted in South Africa, which is more programme and implementation-focused (Doherty, McCoy & Donohue, 2005; Beresford, 2004; Doherty et al., 2003a; Doherty et al., 2003b; McCoy, Besser, Visser & Doherty 2002; Tint et al., 2003), there is a dearth of information regarding the lived experiences of PMTCT in a rural context. None of the above studies have used the methodological triangulation[4] principle to obtain the narratives on the lived experiences of HIV positive women, grandmothers and HCPs. Hence, the current study provides a unique way of understanding the lived experiences in a rural South African context. For instance, not enough is known about PMTCT programme lived experiences of HIV positive women for receiving healthcare services, grandmothers for supporting those receiving PMTCT services and healthcare providers (HCPs) for providing PMTCT services in a rural context such as Mpumalanga Province. Understanding the lived experience of receiving and providing PMTCT service in a rural South African context is crucial in order to establish reasons for the late antenatal care utilisation which could lead to the spread of HIV from the mother to child in this context. Exploring the lived experiences of the three groups of participants was feasible and uncomplicated for the researcher, due to her insight into linguistic and cultural characteristics of the participants.

Moreover, there are no studies in the Mpumalanga Province that have looked at understanding the lived experiences of HIV positive women, grandmothers and HCPs within the PMTCT context in terms of antenatal care initiation experiences, HIV testing experiences, ARV treatment experiences, HIV disclosure experiences, infant feeding experiences, family experiences in participating in PMTCT, PMTCT terminology experiences, and partner involvement experiences. Furthermore, there has been no research conducted on the narratives of lived experiences of HIV positive women participating in the PMTCT programme from the time they enrolled for the antenatal care until the post-partum phase where they received postnatal care services. This means that the lived experience of HIV

[4] Methodological triangulation refers to usage of multiple methods for data collection (Denzin, 1970).

positive women have not been explored at different points of PMTCT service provision. For instance, according to the National Department of Health (2010) PMTCT interventions during antenatal care include providing HIV counselling and testing to identify the woman's HIV status. If she tests positive for HIV, PMTCT interventions include taking CD4 count to check the amount of virus on the body and providing Azidothymidine (AZT) prophylaxis to prevent the unborn child from being infected. Furthermore, at the onset of labour, the HIV positive woman is provided with Nevirapine tablet and AZT to prevent further transmission that could take place during child birth. Postnatal interventions include providing post-exposure prophylaxis to the baby and conducting infant HIV Polymerase chain reaction (PCR) testing at 6 weeks to check baby HIV status and receiving infants' HIV PCR test results.

Additionally, it is not known how women in Mpumalanga's rural communities make decisions regarding their participation in the programme. There is a dearth of information about the lived experience of those who are actually in an experience (Denscombe, 2003) such as receiving and providing PMTCT services. The cultural and linguistic barriers to PMTCT service provision in a rural setting are not documented. The unique lived experiences of the HIV positive women participating in the PMTCT programme have been under-researched, therefore, obtaining such data in the current study may provide guidance regarding further areas which require strengthening within the PMTCT services in Mpumalanga province. Therefore, obtaining insight of a lived experience of receiving PMTCT intervention at different point of PMTCT cascade provides a unique way of understanding a lived experience. Previous experience in PMTCT work in the area of study enabled the researcher to freely explore PMTCT barriers at different points of service provision.

The impact that family has on early participation in the PMTCT programme and on infant feeding is also not known. Although grandmothers' role of caring for their children and grandchildren has been well documented (Mumtaz & Salway, 2007; Barrett, 2008; Barratt & Penn, 2009; Boon, Ruiter, James, Van Den Borne, Williams & Reddy, 2009; Penn, Watermeyer, MacDonald & Moabelo, 2010; Bezner-Kerr, Dakishoni, Shumba, Msachi & Chirwa, 2008; Aubel, 2012), their lived experiences of supporting their sick children who are part of the PMTCT programme are not as well-known. There have been no studies done in the Mpumalanga Province on lay understandings of PMTCT, which also include cultural

views of infant feeding. The kinds of interventions needed for grandmothers to fully participate in the PMTCT programme are thus unknown. Obtaining grandmothers' narratives has the potential to provide family context relating to the above mentioned factors. Family-centered approaches have been shown to assist with the prevention of MTCT of HIV (Betancourt, Abrams, McBain & Smith-Fawzi, 2010). Although grandmothers in this study are not directly related to the HIV positive women, they play a very important caregiving role (Penn et al., 2010) which is mostly due to HIV.

Furthermore, although there are studies that have found challenges regarding PMTCT implementation (Doherty, McCoy & Donohue, 2005; Beresford, 2004; Doherty et al, 2003a; Doherty et al., 2003b; McCoy et al, 2002; Tint et al., 2003; Tabana et al., 2012; Mepham, Bland, & Newell, 2011; Bacheno, Mwanyumba & Mareverwa, 2010), the lived experiences of the HCPs of providing PMTCT services in a rural context (such as Mpumalanga Province) are not known. The findings of the current study thus have the potential to contribute new knowledge towards the improvement or strengthening of the PMTCT programme, because of its uniqueness in providing triangulated data regarding the lived experience of PMTCT services. It is believed that narratives from the three groups of participants (HIV positive women, grandmothers and HCPs) have the potential to improve PMTCT programme services which, in turn, will reduce the elevated incidence of HIV in the country.

1.5 Rationale of the study

Even though there is high coverage of PMTCT in South Africa and a decline of new infections (56.2%) for children nationally (National Department of Health, 2011a), challenges remain with regard to the utilisation and low retention of the PMTCT services in Mpumalanga Province (Ukpe, Blitz, Hugo & Theledi, 2009; Peltzer et al., 2009). The situational analysis conducted by the Human Sciences Research Council (HSRC) in 2008 at Gert Sibande District (the project in which the researcher played a leading role) revealed a significant number of barriers towards the PMTCT programme implementation. These included late antenatal care utilisation, HIV testing obstacles, treatment adherence barriers and family dynamic obstacles (Peltzer et al., 2009). It therefore seems necessary to study the rural lived experiences of those receiving and providing PMTCT programme services

- **Late antenatal care utilization**

The late enrollment in antenatal care services continues to be a challenge in a rural district of Mpumalanga Province (Peltzer et al., 2009). Similar findings have been documented in other developing countries (Coovadia, 2000; Elizabeth & Piwoz, 2002). In Mpumalanga Province, it has been found that because of the late enrollment in the antenatal care services (including PMTCT), women lack information on safer sex practices during pregnancy and early access to antiretroviral (ARV) prophylaxis (like AZT) to prevent the transmission of HIV to the infant (Peltzer et al., 2009). It is therefore, imperative to study the lived experiences of antenatal care attendance by HIV positive women in this context. The lived experience provides an understanding of participants' perceptions, attitudes, beliefs and emotions about being involved on the PMTCT cascade processes which includes antenatal care attendance. Multiple perspectives from the three groups of participants could provide context specific understanding of why late antenatal care practices prevail even when PMTCT programme services are available.

- **HIV testing and counselling barriers**

HIV counselling and testing (HCT) obstacles were also identified in the study conducted by Peltzer et al. (2009). It has been found that women sometimes opt-out of the HIV testing (National Department of Health, 2010) or if they do agree to be tested for HIV, they do not come back for their follow-ups to get ARV prophylaxis which is critical for PMTCT. This behaviour has a negative consequence for the proposed method of provider-initiated routine HIV testing (PICT). In South Africa, the new PMTCT guidelines include routine offer of counselling and testing by the healthcare provider (HCP) (National Department of Health, South Africa, 2010). HIV-testing should be routinely offered to all antenatal care clients (National Department of Health, South Africa, 2010). As found in other studies, the issue is made worse by the fact that some pregnant women fail to return for any follow-up care after testing HIV positive, potentially leading to avoidable perinatal and maternal complications (Myer & Harrison, 2003; Hamilton, Perlmann & De Souza, 1987). The PMTCT challenges are further exacerbated by the fact that some pregnant women in Mpumalanga also change antenatal care sites after they have been diagnosed with HIV at their local PMTCT sites. They prefer going to other healthcare facilities where they are unknown by the HCPs (Peltzer

et al., 2009). Therefore, understanding triangulated lived experiences is useful in exploring and explaining such behaviour.

- **Adherence to ARV prophylaxis barriers**

Adherence to Antiretroviral (ARV) prophylaxis by both the HIV positive women and their children was found to be a problem in Mpumalanga (Peltzer et al., 2009) and in other research settings (UNAIDS, 2012; Laher et al., 2012). Women who test HIV positive have difficulties with adhering to ARV prophylaxis like AZT and Single-dose Nevirapine (sdNVP) provided for the prevention of mother-to-child transmission of HIV. They also do not take their newborn infants to the healthcare facility for the administration of ARV prophylaxis. Similarly, Kasenga, Hurtig and Emmelin (2007); Peltzer, Mosala, Shisana and Nqeteko (2006) and Kuonza, Tshuma, Shambira and Tshimanga (2010) found non-adherence of Nevirapine amongst HIV positive women participating in the PMTCT programmes. Research shows that more often, HIV infected children come to the attention of HCPs only after becoming symptomatic, with mortality as high as 50% before two years of age (Newell, Brahmbhatt & Ghys, 2004). It has also been suggested that if a sdNVP is given to the mother at the beginning of labour and to the baby within 72 hours after delivery, this will reduce HIV transmission rate by almost half (Nolan, Greenberg & Fowler, 2002). AZT also prevents mother- to- child transmission of HIV if taken from the 14th week of gestation. However, these opportunties are lost due to several challenges that have not yet been understood and addressed. These challenges arise from a lack of narrative research on lived experiences of PMTCT in a rural South African context.

- **Family non-involvement barriers**

Furthermore, non-involvement of the family members on the PMTCT programme was found to be a challenge in Mpumalanga Province (Peltzer et al., 2009). Traditionally, HIV prevention strategies focused on the individual and not the family, yet families can have both positive and negative effects on sexual behaviour and dealing with diseases like HIV. It is assumed that the exclusion of the family members from the PMTCT programme might impact negatively on the programme. Family-based prevention and intervention has shown promise in reducing HIV prevalence (Donenberg, Paikoff & Pequegnat, 2006). Family

involvement in the PMTCT programme is thus crucial (Eide, Myhre, Lindbæk, Sundby, Arimi & Thior, 2006). Family involvement in the current study was deemed necessary because of the support that the family members can provide regarding the initiation of antenatal care services, treatment adherence and infant feeding. Family involvement is also important for reinforcing the messages related to the prevention of future sexual transmission of HIV and avoiding infection during pregnancy.

Moreover, it has been shown that research done to assess barriers to successful PMTCT programme components, has been conducted at large urban hospitals and it is not clear whether these experiences can be generalized to rural facilities (Teerarakut et al., 2005; Cartoux, Meda, Van de, Newell, de Vincenzi & Dabis, 1998; Msellati, Hingst, Kaba, Viho, Welffens-Ekra & Dabis, 2001; Ladner et al., 1996). Hence, it is crucial to explore rural lived experiences of HIV positive women participating in the PMTCT programme together with grandmothers (who support HIV positive women) and HCPs (who provide PMTCT services) using a narrative research approach (which has been described in Chapter Four of this thesis). Obtaining views from these three groups of participants provides in-depth information about the underlying reasons for the above-mentioned barriers. Grandmothers and HCPs are useful in providing explanations of why HIV positive women do not participate in all the PMTCT cascade processes. Such triangulation of data on lived experiences seems critical for improving the PMTCT services in a rural context. The current study differs from other PMTCT studies conducted in South Africa in that it looked at the narratives of personal experiences of HIV positive women groups who participated in the PMTCT programme in a rural setting from the time they enrolled on the PMTCT programme until the baby was delivered and mothers had received the HIV test results of the infant. The grandmothers and HCPs views and perceptions also complemented the HIV positive women's narratives of the lived experience of being on the PMTCT programme. The narrative approach seems to be the best way of understanding barriers towards utilisation of the PMTCT service (Varga & Brookes, 2008a). Narratives also provide a deep insight into an experience which would not be as comprehensively and easily understood through a quantitative approach.

1.6 Significance of the study

Whilst the PMTCT programme is regarded as being critical in the provision of treatment, care and support (Moore, 2003), much progress has been made in South Africa as suggested

by the reduction of MTCT rate to 3.5% in 2011 (SANAC, 2011; Goga, Dinh, Jackson & SAPMTCTE study group, 2012). It is worth noting that such improvement mostly occurs in urban areas (Wettstein et al., 2012) whilst the rural communities (such as Nkangala district) continue to be affected by late antenatal care practices, even though timeous antenatal care has been deemed important in the HIV diagnosis of the pregnant women (Levy, 2009). In order to understand the non-utilisation or late utilisation of the antenatal care services, the lived experiences of the three groups of participants are important in providing insight into whether the lack of participation is due to individual, societal, or cultural factors in a rural context. The HIV positive women's lived experiences were in terms of the meaning and emotions they attach to being HIV positive while pregnant. For the grandmothers, their lived experiences were in terms of community beliefs and practices around antenatal and postanatal utilisation. For the HCPs, the lived experience could be in terms of providing health services to both HIV positive women and grandmothers. Such information could assist with the improvement of the programmes for mother and child health. Hence, qualitative insight into what facilitates and hinders early health seeking behaviour is critical for the improvement of the PMTCT services. The multiple perspectives of lived experiences could assist with unpacking the myths and cultural understandings with regard to early health seeking. Such lived experiences could also point to certain women's vulnerabilities posed by the traditional cultural practices (Kako, Stevens, Karani, Mkandawire-Valhmu & Banda, 2012) which have the potential to affect the utilisation of PMTCT services.

In addition to understanding early health seeking behaviour, it is important to explore the narratives of HIV testing provided by women in a rural context, which is also critical for the PMTCT programme. The successful PMTCT programme is marked by high rates of HIV testing (Hanh, Gammeltoft & Rasch, 2011) of both mother and child. As such, the negative infant HIV PCR testing results reveals the positive impact of the PMTCT programme. The late utilisation of the antenatal care services in a rural context suggests that HIV testing rates are also affected. The lived experiences of those receiving PMTCT services, those supporting PMTCT patients and those providing PMTCT services in a rural context, such as Nkangala district, is important for providing an understanding of the local perceptions of HIV testing. The HIV testing beliefs and constructions by the three groups of participants are critical in providing an understanding of the social constructions of HIV and PMTCT in a rural setting.

The intersecting and varying narratives are critical to understand the dynamics of adhering to PMTCT treatment in a rural context. Studies show that even when PMTCT services are available, adhering to some PMTCT activities (including taking ARV prophylaxis) remains a challenge especially in rural areas (Bajunirwe & Muzoora, 2005). Hence, it is important to understand the lived experiences of treatment non-adherence based on social, historical, cultural and geographical factors (Gilbert & Walker, 2009). The HCPs lived experiences could shed light on their observations regarding treatment adherence.

Family involvement in the PMTCT programme has the potential to improve adherence to PMTCT services (Betancourt et al., 2010). An important component of family involvement includes the support of grandmothers and male partners. With the grandmothers being known for their child caring role (Penn, Watermeyer, MacDonald & Moabelo, 2010), understanding their lived experiences of child caring in the context of PMTCT is important. Their lived experiences of infant feeding could provide useful insight into the societal norms and practices related to child feeding. Furthermore, studies have shown that when male partners participate in PMTCT services, such as HIV testing, women tend to adhere to ARV prophylaxis (Peltzer et al., 2010). Understanding the narratives of three groups of participants about male involvement in PMTCT is important for the provision of insight into interventions that may increase male involvement. It is important to examine the lived experiences of the HIV positive women in this study regarding their views of family involvement on the PMTCT programme. Such lived experiences are important because they have the ability to highlight vulnerability felt by the HIV positive women, which may stem from family pressures, related particularly to infant feeding (Aubel, 2012) and antenatal care utilisation.

1.7 Aim and objectives of the research

1.7.1 Aim of the study

To explore the intersecting narratives of PMTCT lived experiences among HIV positive women, grandmothers and HCPs in a rural South African context.

1.7.2 Main Objective of the study

Whilst the main objective of the study is to explore and understand HIV positive women's lived experiences of participating in the PMTCT programme, understand grandmothers views of PMTCT and explore HCPs lived experiences of PMTCT service provision, the specific objectives of the study are to:

- Describe factors that facilitate and hinder HIV positive women from participating in the PMTCT programme early, HIV testing obstacles, adherence to ARV prophylaxis, and family involvement obstacles.
- Explore and understand cultural beliefs and community factors, and their potential to influence the effectiveness of PMTCT services.
- Explore and understand communication factors relating to how PMTCT language is used by the HCPs and how it is understood by the HIV positive women.
- Explore and understand the dynamics of family participation in the PMTCT programme.
- Finally make recommendations for improved utilisation of PMTCT services to the Nkangala District of the Mpumalanga province, South Africa.

1.7.3 Research Questions

The study was guided by the following research questions:

- What are the HIV positive women's lived experiences of PMTCT, grandmothers' views of PMTCT and HCPs experiences of providing PMTCT programme services?
- What are some of the characteristic features of intersecting narratives of PMTCT lived experiences among HIV positive women, grandmothers and HCPs?
- What factors appear to facilitate and hinder the effectiveness of PMTCT programme in a rural context?
    - What cultural beliefs and community factors influence the effectiveness of PMTCT services?
    - What communication practices relating to PMTCT language-use by the HCPs impact on the effectiveness of PMTCT services?

- What family dynamics affect the PMTCT programme effectiveness?

1.8 Outline of the thesis

In total, this thesis consists of Ten Chapters. The study focused on obtaining the intersecting narratives of PMTCT by looking at the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context.

Chapter One provides the background and overview of the study which encapsulates the statement of the problem, overview of PMTCT in South Africa, rationale and significance of the study. It further outlines the aim and objectives of the study informed by specific research questions which guided the study.

Chapter Two outlines the literature reviewed. It provides a detailed account of the HIV pandemic nationally and globally relative to current issues under study. A recent body of literature was reviewed related to narrative research in PMTCT, HIV testing in the context of PMTCT, PMTCT facilitators and inhibitors, narratives of lived experience and the framework for understanding HIV disclosure.

Chapter Three focuses attention on the theoretical framework which underpins this study. This study employed a phenomenological approach to understand the lived experience of HIV positive women, grandmothers and HCPs. The current qualitative research was guided by the social constructionist paradigm, which attests that multiple truths exist in the construction of reality. This Chapter also discusses 'small stories' framework which look beyond the narrative canon.

The research methodology employed for conducting this study is detailed in **Chapter Four**. Apart from the theoretical methodological underpinnings, the Chapter provides an explanation of the research design, sampling method, participant selection procedures and data collection techniques used to carry out the research. This includes the two data analysis approaches that were used to interpret the findings.

Chapters Five to Nine, provide the findings of the study which are divided into themes. Chapter Five pays attention to the thematic findings derived from HIV positive women's

experiences of participating in the PMTCT programme. Chapter Six explores the thematic findings derived from grandmothers' Focus Group Discussions. Chapter Seven addresses the thematic findings derived from the interviews with HCPs. Chapter Eight provides intersecting narratives derived from the HIV positive women, grandmothers and HCPs. Chapter Nine presents data that was analyzed using the small story analysis framework.

Chapter Ten presents a general discussion, incorporating all the findings, methodological reflections, limitations of the study, conclusion, and implications for HCPs and the Department of health.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

Firstly, this study aimed to explore the lived experiences of HIV positive women participating in the prevention of mother to child transmission (PMTCT) of HIV programme. Secondly, it aimed to explore the grandmothers' views and healthcare providers' lived experiences of the PMTCT programme. With this in mind, Chapter Two commences by exploring a global overview of HIV and then the South African HIV epidemic. As a prelude to unpacking other PMTCT related issues, this Chapter also gives theoretical background of PMTCT in the South African healthcare system. The following bodies of literature were also reviewed: HIV testing in the context of PMTCT, PMTCT facilitators and inhibitors and frameworks for understanding HIV disclosure.

2.2 Global overview of HIV epidemic

In 2011, there were 34 million people [31.4-35.9 million] living with HIV globally (UNAIDS, 2012). HIV prevalence continues to be high in sub-Saharan Africa (SSA) accounting for 69% of people living with HIV globally (UNAIDS, 2012). Additionally, in terms of new HIV infections, there has been a decrease globally. For instance, in 2011 there were 2.5 million new infections among both children and adults. This suggests that this is 20% lower than the new infections noted in 2001 (UNAIDS, 2012). Women that are of child-bearing age account for almost half of those infected with HIV in the world (UNAIDS, 2008). In order to overcome the high prevalence of HIV globally, there are targets set by the UNAIDS to promote the reduction of HIV by 2015:

a) "Reduction of sexual HIV transmission by 50%."

b) "Elimination of new HIV infections for children and maternal death by 2015."

c) "Antiretroviral provision to 15 million people."

d) "Increase in girls' and women's capacity for self-protection from HIV infection."

e) "Elimination of HIV stigma and discrimination."

(UNAIDS, 2012, p.6)"

In terms of the mortality rate, UNAIDS (2012) indicates that there has been a significant decline in the number of people dying from AIDS related causes in most parts of the world. This fact is supported by 2011 statistics which show that only 1.7 million people died from HIV. In SSA, the declines were as drastic as 35% between 2005 and 2011. UNAIDS attribute this change to the scaling up of the antiretroviral therapy. Since 1995, nine million people in SSA were saved by the implementation of antiretroviral therapy (UNAIDS, 2012). However, the same cannot be said for other regions such as Eastern Europe and Central Asia (21%) and the Middle East and North Africa (17%). Furthermore, UNAIDS (2012) indicates that there is also a decline in the number of children infected with HIV. Globally, in 2011, about 330 000 [280000-390000] children were infected with HIV which is 24% less than 430000 [370000-490000] that was reported in 2009. The fact that 90% of the children infected with HIV are from SSA is of great concern. A more comforting fact is that there has been a significant increase in "mother-infant pair" receiving ARV prophylaxis during breastfeeding in countries with generalized epidemics since 2009 (UNAIDS, 2012, p. 46).

2.3 HIV epidemic in South Africa

As indicated in Chapter One, the National Department of Health, South Africa (2013), reported that the national HIV prevalence amongst antenatal women in 2012 was 29.5% [95% CI 28.8-30.2]. This means that there was slight decrease in the HIV antenatal prevalence in 2010, which was 0.7% from 30.2% [95% CI 29.4-30.9]. This also suggests that the HIV antenatal prevalence in the country has actually been in close range of 29% over the past six years. The six yearly HIV antenatal prevalence figures attest this point: year "2007=29.4%; year 2008=29.3%; year 2009=29.4%; year 2010= 30.2%; year 2011= 29.5 and year 2012=29.5%" (National Department of Health, South Africa, 2013, p.65). In 2012, an estimated 6.1 million [5.800 000-6.400 000] people in South Africa were living with HIV. According to the National Department of Health, South Africa (2013, p.65), the HIV incidence seems to be decreasing. A significant decrease has also been noted in the number of new infections among children aged 0-14 estimated to be "21 000 [19 000-32 000] in 2012".

The estimates for the HIV prevalence in Mpumalanga Province (the area of this study), have increased from 32.1% in 2006 to 34.6% in 2007, 34.7% in 2009 to 35.1% in 2010, 36.7% in 2011 and decreased to 35.6% in 2012 (National Department of Health, South Africa, 2013). In Nkangala district where the current study was conducted, the HIV prevalence has increased from 26.8% in 2006 to 31.8% in 2008. In 2010 it decreased to 27.2%, in 2011 it increased again to 29.6% and in 2012 it increased further to 32.1 (National Department of Health, South Africa, 2013). Such a rise may be due to poor utilisation of the HIV intervention programmes. The Mpumalanga HIV prevalence for 2012 is shown by district in figure 2.1 below. Although the HIV prevalence in Nkangala district seems lower (32.1%) compared to other districts in Mpumalanga Province, it is higher than the national HIV prevalence which is 29.5%. The findings of this study in forthcoming Chapters provide an explanation for this increase.

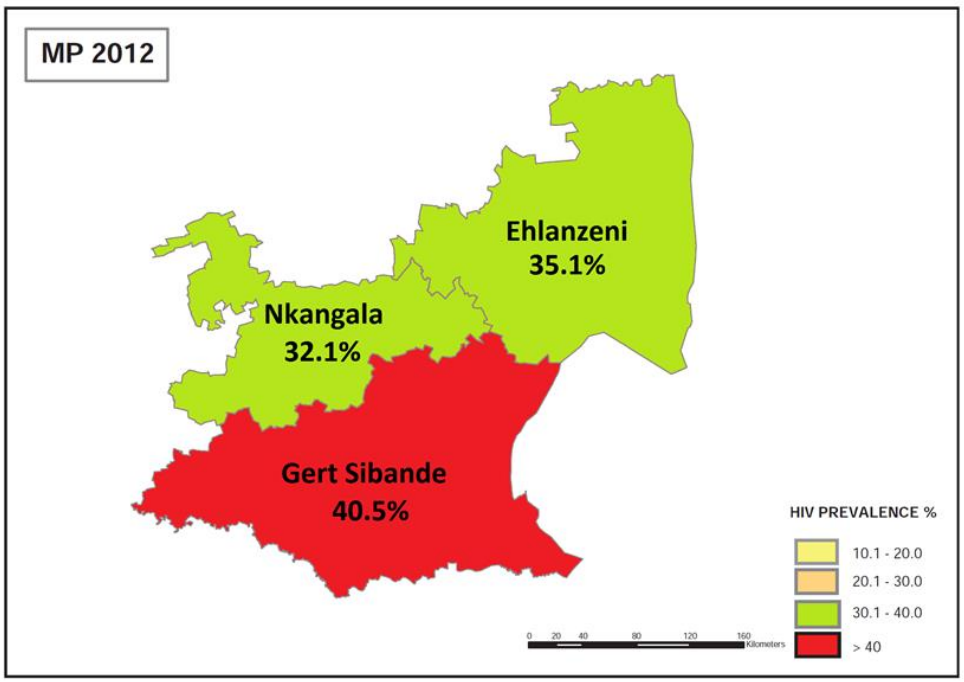


Figure 2.1 HIV prevalence shown by districts within Mpumalanga Province (Source: NDoH, 2013, p.52)

2.4 Discourses of AIDS denialism in South Africa

Although South Africa has made significant progress in implementing interventions for preventing and reducing the HIV spread (such as PMTCT programme), the emergence of AIDS was characterised by high denialism. According to Diethelm and Mckee (2009), denialism means opposing an idea which is scientifically sound. This could be by

individuals, groups, government etc. Denialism in the context of HIV refers to a stand taken by a group to question the relationship between HIV and AIDS (Mulwo, Tomaselli & Francis, 2012). According to Gilbert and Walker (2002), South Africa's first AIDS case was discovered in 1982 and it was mainly found among heterosexual men.

Mbali (2004) study shows the South African government AIDS denialism. The former South African government under the leadership of President Thabo Mbeki questioned "HIV causative role in AIDS" (Cameron, 2005: p. 103). Such denialism also involved raising questions about whether AIDS could be treated medically or through other alternatives. According to Cameron (2005), the main concern around treating HIV medically was due to the treatment side effects. Cameron further indicated that Mbeki also questioned the effectiveness of AZT in relation to its effectiveness to PMTCT. Cameron (2005: p. 104-105) provides forms of denialism which shows an array of claims:

- "HIV is non-existent."
- "If HIV exist, it has not been isolated" (p.104)
- "HIV is not infectious."
- "HIV tests are not accurate or are even misleading."
- "HIV does not cause AIDS."
- "AIDS is caused by sexually transmitted diseases is a hypothesis" (p. 105)

In addition, Nattrass (2007) argue that AIDS denialists are characterised by a strong belief that "existing canon of AIDS is wrong and that AIDS deaths are caused by malnutrition, narcotics and ARVs…" (p. 31). They also hold the view that HIV is harmless (Nattrass, 2007: p. 31). President Thabo Mbeki argued that AIDS is caused by malnutrition and poverty, hence the minister of Health campaigns during that time focused on healthy eating (Cameron, 2005). In addition to this, Cameron (2005) argues that such denialism affected the effectiveness of public health messages. Mbeki's argument seems to have been supported by studies which also pointed to the relationship between HIV infection to poverty (Chirongoma, 2006; Nduku, 2008). At the first International AIDS Conference in Africa, distinguished Scientists signed a declaration that "HIV causes AIDS" (Cameron, 2005: p. 108). At an AIDS conference in 2005, the late Dr Manto-Tshabalala- Msimang said: "She was weary of hearing people talk of nutrition and ARVs when it should be a question of either or" (AIDS Conference special, 2005: p. 458-459). According to Hassan (2005), the confusion of messages about the causes of HIV resulted in fewer people utilising healthcare

services. This also included poor utilisation of HIV testing services and treatment adherence. Such behaviour limits access to interventions that could save life (Hassan, 2005). This means that, at the time of AIDS denialism, the society received ambiguous messages about medical treatment adherence and taking multivitamins and healthy eating. According to Bateman (2007), because of the former president Thabo Mbeki of South Africa, access to treatment was denied for HIV positive women who could have prevented their babies from being infected. Mbali (2004) argues that although the links between nutrition and AIDS exists, this cannot be argued without scientific explanations of the "viral cause of AIDS in the body" of HIV infected people (p. 108). Other studies discuss other forms of AIDS denialism. For instance, Heywood (2004), indicates that denial is normal for a person who has just been diagnosed of HIV. Heywood continues to say that fear and ignorance may lead to denial of disease existence. Denial can be shown in terms of the following: stigma and non-acceptance of HIV disease (Heywood, 2004). It is important to understand the context of denialism as these might provide an understanding of the ongoing PMTCT challenges especially in a rural context.

2.5 PMTCT in South African healthcare system

2.5.1 Definition of MTCT and PMTCT

Mother-to-child transmission (MTCT) is when the woman who is HIV positive vertically transmits HIV to her baby (WHO, 2010). The vertical transmission of HIV can occur in one of the following stages of a woman's life: pregnancy, labour and delivery, or breastfeeding (WHO, 2010). Without treatment, around 15-30% of babies born to HIV positive women will become infected with HIV during pregnancy or the delivery process, with about 5-20% becoming infected through breastfeeding (de Cock et al., 2000). The primary aim of the PMTCT programme is to decrease the number of HIV infected babies born to HIV positive mothers. It has been shown that virtual elimination of MTCT of HIV is possible (UNAIDS, 2010) especially when relevant interventions are applied.

2.5.2 PMTCT Coverage

The overall coverage of pregnant women receiving PMTCT treatment services in SSA is 59% out of 92% of pregnant women who are HIV positive, with a range of 53-66% reflecting

varying levels of implementation within each country (UNAIDS, 2012). South Africa is one of the SSA countries which has reached more than 75% of the PMTCT coverage (UNAIDS, 2012). For instance, approximately 95% of the HIV positive women in South Africa were in the PMTCT programme in 2011 (National Department of Health, South Africa, 2011a). PMTCT in South Africa was formally introduced and piloted in 2001 in the antenatal healthcare facilities of all of the nine provinces in South Africa (Varga & Brookes, 2008b). It started as a pilot programme at 18 pilot sites (two in each of the nine provinces) of South Africa (Doherty, et al., 2005). The pilot sites were used as trial sites which assisted with testing the feasibility of and requirements for PMTCT implementation (Doherty, et al., 2005). Ever since the pilot implementation, the roll-out of the PMTCT programme has expanded dramatically over recent years in South Africa, with the proportion of pregnant women receiving HIV counselling and testing increasing from approximately 7% in 2001/2 to 80% in 2007/8 (Day, Barron, Monticelli & Sello, 2009). Although the pilot for the PMTCT started in 2001 in the various provinces, it formally started in 2005 at the Nkangala district, which is the current study area.

Just as there are global targets set for the reduction of HIV by 2015, the South African Health Department also has plans in place to reduce the HIV infection of children. For instance, the HIV & AIDS and STI strategic plan for South Africa aims to reduce the MTCT of HIV to less than 2% at 6 weeks by 2016 (SANAC, 2011). The fact that there is already a reduction in the rate of HIV transmission is commendable. The Medical Research Council reported that the MTCT rate in South Africa was 3.5 in 2011, suggesting a significant decline from the 8% transmission rate reported in 2008 (Goga, Dinh, Jackson & SAPMTCTE study group, 2012). The infant HIV PCR testing rate in the Mpumalanga Province also improved. It has increased from 16.2% in 2008 to 45.4% in 2010. For the Nkangala district, the infant HIV PCR testing rate increased from 16.4% in 2008 to 39.3% in 2010 (Sherman & Lilian, 2011). Although the rate of infant HIV PCR testing is still low in Nkangala district, the increase suggests that more HIV positive mothers now take their children for HIV PCR at six weeks of birth.

The PMTCT programmes are being up-scaled at a national level in many SSA countries that have a high HIV prevalence. PMTCT programmes are now being provided as a routine procedure in antenatal settings. Global commitments have also been made to tackle the challenges of HIV/AIDS and in particular, mother-to-child transmission of HIV for the

period of 2010-2015. UNAIDS (2012) recommends the following four key pillars which are also adopted in the South African PMTCT guidelines for 2010:

a) "Primary prevention of HIV among child-bearing age women".

b) "Prevention of unintended pregnancies among HIV positive women".

c) "Prevention of transmission of HIV from mother to child".

d) "Treatment, care and support for mothers living with HIV together with their children and families".

(UNAIDS, 2012, p. 44; National Department of Health South Africa, 2010, p.8.)"

These targets seem to be aimed at all women, regardless of their HIV status. Once a woman has been diagnosed with HIV, there are also components that protect the child from being infected with the virus.

2.6 PMTCT Benefits

PMTCT programmes serve as a channel for providing a multifaceted range of care, treatment and support to HIV positive mothers, infants, partners and families (Moore, 2003). Antenatal services are a critical avenue for identification of HIV-infected women for long-term HIV care and treatment. Studies suggest that women in Sub-Saharan Africa (SSA) are learning about their HIV status through the PMTCT programme more frequently when they attend antenatal care (Levy, 2009). This suggests that early uptake of antenatal care services is crucial for the effectiveness of the PMTCT programme, and that each part of the programme is important. As such, a weakness in any of the programme's aspects will impact negatively on the overall effectiveness, thereby compromising the ultimate goal of PMTCT (Jackson et al., 2007). The importance of HIV treatment as part of PMTCT programme has been highlighted in that it has been shown globally that without the treatment of HIV, multitudes of children diagnosed with HIV pass away before they turn two years of age or before they begin school (UNAIDS, 2012).

The PMTCT package comprises of a series of interventions namely: provision of HIV counselling and testing services to pregnant women in the antenatal care settings and treatment for those women who test HIV-positive. Women are also provided with counselling on infant feeding practices, safe obstetric procedures, AZT and single dose Nevirapine (sdNVP) (Levy, 2009). Prior to 2011, HIV positive women who chose to formula feed and were able to do it safely, in an "acceptable, feasible, affordable and sustainable (AFASS)" manner (Doherty et al., 2005, pp. 213-214) were also provided with formula at the healthcare facility (National Department of Health South Africa, 2009). Another beneficial aspect of the PMTCT programme is health education. For instance, healthcare providers (HCPs) give health talks which focus on healthy living, PMTCT, HIV and the benefits of HIV testing during pregnancy (Levy, 2009).

PMTCT programmes thus effectively allow for HIV status to be established and interventions to be provided, in order to prevent transmission of the infection to the infant. According to Nguyen, Oosterhoff, Ngoc, Wright and Hardon (2008), minimal PMTCT service is understood as access to HIV testing and at least receiving SD-NVP for mother at delivery and NVP for the child post-delivery. According to WHO (2007), even in resource-constrained settings, the use of simple and less combination antiretroviral prophylactic regimes, such as short-course zidovudine (AZT) combined with single-dose Nevirapine, can reduce significantly in utero and intrapartum transmission.

Before the year 2010, the PMTCT interventions in South Africa focused only on the perinatal period. This was done by ensuring that all infants born to HIV positive mothers who were not on ART were to take Nevirapine as a prophylaxis for preventing the transmission of HIV (National Department of Health, South Africa, 2010). Moreover, during the initial stages of the PMTCT programme implementation, the mother enrolled in PMTCT was viewed as the channel for growing a healthy baby (Attawell, 2008). This implies that the role of the mother was similar to that of a transporter whose needs were ignored in terms of receiving proper healthcare services that would also allow her to live longer. In viewing the mother as a conduit for growing a healthy baby (Attawell, 2008), the mother was provided with ARV therapy while pregnant and when lactating for the prevention of mother to child transmission of the HIV virus. However, it is now recognized that the most successful way to prevent MTCT is to deliver more effective programmes to the women, not only to prevent transmission to their infants, but also to preserve their own health and the health of their

family (UNAIDS, 2011). Keeping the mothers alive is one of the biggest global strategies for reducing HIV prevalence (UNAIDS, 2011; UNAIDS, 2012).

2.7 PMTCT Integration within the healthcare system

The WHO (2010) strategic direction three indicates the promotion of the integration of the HIV prevention, care and treatment services within the following programmes: maternal health, newborn and child health and the reproductive health programme. There is no universally accepted definition of integrated care (Atun, De Jongh, Secci, Ohiri & Adeys, 2010; Shigayeva, Atun, Mckee & Coker, 2010). Car et al. (2012) define integration as the joining of the PMTCT services with other health system programmes at a single point. Moreover, these authors define partially integrated PMTCT programmes as those programmes that refer women to a separate facility to receive PMTCT intervention. It has been accepted that integration happens at different levels (local, district, regional, national) of the healthcare system (Atun et al., 2010). Hence, integration can involve different healthcare system functions such as governance, financing, planning, service delivery, monitoring and evaluation (Atun et al., 2010). The South African PMTCT guidelines stipulate that PMTCT services should be integrated within basic antenatal care (BANC), sexual and reproductive health (SRH), and child and adolescent health (National Department of Health, South Africa, 2010). The integration of PMTCT services has been shown to have multiple benefits. For instance, studies have shown that integrating PMTCT programmes assists with stigma reduction for HIV positive people (IPPF, UNFPA, WHO, UNAIDS, GNP, ICW & Young Positives, 2009). Moreover, a study conducted by Kasenga, Byass, Emmelin, & Hurtig (2009) shows a significant increase in HIV testing after the integration of HIV testing into antenatal care.

On the other hand, non- integrated PMTCT services are referred to as those programmes that are stand-alone or detached, without any links of referrals to other health systems (Car et al., 2012). For instance, in low and middle income countries, PMTCT programmes were introduced as stand-alone programmes. They were gradually integrated into maternal and newborn healthcare services (Mazia et al., 2009). The non-integration of the PMTCT services has shown various setbacks. For instance, a study conducted in South Africa found that when PMTCT services were not integrated into routine care, women were reluctant to attend specialized HIV clinics (Horwood, Haskin, Vermaak, Phakathi, Subbaye & Doherty,

2010). Other studies have shown that non-integration leads to limited infant follow-up consultations (Varga & Brookes, 2008a). On the contrary, other studies have shown the challenges of integrating maternal and child healthcare services. For example, the integration has been suggested to burden the healthcare system which is already weak (WHO, 2010). The literature thus seems to suggest that the integration of PMTCT services into other programmes would make it effective in certain cases, but bring about challenges to the healthcare system in others.

2.8 PMTCT cascade

The PMTCT cascade steps shown in Figure 2.2 are also followed in the primary healthcare facilities of Mpumalanga Province. However, women are generally referred to the hospital for the delivery of the baby.

PMTCT cascade

1. Utilisation of antenatal care
2. Receiving HIV pre-test counselling
3. Acceptance of HIV testing
4. Receiving HIV test results and post- test counselling
5. Undergo CD4 count assessment
6. Use of ARV prophylaxis by mother/ infant
7. Use of labour and delivery services with PMTCT interventions
8. Follow safe infant feeding practices
9. Postnatal follow-up for mother and child with infant PCR testing and treatment, care and support.

Figure 2.2 PMTCT cascade steps (continuum of care)(Source: Adapted from Marcos, Phelps, & Bachman, 2012)

Although the PMTCT cascade clearly shows the steps to be followed by pregnant women and mothers who have given birth, studies indicate that loss to follow-up occurs at many steps of the PMTCT cascade. For instance, in SSA, many women deliver without really attending antenatal care or ever being tested for HIV. The few that attend antenatal care are lost to follow-up process prior to delivery (Jones, Sherman & Varga, 2005; Kurewa et al., 2011). The loss to follow-up within the PMTCT cascade occurs when the women test for HIV but do not return to obtain the results, or when the woman is diagnosed as HIV positive but does not commence ARV prophylaxis to prevent vertical transmission. It also happens when the

infant is not tested for PCR so that he or she can receive the necessary treatment (Teasdale & Besser, 2008). The next section addresses HIV testing, which is one of the critical components of the PMTCT cascade.

2.9 HIV testing among pregnant women in the context of PMTCT

2.9.1 Provider initiated counselling and testing for women and opt-out approach acceptance

A key factor for a successful PMTCT programme is HIV testing (Hanh, Gammeltoft & Rasch, 2011). The South African clinical PMTCT guidelines (National Department of Health, South Africa, 2010), indicate that all women attending antenatal care, whether first time attendees or follow-up visits, should go through Provider Initiated Counselling and Testing (PICT) in which they have an opportunity to opt-out should they not wish to test for HIV. An opt-out approach of HIV testing was introduced as a way of reducing the fear or refusal of HIV testing (WHO/ UNAIDS, 2007). This suggests that it was implemented to reduce the stigma associated with HIV testing and to normalise the process of HIV testing. Moreover, the opt-in approach was regarded as time consuming because of the pre-test counselling. Figure 2.3 below shows the PICT process that the HIV positive women in this study went through.

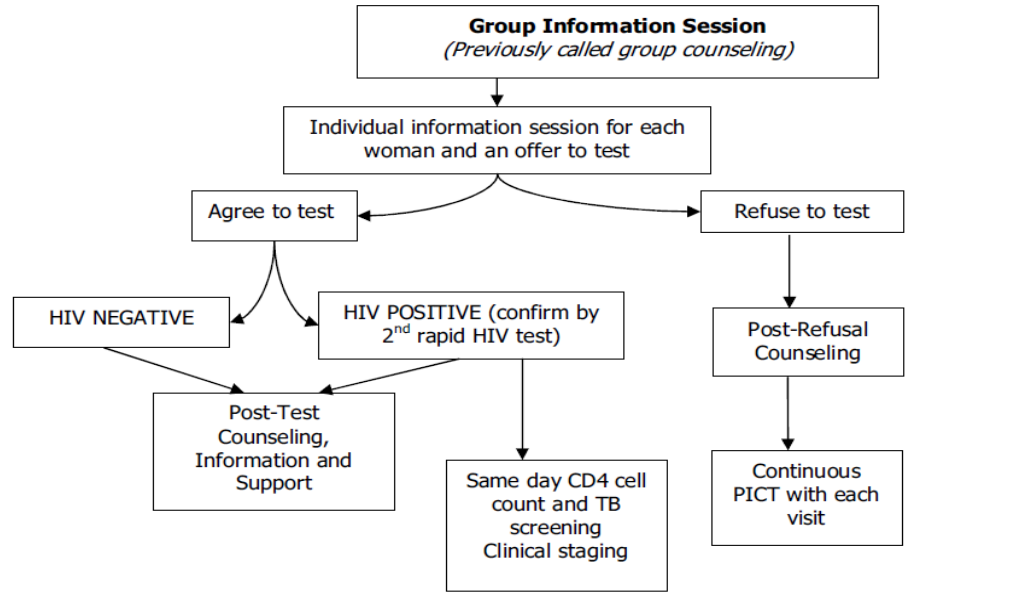


Figure 2.3 Provider initiated counselling and testing in South Africa

(Source: National South African Department of Health: PMTCT Guidelines Revised, March 2013)

HIV testing is integrated within the antenatal care services provided at the primary healthcare level. Even though there is such integration, studies show that a high number of women are still only tested during labour. This suggests that they forfeit the benefits of early antenatal care (Morch, Thu Anh, Ha & Hanh, 2006; Pai et al., 2008). In Botswana, barriers to participation in PMTCT were linked to fear of testing and knowing ones status (Kebaabetswe, 2007). According to Bwirire et al. (2008) reasons for the loss of follow-up amongst mothers in a PMTCT programme in rural Malawi were due to HIV testing, stigma and disclosure of HIV testing status, and partner support etc. In a study conducted by Msellati (2009) in West Africa, it was also found that there was a high rate of compliance with HIV testing, but the rate of returning to obtain the results was low.

Numerous benefits of PICT have been noted, for instance, in South Africa, PICT assists in presenting new patients at STI clinics who are tested for HIV (Leon, Naidoo, Matthews, Lewis & Lombard, 2010). It has also increased the number of TB patients who received HIV counselling and testing (Pope et al., 2008). It has been shown that the HIV testing policy shift from the voluntary counselling and testing (VCT) to PICT has increased the number of women testing for HIV during antenatal care (MacCarthy, Rasanathan, Ferguson & Gruskin, 2012). In a study conducted to evaluate the institutional capacity for implementing PICT as part of healthcare in Zimbabwe, they found a generally a high acceptance of PICT among staff and patients because it assisted with the early detection of HIV and therefore saved lives. This was in spite of increased workload that occurred as a result of few staff that was trained (Sibanda, Hatzold, Mugurung, Ncube & Dupwa, 2012). In Uganda, PICT increased the knowledge of HIV status for partners (Kiene, Bateganya, Wanyenze, Lule, Nantaba & Stein, 2010). At a programme level the "opt-out" PICT and mobile HIV testing assisted with reducing the fear of HIV testing (Musheke et al., 2013). Even though PICT has been accepted in South Africa (Dalal et al., 2011) and other countries in SSA (Evans & Ndirangu, 2009), Zimbabwe identified space, staff and HIV test kit shortages as obstacles to the smooth running of PICT (Sibanda et al., 2012).

2.9.2 Provider initiated counselling and testing for women and opt-out approach non-acceptance

According to the South African Department of Health (2013), post-refusal HIV counselling should also be provided to obtain the reasons for the refusal. Even though PICT is acceptable in most of the countries in SSA, other studies have argued this. For instance, Msellati (2009) suggested that the opt-out approach is another approach to assist with HIV testing refusals. According to Angotti, Dionne & Gaydosh's (2008) study conducted in rural Malawi, provider-initiated routine HIV testing was perceived to be compulsory by the participants. This led them to believe that PICT does not give them the option to opt-out, especially because messages of HIV testing were brought to them by the HCPs. Participants in Angotti's study believed that refusing to test would mean not getting access to care while pregnant. As a result, they believe that HIV testing while pregnant is "an offer you can't refuse" (Angotti et al., 2008, p. 1). Furthermore, Njeru, Blystad, Shayo, Nyamongo & Fylkesnes (2011) argue that PICT adds burden to pregnant women who discover that they are HIV positive, as they have to disclose their status to their partners and encourage them to test at a healthcare facility. As a result, there has been a call for the review of PICT in terms of how it is implemented (Njeru et al., 2011). Alternatively, the lack of compliance and interest in PICT has been suggested to be due to lack of understanding of what it meant. For instance, a study conducted in rural Kenya found that the majority of pregnant women in the study (83%) lacked understanding of opt-out HIV testing (Ujiji et al., 2011). This, therefore, suggests that the pre-test counselling received was unclear (Ujiji et al., 2011). In a study conducted in South Africa among antenatal clients, they found that when utilising the opt-out approach, women felt they were indirectly coerced to do HIV testing for the benefit of the child's health (Groves, Maman, Msomi, Makhanya & Moodley, 2010).

Hardon, Vernooij, Bongololo-Mbera, Cherutich and Desclaux (2012) conducted a study on women's views of consent, counselling and confidentiality in the context of PMTCT. They found that HIV testing for women was not difficult because of prior HIV testing experience. They also found that the fact that women were faithful to their male partners motivated them to test for HIV. Moreover, HIV testing was done to protect the health of the unborn child. Hardon et al. (2012) further found that women in urban Uganda refused to test because they did not feel ready to test. Similar to the study by Groves et al. (2010), some of the women in Hardon's study felt coerced into HIV testing because of the belief that they would not receive

HIV treatment if they did not test. Other participants in Hardon's study likened HIV testing to the violation of human rights. This means that an individual's choice to test for HIV should be respected.

A review study found the following reasons for not testing for HIV: low-risk perception, fear of HIV stigma, an undermining quality of HIV testing services, lack of trust in the healthcare system, accessibility of services and psychological burden (Musheke et al., 2013). Other studies also argue that lay constructions of risk have influence on utilising HIV testing services (Paicheler, 1999). The lay construction of risk is based on the perceptions regarding sexual behaviour for oneself and one's partner, coupled with experiences of one's own health (Paicheler, 1999). This suggests that one looks at her own and partner's sexual behaviour, as well as their overall health and concludes that they are healthy. Other studies found that HIV testing happens when one's health status has deteriorated (Musheke et al., 2013). Cunning, Sohler, Korin, Gao and Anastos et al. (2007) also found that a lack of trust in the health workers leads to refusal to test for HIV. In concurrence with this, Bogart and Thornburn (2005) suggested that mistrust of health workers by patients affects patients' utilisation of the health care services.

Other non-HIV testing behaviour could be due to challenges related to informed consent for HIV testing. For instance, Penn and Evans (2010) found that the informed consent process could be enhanced by cultural and linguistic modifications. This has implications for policy changes, whereby language specialists should be involved in research ethics committees (Penn & Evans, 2010).

2.9.3 Children HIV testing in the context of PMTCT

Pediatric HIV testing is critical especially for children born to HIV positive mothers, as it measures the success of the PMTCT programme. This is because the higher the negative HIV PCR test outcomes, the more success is attributed to the effectiveness of the PMTCT programme. In Malawi, because of PICT, a high proportion of children was tested for HIV and received ARV treatment (Weigel, Kamthunzi, Mwansambo, Phiri & Kazembe, 2009). In a study conducted in Kwa-Zulu Natal (KZN), South Africa, they found that acceptability of children's HIV testing by HIV positive women was high with the overall children sero prevalence of 4.9%. Women with HIV were found to have a high acceptance of child HIV

testing (Chhagan et al., 2011). This study also found a low rate of HIV testing among children. Other studies ensured the HIV testing of children by encouraging HIV positive adults who are on ART to refer family members (Sheehy, Scorgie, Mini, Tun & Kellerman., 2009; Jonathan et al., 2010). It is concerning that of the two million children diagnosed with HIV, only 35% are receiving treatment (WHO, 2009). Since HIV testing is critical for the success of PMTCT (Hanh et al., 2011), the next section addresses the role of lay counsellors in HCT.

2.9.4 The role of lay counsellors in HIV counselling and testing (HCT)

Counselling has been noted to be a significant component of the HIV testing process (Rohleder & Swartz, 2005) which also assists in reducing further HIV transmission (Brouard, 1998). As a result, HIV counselling has been added as one of the healthcare elements which requires specialised individuals (such as lay counsellors) to execute the counselling services (Rohleder & Swartz, 2005). The lay counsellors form part of the health system in South Africa, which seeks to combat HIV (Schneider, Hlophe & van Rensburg, 2008). Their role is mostly related to motivating change in behaviour and encouraging HIV positive individuals to adhere on ARVs (Evangeli, Longley & Swartz, 2011). The integration of lay counsellors (LC) into the healthcare system involves utilising non-profit organizations (NGOs) to provide training on important counselling aspects (client-centered counselling) in order to enable the counsellors to work with the nurses at public clinics (Rohleder & Swartz, 2005). Although there are varying approaches to HIV counselling (health education, psychoanalysis, behavioural therapy etc.) in South Africa, the predominant method for counselling is provision of advice using health counselling methods (Richter, Durrheim, Griesel, Solomon & van Rooyen, 1999).

HIV counselling has also been found to be effective in introducing interventions that are beneficial to women. For instance, a study conducted in a clinic setting in Johannesburg found that women coming for Voluntary Counselling and Testing (VCT) services were in favour of intimate partner violence (IPV) screening during the VCT sessions (Chrsitofides & Jewkes, 2010). The participants in this study indicated that such IPV screening could facilitate early access to receiving help and support. Chrsitofides and Jewkes (2010) concluded that lay counsellors' training should also incorporate "gender-power inequality and IPV awareness" (p. 283). A study conducted by Naik, Tabana, Doherty, Zembe and Jackson

(2012) in a rural KZN, South Africa, found that lay counsellors play an essential role in home-based HIV counselling and testing (HBHCT). This study found that HBHCT was acceptable in a rural setting with the highest percentage of female testing (73.7%).

Another significant role was suggested by the lay counsellors' implementation of a family-based intervention to facilitate maternal HIV disclosure to HIV infected children in a rural KZN community (Rochat, Mkhwanazi & Bland, 2013). The results of this study suggest that the intervention was feasible and culturally acceptable in a rural setting. This intervention clearly supports maternal HIV disclosure to children. Other studies also show the success of the implementation of a counsellor-delivered HIV risk reduction intervention in KZN in South Africa (Cornman, Christie, Shepard, MacDonald, Rivet Amico & Smith, 2011). In order to ensure the sustainability of the work done by the counsellors, Richter et al. (1999) suggest that they should be fully integrated in the healthcare system. Such integration could be achieved by creation of permanent jobs for them (Richter et al., 1999). Other studies indicate that although counsellors are suggested to play an important role in HIV testing and implementation of the PMTCT cascade processes (Rohleder & Swartz, 2005), they seem to be unclear about their roles in the healthcare system (Rohleder, 2003). This confusion could be due to the lack of integration of the counsellors into the health system (Richter et al., 1999). The importance of lay counsellors has also been noted in the findings of the current study. In order to further understand the PMTCT utilisation and non-utilisation factors, the next section provides a brief discussion about access to healthcare services, by specifically focusing on the demand and supply framework. This will assist in understanding the factors that lead to non-utilisation of the PMTCT services that are outlined in the PMTCT cascade in figure 2.2.

2.10 Factors facilitating and inhibiting PMTCT utilisation

2.10.1 Definition of access to healthcare services

There is a great deal of evidence to suggest that many women enroll in the PMTCT programme, but drop out later. This is reflected by the statistical data from healthcare coverage which has shown that the higher percentages of women attended antenatal care services only a few times (Frizelle, Solomon & Rau, 2009). For instance, about 94% of women attended antenatal care at least once and 73% attended antenatal care four or more

times. The data shows a very low percentage of women who started attending antenatal care by the time their infant was at least 20 weeks old (27%) (Frizelle et al., 2009). Countless barriers to healthcare contribute to the poor utilisation of PMTCT services. In order to understand barriers to care, it is important to define access to care. As pointed out by Oliver & Mossialos, (2004), there is no universally accepted definition of access to care. For this study, I have adopted the definition by Peters et al. (2008) which describe access to care as well-timed utilisation of service when it is needed. Therefore, the utilisation of healthcare means having access to a service when it is needed.

According to O'Donnell (2007, pp. 2821-2834), access to care in the health context consists of four key dimensions which include: "availability of services, geographic accessibility of services, affordability and acceptability of services". Failure to meet any of these four components suggests the presence of barriers to access to care. This means that barriers to healthcare are obstacles that prevent vulnerable patient populations from getting the needed healthcare, or that cause them to get inferior healthcare, compared to advantaged patient populations. Such barriers are present in the PMTCT service and they hinder the smooth operation of the programme. Ensor and Cooper (2004) provide a framework which shows that patient barriers stem from the supply and demand side. For instance, they argue that determinants of the demand side are factors influencing the utilisation of healthcare services at an individual, household and community level, while the determinants of the supply side are aspects inherent in the healthcare system that hinder the uptake of services by individuals, households and communities (Ensor & Cooper, 2004).

The current study considered the quality of care as an integral component to each of the four dimensions (Peters et al., 2008). The lived experiences of PMTCT by HIV positive women, grandmothers and HCPs provide an understanding of the demand and supply side determinants (Ensor & Cooper, 2004). For instance, in the context of PMTCT, the demand side barriers provide an understanding of family expectations, community expectations, cultural preferences, infant feeding expectations, gender and socio-economic issues, PMTCT language challenges, HIV treatment and male involvement matters as barriers. Whilst on the other hand, the supply side barriers give an understanding of issues that have to do with healthcare service provision. As a prelude to the discussion of the PMTCT barriers, the next section briefly discusses the health seeking behaviour model which is mostly influenced by the demand side barriers.

2.10.2 Health seeking behaviour model

Before highlighting varying PMTCT barriers, this section commences by discussing the health seeking behaviour model, which provides the reasons for the usage and non-usage of health services. In Rosenstock's (2005, p. 6) model, the individual's health seeking behaviour is determined by the "state of readiness" to take action and the extent to which action is believed to be beneficial. Rosenstock (2005, p .6) defines readiness to act as a way in which the individual views the "seriousness and susceptibility" of a health situation. Perceived susceptibility refers to the "subjective views of disease contraction" (Rosenstock, 2005, p .6). Depending on the perceived susceptibility, health seeking behaviour varies among individuals. If the individual perceives him/ herself to be at risk of contracting the disease, they would seek medical help and vice versa. Therefore, perceived seriousness depends on the emotional arousal of thinking about the disease and its effects (Rosenstock, 2005).

Accepting susceptibility leads to action taking. Action taking is also influenced by the individual's beliefs and social norms and pressures about the disease (Rosenstock, 2005). Seeing an action as a threat, leads to motives of avoidance. If the readiness to act is low and the negative thoughts about the service are strong, that serves as a barrier to action taking (Rosenstock, 2005). In cases where the feeling of readiness to seek medical help is high and the barriers for taking such action also seem high, then an individual is faced with the dilemma of whether to take an action or not (Rosenstock, 2005). This suggests that an individual would have equal chances of utilising or not utilising a health service. In the context of PMTCT, an individual may know the benefits of participating in PMTCT cascade processes, and because of conflicting feelings about the action, he/she may choose to not act at all. Having conflicting feelings about whether to use a health service or not could also result in one taking an action once but failing to adhere to subsequent utilisation of the health services (Rosenstock, 2005). Using the same principle, the next section discusses barriers leading to PMTCT non-utilisation.

2.10.3 Supply and demand barriers affecting utilisation of PMTCT services

2.10.3.1 Community Barriers and late antenatal care utilisation

Numerous studies have shown that barriers to utilisation of the PMTCT services occur at a community level (Busza, et al., 2012; Bajunirwe & Muzoora, 2005) and not necessarily at the healthcare setting. Thompson et al. (2012) argue that interventions to monitor and retain HIV patients in a particular programme, should consider context specific barriers which are mostly influenced by the societal norms and cultural beliefs about the particular programme. Therefore, to improve the PMTCT hindrances, it is important to understand the context of the specific barriers (Busza et al., 2012). In a review study conducted by Busza et al. (2012) they identified barriers to PMTCT uptake and retention. In order to be context specific, they grouped PMTCT barriers on many levels ranging from an individual to a community level. The context specific interventions assist in developing multiple interventions for a programme (Busza et al., 2012). For instance, Busza et al. (2012) found that the non-utilisation of the PMTCT could be due to risk perception. Therefore, the low risk perception could lead to non-service usage. Similarly, Wringe et al. (2008) indicate that if the risk perception is low, women would present themselves late for the HIV testing.

The problem of late antenatal care utilisation seems to jeopardize the effectiveness of the PMTCT programme because it means that interventions to prevent the child from being infected with HIV are accessed late in the pregnancy. Numerous reasons are always given for such behaviour by women. For example, a study conducted in Johannesburg, South Africa, found that health system challenges such as booking for antenatal care and delays in pregnancy diagnosis lead to late antenatal care utilisation (Solarin & Black, 2013). In this study, early antenatal care attendance was linked to demographic characteristics such as having completed secondary education (53.9%) and being self-employed (80%). A study conducted in Uganda found that the reasons for late antenatal care attendance were due to affordability (lack of transport money) and lack of knowledge about whether antenatal care services are free or not (Kisuule et al., 2013). Other reasons found in this study included not being sick while pregnant, therefore, early antenatal was seen as not necessary (Kisuule et al., 2013).

In discussing the motivation issue surrounding service utilisation, Mepham, Bland and Newell (2011) found that some women in their study were motivated to seek medical help early because of the development of symptomatic sicknesses, whilst other participants did not utilise the services because of the fear of receiving HIV positive results. Other community barriers could be due to stigma and social networks. For instance, other studies show that women who anticipated the stigma from both the healthcare providers and community members (Merten, Kenter, McKenzie, Musheke, Ntalasha & Martin-Hilber, 2010; Selin, Mills, & Nachega, 2007; Nam, Fielding, Avalos, Dickinson, Gaolathe & Geissler, 2008) were reluctant to use the services. Therefore, according to Busza et al. (2012) the traditional world views are responsible for shaping how one engages with healthcare services. In the context of PMTCT, other studies indicate paranoid beliefs or mistrust about how healthcare workers and community members perceive HIV positive women (Doherty, Chopra, Nkonki, Jackson & Greiner, 2006). In the end such mistrust leads to non-utilisation of PMTCT services.

Individual beliefs have a great influence on usage and non-usage of service. Golooba-Mutebi and Tollman (2007) conducted a study in a rural village of South Africa on factors that influence health seeking behaviour. They found that folk beliefs about illness and its cause have a huge influence on health seeking behaviour. For instance, participants linked illnesses to things such as witchcraft and poisoning. Such beliefs delayed health seeking behaviour. A study conducted in rural Limpopo about death escalation in the community found that participants seldom linked AIDS to death (Posel, Kahn & Walker, 2007). This study found that death in the community was linked to cultural taboos regarding sexual practices, especially while mourning for a loved one. This seems to suggest that there will be no behaviour change on factors that leads to contraction of HIV disease because of cultural influence on health issues.

2.10.3.2 Infant feeding barriers within the PMTCT programme

Infant feeding has been regarded as a major global health dilemma which has brought about numerous controversial discussions regarding MTCT (Moland et al., 2010). For instance, South Africa has been identified as a country which is dominated by poor infant feeding habits (Goga, Doherty, Jackson, Sanders, Colvin & Kuhn, 2012), even in the context of PMTCT. The dilemma is brought about by the fact that the WHO now recommends only one infant feeding option, which is exclusive breastfeeding (WHO, 2010 guidelines) when

previously, it used to have two infant feeding options, including the exclusive formula feeding (Moland et al., 2010). Studies show that WHO infant feeding guidelines have been changing over the years since 1992 due to new emerging knowledge and technology related to infant feeding. The table below shows the changes over the years and how South Africa was affected by these on-going changes in infant feeding policies.

Table 2.1 Trends of WHO infant feeding guidelines conversion

WHO Infant Feeding guidelines		South Africa Infant Feeding Guidelines	
Year	Message	Year	Message
1992	"Breastfeeding by all women (HIV-/+)"	-	-
1998-2001	• "Replacement feeding for all HIV+ women choosing not to breastfeed"	2001	• Start of PMTCT programme in South Africa • "Replacement feeding for all HIV+ women choosing not to breastfeed"
2002-2005	• "Exclusive Breastfeeding for 6 months or exclusive formula feeding for 6 months" using AFASS criteria	2002-2005	• "Exclusive Breastfeeding for 6 months or exclusive formula feeding for 6 months" using AFASS criteria
2006	• Incorporated evidence that administration ARV to HIV+ mothers while breastfeeding could reduce risk of postnatal HIV transmission	2006	• Administration of highly active ARV therapy (HAART) for mothers and Nevirapine prophylaxis to infants (for duration of breastfeeding • "Exclusive Breastfeeding for 6 months or exclusive formula feeding for 6 months" using AFASS criteria
2009	• Countries to decide on single infant feeding practice	2009	• Problem with 2 options: Mixed feeding • "Exclusive Breastfeeding for 6 months or exclusive formula feeding for 6 months" using AFASS criteria
2010	• Discontinue distribution of free formula milk • "Exclusive breastfeeding by all the women (both HIV- and HIV+)	2010	KZN first province to implement WHO recommendation; ""Exclusive breastfeeding by all the women (both HIV- and HIV+)"
	•	2011	All the Provinces in SA implemented WHO recommendation: "Exclusive breastfeeding for all"

Source: Summary based on Ijumba, Doherty, Jackson, Tomlinson, Sanders, & Persson et al. (2013)

Infant and young child feeding practices directly affect the nutritional status of children, and ultimately, impact child survival (WHO 2007). Improving infant and young child feeding and care practices in children is therefore critical to improve the nutrition, health and development of children (WHO 2007). The infant feeding guidelines provided by the WHO

(2010) clearly stipulate exclusive breastfeeding for six months for all new mothers regardless of their HIV status. However, for HIV positive women, there should be ARV prophylaxis for both the mother and the child. Exclusive breastfeeding for the first six months of life is believed to protect an infant against HIV transmission (WHO, 2010). The South African government adopted exclusive breastfeeding as the national infant feeding strategy in August 2011 and, therefore, withdrew the supply of free formula milk in the PMTCT programme (Ijumba, Doherty, Jackson, Tomlinson, Sanders & Persson, 2013).

One of the biggest barriers towards the non-effectiveness of the PMTCT programme is mixed feeding. Mixed feeding refers to provision of breast milk together with other liquids or solids within few days of birth (Coovadia et al., 2007). According to the South African Department of Health, about one-third of pediatric infections occur because of mixed feeding. Previously, mixed feeding used to be attributed to the low supply of free formula milk at the healthcare facilities which left HIV positive mothers who were formula feeding with no choice but to breastfeed (Doherty et al (2003a). Some recent literature also suggests that mixed feeding behaviour could be due to family pressure and the HIV stigma (Doherty, Chopra, Nkonki, Jackson & Greiner, 2006). A study conducted in Burkina Faso shows that mothers opted to breastfeed because of the fear of family rejection (Cames, Saher, Ayassou, Cournil, Meda & Simondon, 2010). Similarly, a study conducted in KZN, South Africa found that socio-cultural factors influenced infant feeding choices. For instance, family members pressurize HIV positive women to always feed the child (Thairu, Pelto, Rollins, Bland & Ntshangase, 2005). Thairu et al (2005) further argue that stigma, maternal age, economic circumstances, HIV transmission beliefs and the quality of milk (breast vs formula) influence the decisions about infant feeding.

A study conducted by Ladzani, Peltzer, Mlambo and Phaweni (2011), found a 12.4% prevalence of mixed feeding by HIV positive mothers in a rural Mpumalanga district. The reasons given by HIV positive mothers in this study varied. They found that vaginal delivery, having fewer antenatal care visits, not taking Nevirapine for both mother and child, not knowing HIV status of the infant, child's hospital admission and incorrect knowledge of HIV transmission through breastfeeding were associated with mixed infant feeding. In this study, they also found that even though mixed feeding was high in prevalence, most mothers preferred exclusive formula feeding (60%). This finding is similar to other studies which found that exclusive formula feeding was the preferred method (Leroy et al., 2007; Ukpe,

Blitz, Hugo & Theledi, 2009); Doherty, Chopra, Jackson, Goga, Colvin & Persson, 2007). Another study found that formula feeding was preferred because women hoped to receive money for buying milk from their partners (Ijumba et al., 2013). The women in this study also expressed negative views about the cost of the formula milk which ultimately led to the risky behaviour of mixed feeding.

Goga, Doherty, Jackson, Sanders, Colvin and Kuhn (2012) conducted a prospective observational study among the HIV negative and positive mothers to assess their infant feeding practices. In this study, they found that although infant feeding practices amongst both HIV positive and negative women were poor, HIV positive mothers adhered better to the safer infant feeding practices. The HIV positive women's adherence to the safer infant feeding practices was attributed to infant feeding counselling which is normally provided in the healthcare facilities during antenatal and postnatal care. Similarly, Doherty et al. (2006) found that even though family plays a significant role on the choice of method regarding infant feeding, some HIV positive women were not easily coerced into mixed feeding. Women who exclusively breastfed did so because of the belief that breastfeeding is beneficial to the child. They also noted that a supportive environment was critical. Doherty et al. (2006) also conducted a study on the effects of the HIV epidemic on infant feeding in South Africa. They found that the HIV positive status led women to feel discriminated against, despair and powerlessness. These attributes appeared to lead to behaviours, such as mixed feeding.

A study conducted in a peri-urban community in South Africa found that exclusive breastfeeding was not prevalent and that the introduction of solids started as early as 1 month (Sibeko, Coutsoudis, Nzuza & Gray-Donald, 2009). Participants in this study cited nurses (70%) as the ones who influenced their infant feeding choice. Another infant feeding barrier identified by Sibeko et al. (2009) was that mothers preferred traditional medicines to strengthen their babies. This meant that the first dose of traditional medicine was also administered from one month after birth. Similarly, a study conducted in Vhembe district in Limpopo Province, South Africa, found that 76% of HIV positive women practiced exclusive breastfeeding, 43% introduced solid food when the baby was 3 months and 15% introduced it at 2 months (Mushaphi, Mbhenyane, Khoza & Amey, 2008). Another study conducted in Mpumalanga Province found that 23% of HIV positive women practiced mixed feeding (Ukpe et al., 2009). This percentage is higher than the one found by Ladzani et al. (2011) in the same province. Cultural systems have also been found to play a significant role in

nutrition and some of the practices related to health seeking (Aubel, 2012). This study shows the importance of paying a close attention to "social structures such as family, kinship, roles, hierarchies, communication nets…"(p.22) which seem to have a strong influence on cultural expressions (Aubel, 2012).

Another different view is expressed by the study which found that the early introduction of formula milk is related to not involving teenage mothers in caring for their own children (Ijumba et al., 2013). This study found that formula feeding gave teenage mothers freedom to leave their babies with their mothers. Grandmothers have also been identified as a barrier to recommended infant feeding procedures. For instance, in a study conducted by Ijumba et al. (2013), it was found that the use of formula milk is implemented because grandmothers take over the caring of children and therefore become "replacement mothers". In a study by Falnes, Moland, Tylleskär, de Paoli, Leshabari and Engebretsen (2011) the mothers-in-law were also grandmothers who saw themselves as experts of health issues in the family. It was found that mothers-in-law were generally knowledgeable about PMTCT. However, they were resistant to the infant feeding guidelines which suggested that breastfeeding should only occur for a duration of six months. For the mothers-in-law in this study, breastfeeding was associated with the survival of the child. The participants in Falnes's study expressed their lack of trust for mothers-in-law, especially with regard to keeping confidentiality about health issues. Similarly, a study conducted in Malawi found that the grandmothers' role in caring for the newborn child and introducing "early child feeding" (Bezner-Kerr et al., 2008, p. 1099) is mostly related to traditional herbs which are believed to strengthen the immune system of the child. In this study, they also found that grandmothers play a huge role in ascertaining whether or not the mother has enough milk. If not, they introduce solid food at an early age. According to Bezner-Kerr et al. (2008), mixed feeding confusion is brought about by the fact that grandmothers believe that children are born with hunger, and that water mixed with traditional herbs stop the child from crying (Bezner-Kerr et al., 2008). Grandmothers also play a care-giving role when the child is being weaned (Bezner-Kerr et al., 2008). Besides infant feeding guidance, other roles played by grandmothers included providing seeds for having children, advise about childcare (nutrition) and advise on divorce (Bezner-Kerr et al., 2008). Similarly, other studies acknowledged that across cultures, the grandmother's role has always been that of household advisor and caregiver (Barrett, 2008). In concurrence, Aubel (2012) shows that the support provided by grandmothers includes giving advise on infant feeding with regard to the following aspects: initiating breastfeeding,

introduction of complementary foods and general guidance on diet of the mother before and after pregnancy and while breastfeeding. This kind of guidance is mostly provided to first time mothers who are inexperienced (Aubel, 2012). Studies have found that the young mothers find it difficult to ignore any advice which is given by the elderly women (Gryboski, 1996), hence, the practice of mixed feeding occurs. This is because the elderly women are considered to be wise and well informed when it comes to child care (Mumtaz & Salway, 2007). Senior women have the responsibility of looking after the mother and child during the postpartum phase (Aubel, Mhango, Gondwe, Munthali, Hara, & Zimba, 2006). Another role played by the grandmother includes emphasising the importance of a seclusion period by mother and child at home immediately after birth (Barrett, 2008).

Another barrier is the lack of communication regarding infant feeding policy change at a societal level. In a study conducted by Ijumba et al. (2013), it was found that community members were not knowledgeable about the reasons for discontinuation of free formula milk (FFM), suggesting limited communication about policy change issues at the community level. As such, participants had to guess reasons for FFM discontinuation, such as insufficient supply, abuse of FFM (fraud of buying and selling the milk), teenage pregnancy etc. According to Bateman (2011), fraud and corruption are highly prevalent in South Africa, which explains why participants in Ijumba's (2013) study mentioned it as one of the reasons for FFM discontinuation.

2.10.3.3 Poverty and HIV linkages

Poverty may be defined as the inability to attain a minimum standard of living (May, 2000). Therefore, this encompasses the "inability of individuals, households or entire communities to command sufficient resources to satisfy a socially acceptable minimum standard of living" (May 2000, p. 5). Poverty is also measured by the lack of access to basic services such as water, electricity and sanitation. For example, the World Bank (1994, p. 20) defines the poor as "those who are unable to consume a basic quantity of clean water and who are subject to unsanitary surroundings…lack the minimum energy requirement…" Moreover, Dasgupta and Wealer (1992) argued that poverty can be gauged/ measured by the state of well-being. Therefore, the determinants of well-being include factors such as "health, welfare and human rights" (May, 2000, p. 21). Well-being could also be defined as the "availability of shelter, healthcare, education facilities and income" (May, 2000, p. 21). Sen (1999) argues that in

order to achieve freedom of development, the following obstacles should be removed: "poverty, lack of opportunities, social deprivation, and neglect of public services…" (p. 366). This suggests that development provides freedom of well-being (Sen, 1999).

According to Francis (2006), how people act in response to poverty, is influenced by their institutional environment. This means that reactions to poverty are mediated by an individual's social environment and cultural practices. Gilbert and Walker (2002) identified various factors as contributors to social inequalities: "geographical location, racial composition, socio-economic status" (pp. 1100-1103). According to Gilbert and Walker (2002), "the lower the socio-economic status, the more likely it is for the people to be unhealthy" (p.1103). Due to poverty, many communities and families are disrupted because of the high number of people who enter and reside in their home town to seek employment opportunities. Studies have shown that South Africa is one of the countries that suffer from "chronic poverty" (Soskolne, 2003).

Various pathways through which poverty contributes to the transmission of HIV have been identified. For instance, as a result of poverty, people engage in survival strategies that put them at risk of contracting HIV (van Donk, 2002). The lack of adequate education also places people at risk of contracting HIV (van Donk, 2002). As a result, such behaviour leads to high rates of teenage pregnancy. This suggests that socio-economic barriers could impact greatly on the PMTCT programme. According to van Donk (2002), migration which is mainly a livelihood strategy to improve poor socio-economic status, increases the spread of HIV infection. Studies suggest that the HIV prevalence is higher among South African migrants (Lurie et al., 2003). Poverty is therefore regarded as co-factor leading to HIV infection.

In addition to that, Krishnan, Dunbar, Minnis, Medlin, Gerdts, and Padian (2008) conducted a study which looked at identifying structural pathways which leads to women's contraction of HIV. Poverty and inequality were the underlying risk environments leading to structural pathways of HIV contraction. Krishnan et al. (2008, p.102) identified the following four key structural pathways to HIV risk:

- "Lack of access to critical information and health services for HIV/ STI prevention."

- "Limited access to formal education and skill development"
- "Intimate partner violence (IPV)"
- "Migration negative consequences due to insufficient economic resources."

Krishnan et al. (2008, p.102)

According to Krishnan et al. (2008), IPV is made worse by poverty and migration, which are greatly influenced by the lack of financial resources. Farmer, Connors and Simmons (1996) argue that the cause for sickness may be due to structural violence which is not necessarily caused by nature or any individual/ anybody's fault, but is due to history (economic situation. As such, because of being born in poverty, any attempt to run from it (poverty) subjects people (especially women) to being infected with HIV. According to Gilbert and Walker (2002), poverty seems to be the determining factor for the poor women's health status, especially in relation to HIV exposure. The association between gender and HIV is discussed in detail in the next section of this Chapter. In line with Krishnan et al. (2008), UNAIDS (2005) also highlights that lack of access to health information and services for HIV prevention forms a pathway to HIV infection because of rural locality challenges.

Parker (2012) found that economic factors such as poverty and unemployment, as well as environmental factors, such as context related non-utilisation of health services contribute to the high spread of HIV (p.9). Parker also showed other numerous factors that lead to HIV infection burden, including individual factors such as inconsistent condom use, low HIV testing rates, single parenting, transactional sex, alcohol etc. In addition, Parker (2012) identified psychological factors which ranged from the lack of satisfaction with circumstances to the desire to love and be loved as the ones contributing to HIV infection. Parker (2012) continues to argue that sociocultural factors such as cultural acceptance of late marriage, non-marriage, tolerance of infidelity, violence, silence about rape etc. also increase the HIV pandemic.

There are studies that have been conducted which show that poverty affects the effectiveness of the PMTCT programme. In the Eastern Cape Province in South Africa, Skinner, Mfecane, Gumede, Henda, and Davids (2005) found that poor socio-economic conditions in rural communities serve as a barrier towards the provision of the PMTCT services. They also found that transport challenges which are due to poor infrastructure in the rural communities

of the Eastern Cape, make healthcare accessibility difficult. Although there was an understanding of broad PMTCT facts, there was poor knowledge of PMTCT among women. The current study describes factors that facilitates and hinder rural HIV positive women from participating in the PMTCT programme. Therefore, the findings will indicate whether poverty is one of the contributing factors or not.

2.10.3.4 Gendered HIV vulnerabilities

- **Women's vulnerability to HIV infection**

According to Squire (2007), HIV is a gendered pandemic and therefore seems to have powerful consequences for women. More women are infected with HIV than men in SSA, and yet it is women who take on the responsibility of caring for other HIV infected family members. Standing (2010) writes that gender is one of the profound markers of differences in epidemiology, health status, health behaviours, health risks, vulnerabilities and access to and use of health resources. Squire (2007) also writes that other women even lose education and employment opportunities, due to burdensome responsibilities. According to Krishnan et al. (2008), "gender power imbalances" contributes to high HIV infection rates. In support of the above studies, UNAIDS (2012) indicates that the population which is most susceptible to contracting HIV is women and girls. As a result, the prevalence of HIV remains high among women in SSA, accounting for 58% of people living with HIV worldwide. In South Africa, statistics reflect that HIV positive women aged 15-24years are at least three times as many (UNAIDS, 2010). Pettifor et al. (2004) also found that the young women aged 15-24years old were more at risk of contracting HIV than men, with women accounting for 77% of the people with HIV infection. HIV affects more women because they are physiologically susceptible to the infection through heterosexual sex (Pettifor et al., 2004). Gilbert and Walker (2002) conducted a study that aimed to understand the impact of social inequality on patterns of HIV and AIDS. In that study, they found that the epidemic is mainly heterosexual. They found that there is a higher HIV prevalence among women than men, and that a high prevalence of the HIV infection was often found in young girls. Similarly, Shisana et al. (2005) found that the gender distribution of people living with HIV reflects greater vulnerability of women in SSA. The HIV prevalence among women aged 15-24years is 17% as opposed to 4% amongst men (UNAIDS, 2010). Rehle, Shisana, Pillay, Zuma, Purren and Parker (2007) also found that HIV infections among the same age group

accounted for 90% of all people infected with HIV. Moreover, a population survey conducted by Shisana et al. (2009) showed that the HIV prevalence remains disproportionally high amongst females, hence it is seen as a gendered pandemic. A study conducted in rural KZN, South Africa, also showed high levels of HIV incidence among women aged 25-34 (Bärnighausen, Tanser, Gqwede, Mbizana, Herbst & Newell, 2008).

In South Africa, there has been an HIV prevalence increase of 4% among women aged 35-39 years from 35.4% in 2009 to 39.4% in 2011; among 40-44 years increased from 25.6% in 2009 to 31.75 in 2011, (6.1% increase) and among 45-49 years increased from 23.9% in 2009 to 30.4% in 2011 (6.5% increase) (National Department of Health, 2011a). These shifts in HIV prevalence in older women are due to a need for survival. Although women are often blamed for contracting HIV (Esplen, 2007), they are vulnerable because of factors such as lower-economic status, poor education and lack of employment (UNAIDS, 2012). Additional factors contributing to women vulnerability include "poverty, gender inequality, violence, substance abuse and multiple partnerships (Wechsberg, Parry & Jewkes, 2008). Moreover, Parker (2012) indicated that the HIV epidemic is worsened by the social and economic inequalities between men and women. This is shown by the differences in HIV prevalence levels which are higher among women than men (de la Torre, Khan, Eckert, Luna & Koppenhaver, 2009).

Dunkle, Jewkes, Brown, Gray, Mcintyre and Harlow (2004) also argue that women are mostly affected because they are socially vulnerable to unsafe sexual behaviour in violent situations, coercion and economic deprivation. Similarly, Soskolne (2003) argue that rural women's experiences of the HIV disease are worsened due to the vulnerable and subordinate positions that they hold in society. Rural women lack political power and economic resources and, therefore, are vulnerable because of their dependence on men (Strebel, 1995). A report by Abt Associates Inc. South Africa (2000) demonstrates some distinct factors which lead to high HIV infection rates among women. These include:

- "Low status" of women in society (Abt Associates Inc. South Africa, 2000, p. 4). This particularly stems from the poor socio-economic status of women.

- "Women hold a subordinate role in family" (Abt Associates Inc. South Africa, 2000, p. 4). This means that the position one occupies in society defines the quality of social life. Women hold lower positions of no power.

"Social and cultural sexual norms" (Abt Associates Inc. South Africa, 2000, p. 4) which seem to support that men can have many sexual partners and may force themselves on a woman (Leclerc-Madlala, 2000). This implies that, women are very vulnerable to behaviours that lead to HIV infection because of poverty. Vulnerability for women and girls also seems to be because of difficulties with negotiating safe sex, due to gender-related social and economic power imbalances (UNAIDS, 2012; Wechsberg et al., 2008). A longitudinal analysis of data from cluster-randomised controlled trial conducted in the Eastern Cape Province, South Africa also revealed that 'intimate partner violence and relationship power inequity' increased the risk of HIV infection in women (Jewkes, Dunkle, Nduna & Shai, 2010). Studies show that masculinity perceptions encourage the domination of decision-making on sexual activities. As such, it results in actions that lead to violence against women and it also affects the utilisation of healthcare services (Greig, Peacock, Jewkes & Msimang, 2008). In most cases, the risk of gender based power is accentuated by older men having sexual relations with younger women (Leclerc-Madlala, 2008). Therefore, this suggests that the women's vulnerability to HIV infection is brought by the lack of decision making power in sexual relationships which is caused by gender inequality (Ghanotakis, Peacock & Wilcher, 2012). A number of studies have been conducted which show women's vulnerability to HIV infection (Kako et al., 2012; Pettifor, MacPhail, Anderson & Maman, 2012). For example, in a study conducted in rural Kenya by Kako et al. (2012), it was found that there were gender-based obstacles related to condom refusal by male partners, even in the case of individuals who had a known positive HIV status. This study found that some men denied condom use because of the belief that women do not really have HIV (Kako et al., 2012). The refusal to use condoms put women in double jeopardy of being pregnant and also being infected with HIV (Kako et al., 2012). In this study it was also argued that women's vulnerability was also brought on by male partners who have multiple sexual partners. Several studies have also found that multiple concurrent partnerships drive the generalized epidemics in Southern and Eastern Africa (Halperin & Epstein, 2007; Shelton, 2007; Soul City Institute, 2008). Studies show that men are not as vulnerable as women, because they seem to be protected by gender norms which appear to condone their poor utilisation of healthcare services (Peacock, 2003).

Gender inequality affects the PMTCT progress (Ghanotakis et al., 2012). Gender based violence affects women and PMTCT programme negatively in terms of the following: family planning, HIV infection, utilising and adhering to services relating to HIV prevention, treatment and care (WHO, 2009). Hence, getting PMTCT narratives from HIV positive women, grandmothers and HCPs provides an opportunity to identify additional factors that highlight women's vulnerabilities further, even in the context of the PMTCT programme. As such, identification and exploration of these narratives will assist with curbing the spread of HIV (UNAIDS, 2012). There are global targets that have been put in place in response to the severe HIV epidemic. For example, Target Seven of the global report on HIV/ AIDS aims to eliminate gender inequalities (UNAIDS, 2012). The pervasive gender inequalities and structural violence seem to be the elements fuelling HIV infection among women (UNAIDS, 2012). Links have been found between Violence Against Women (VAW) and the high spread of HIV (Dunkle, Head & Garcia-Moreno, 2009). Stepping Stone programme which is aimed at promoting gender equality by working with both men and women could promote better adherence to PMTCT services. This programme was found to reduce risk behaviours which affect PMTCT (Jewkes et al., 2008).

- **Women's vulnerability to HIV infection and family**

The vulnerability of HIV positive women is also imposed through the family support system, such as grandmothers' involvement on infant feeding issues. Grandmothers have been shown to play a significant role in child care (Penn et al., 2010), including infant feeding. Vulnerability and disempowerment of HIV positive women seems to also emerge as a result of these women feeling forced to adhere to grandmothers' recommendations related to infant feeding methods, such as mixed feeding. According to Aubel (2012), grandmothers play a care-giving role and advise young women, especially on nutrition related issues. Hence, because of this role, HIV positive women might find it daunting to challenge grandmothers who have been playing this role for decades. Bezner-Kerr, Dakishoni, Shumba, Msach and Chirwa (2008) indicate that instead of following healthcare provider advice on infant feeding, women would choose to adhere to paternal grandmothers' advice. The mother-in-laws have been found to impede proper infant feeding procedures (Becquet, Ekouevi, Viho, Sakarovitch, Toure, Castetbon et al., 2005; Leshabari, Koniz-Booher, Astrom, de Paoli & Moland, 2006). Other studies show that the mother-in-laws' rules on infant feeding are followed by mothers in order to have her continual love (Falnes et al., 2011). This study

found that mothers-in-laws viewed family health to be their responsibility because of being elders and grandmothers. As such, they also did not support exclusive breastfeeding. It was found that in a rural context, where exclusive breastfeeding is the norm, HIV positive women who do not disclose their HIV status are often expected to breastfeed (Desclaux, Msellati & Walentowitz, 2009). In cases where exclusive breastfeeding for six months is a challenge, women often find themselves having to enter into negotiations with biomedical recommendations and the acceptable local infant feeding habits (Desclaux et al., 2009). In another study, researchers found that if a woman decided to disclose her HIV status to her partner (Tijou Traore, Querre, Brou, Leroy, Desclaux, & Desgrees-du Lou, 2009), certain partners who were accepting often preferred other forms of infant feeding (instead of breastfeeding), to decrease the chances of HIV transmission to the child (Desclaux et al., 2009). This shows women disempowerment in the context of PMTCT which involves men and grandmothers making decisions on how the infant is supposed to be fed. Studies have shown that decision making regarding utilisation of healthcare services is often men's prerogative or other senior members of the household (Molyneux, Murira, Masha, & Snow, 2002; Orunuloye, 1991). Other studies have shown that the decision making power for the mother to seek medical help for the child was also controlled by the father (Tolhurst, Amekudzi, Nyonator, Bertel Squire & Theobald, 2008). The power to make decisions (on PMTCT aspects such as infant feeding) and have control over it can greatly enhance the effectiveness of the PMTCT programme. The plethora of issues surrounding infant feeding becomes the responsibility of the woman who is still fragile and vulnerable after having just discovered her HIV status. It is vulnerabilities such as this that lead women to succumb to situations without following the proper PMTCT cascade processes indicated in Figure 2.2 of this Chapter. The women's subordinate position within the family (Soskolne, 2003) seems to affect their ability to make decisions on infant feeding, hence this is a reflection of woman's status.

According to UNICEF (2011), the women's status refers to "positions occupied by women compared to men in a community which usually mediates their decision making power and the ability to access resources within the household or the wider community" (p.14). Having the power to make decisions and taking charge of resources are two important aspects which enables a woman to have "bargaining power" in the family (UNICEF, 2011, p. 16). Sen (1990) argues that having power to make decisions and the ability to take charge of resources reflect inequality even amongst members of the household. This suggests that it is the

individuals' prerogative which allows them to have power to make decisions and control resources in a household. Because women are of low status when it comes to making decisions on child caring including proper infant feeding, they often do not have power to do so. Because of the lower positions they occupy within the household, they are more vulnerable due to lack of power to act. The figure below shows how women's low status within the household and community affects child survival, health and nutrition.

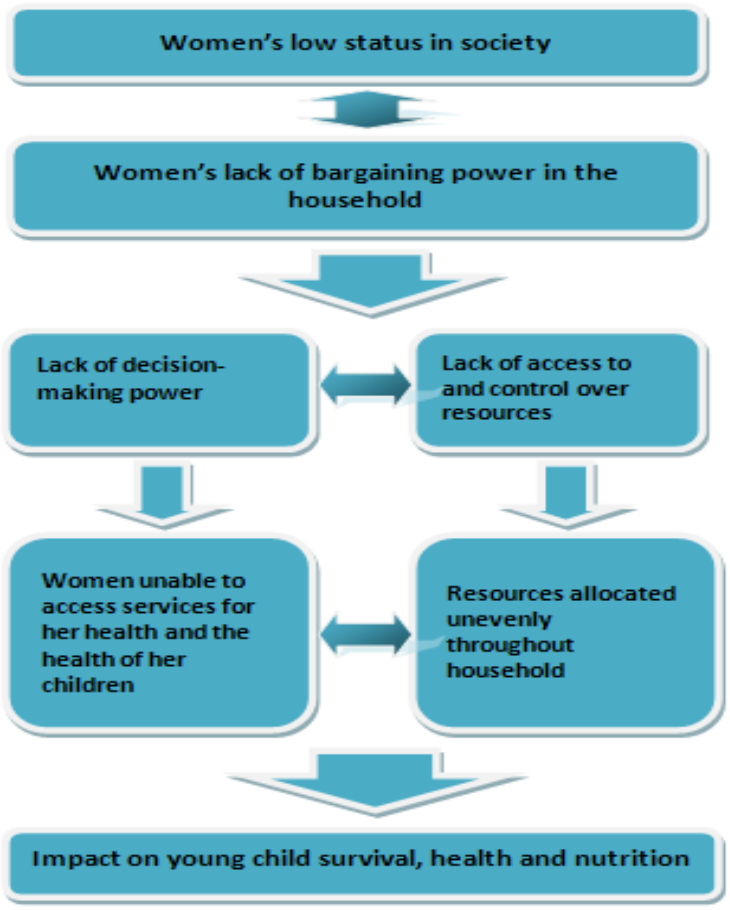


Figure 2.4 Women's status in a household (Source: UNICEF (2011:p. 17): Relationship between women's status, household bargaining and child survival, health and nutrition

The lack of power to make decisions on utilisation of healthcare services and proper infant feeding practices, can greatly affect the effectiveness of the PMTCT programme. Women's vulnerability comes with expectations of early antenatal care by the HCPs and the healthcare system. The eagerness of women to participate in healthcare services when pregnant could be disturbed by anticipated stigma perceived by the women (Obermeyer, Parsons, Sankara & Bastien, 2009). Hence, women often experience conflict between community norms and

individual beliefs about early antenatal care. Studies have shown that PMTCT services non-utilisation is related to women disempowerment (Besser, 2010a; Besser 2010b). Furthermore, studies have revealed difficult relationships caused by the lack of decision making power and access to and taking charge of resources (Desclaux & Alfieri, 2009). In this study, men had to make decisions on infant feeding because of the responsibility of purchasing milk. Similarly, paternal grandmothers influenced decisions on child caring and feeding. It is therefore important to take into consideration the system of infant carers which has the potential to influence how a child is cared for and fed (Aubel, 2012). Although the literature suggests that grandmother's and men involvement on infant feeding could greatly enhance/ improve child's health (USAID, 2011), it is important to challenge gender norms with the potential to damage child health (UNICEF, 2011).

- **Women's vulnerability to HIV infection and culture**

In addition, the vulnerability of HIV positive women is suggested to also be caused by traditional cultural practices. A study conducted in Malawi found that culture was a facilitator for social disempowerment (MacIntyre, Rankin, Pinderhughes, Waters, Schell & Fieldler, 2013). According to this study, culture presents gender stereotypes which make women to be the subordinates of men. Culture is regarded as a source of limiting power to act or make decisions. MacIntyre et al. (2013) argue that men and women have internalized cultural belief which regards women as inferior to men. Because of such internalized belief of being subordinates, women are limited from making decisions. Kako et al. (2012) states that factors, such as polygamy, seem to be acceptable in some African cultures and as a result, women are more exposed to vulnerabilities of contracting HIV. In such a case, it is difficult for women to argue against the long standing traditional practices, such as polygamy. In Kenya, another cultural practice which made women vulnerable to contracting HIV was that of a woman approaching another woman and agrees for her to sleep with other men to try and bear male children for her. Kako et al. (2012) also noted poor socio-economic status as another cause for vulnerability to HIV infection. Women seem to feel obliged to continue having unprotected sex in order to satisfy the man as the provider.

- **Women's vulnerability to HIV infection and challenges of managing self**

Because of women's vulnerability, it becomes imperative for them to maintain certain behaviours in managing selves in order to sustain their health (Webel et al., 2013). According to Webel et al. (2013, p. 147), "self -management" is challenged by varying "social context" vulnerabilities. Self-management involves performing certain daily duties in trying to manage a chronic disease, such as HIV (Richard & Shea, 2011; Ford, Calmy & Mills, 2011). Self-management includes activities such as diet improvement, exercising, adherence to medication, psychological and emotional wellness and social relationship improvement (Swendeman, Ingram & Rotheram-Borus, 2009). The social context affecting woman's health could include varying social roles that a woman has to play in a home, such as being a partner, and mother etc. (Webel etal., 2013, p. 148). Other challenges include structural factors such as poverty (Webel & Higgins, 2012). A study conducted by Webel et al (2013) found that self-management of HIV becomes difficult when women are faced with various social contexts. Hence, self-management challenges have the potential to affect the effectiveness of PMTCT services.

- **Women's vulnerability to HIV infection and transactional sexual relationships**

Another cause of vulnerability to HIV that women face is caused by transactional sexual relationships. Transactional sex is defined as the type of sexual relationships which involves exchanges of visible material goods and money for sexual intercourse (Norris, Kitali & Worby, 2009; Moore, Biddlecom & Zulu, 2007; Stoebenau et al., 2011). Transactional sex is also carried out for the exchange of food, capital and accommodation (MacPherson et al., 2012, p. 17364). Evidence suggests that SSA is mostly affected by transactional sexual relationships (Moore et al., 2007) and as a result, women in this region are more vulnerable to HIV. Structural drivers such as gender, age, socio-economic factors seem to increase women's vulnerability to HIV (Gupta, Parkhurst, Ogden, Aggleton & Mahl, 2008).

Krishnan et al. (2008) also identified transactional sex as one of the pathways which leads to risky sexual behaviour of women. This means that young girls get into transactional sexual relationships because of their lack of knowledge regarding its repercussions and their lack of

financial resources to buy food and pay for education. Krishnan et al. (2008) further highlight that women basically remain in risky and violent relationships as a result of economic dependency. Similarly, Farmer et al. (1996) argue that structural violence, such as poverty, causes young girls to be involved in commercial sex.

Transactional sexual relationships could also be fuelled by men who believe that they are providers for women and therefore are entitled to be rewarded with sex in exchange (Jewkes, Morell, Sikweyiya, Dunkle & Penn-Kekana, 2012). This study also suggests that prohibiting transactional sex among men might not suceed unless there is an understanding of how men perceive themselves. A longitudinal analysis of data carried out by Jewkes, Dunkle, Nduna and Shai (2012) has shown that a high HIV incidence is aggravated by transactional sexual relationships. This study found that having transactional sexual relationship with a "once off partner" and secret lover "khwapeni" increased HIV incidence among young women in South Africa (Jewkes, Dunkle, Nduna & Shai 2012, p. 5.).

According to MacPherson et al (2012, p. 17364), engaging in transactional sex seems to be one of the "gendered structural drivers of HIV". This study that was conducted in fishing communities in Malawi found that women were vulnerable to contracting HIV because of indulging in sexual intercourse in exchange for fish (MacPherson et al., 2012). As a result, their need for food placed them at risk of not being able to negotiate safer sex with the fishermen. A paper written by Wechsberg, Parry and Jewkes (2008, p.1) shows "intersection of HIV/AIDS with vulnerable women". This paper indicates that the high spread of HIV is caused by various factors such as "poverty, gender inequality and violence, substance abuse and social norms" which encourage multiple concurrent partnerships (MCP). Similarly, previous research indicates that economic vulnerability leads to having MCPs (Epstein, 2008). It is also suggested that women are often at risk of contracting HIV because they sometimes resort to transactional sex in order to improve their livelihood (Wechsberg et al., 2008). A study conducted in the township of Soweto, South Africa, found that whilst transactional sex is practiced by men to gain sexual pleasure, it is primarily practiced as a survival strategy by women (Dunkle, Jewkes, Brown, Gray, Mcintryre & Harlow, 2004).

In the context of PMTCT, studies have found that although ARV treatment has been rolled out widely, challenges still exists with programmes geared towards preventing HIV (Coates, Richter & Cacares, 2008). The need to improve economic livelihood (Dunkle, Jewkes,

Brown, Gray, Mcintryre & Harlow, 2004; MacPherson et al., 2012) might impact negatively on adherence to HIV prevention programmes (Coates et al., 2008) such as PMTCT.

2.10.3.5 Cultural and linguistic barriers and access to care

Language barriers have been linked to poor access to healthcare services. Studies show that language barriers leads to poor utilisation of the healthcare service (Feinberg, Swartz, Zaslavsky, Gardner & Walker, 2002). Language is a means by which a patients access the healthcare system, learn about services and make decisions to utilise such services (Woloshin, Shwartz, Katz & Welch, 1997). It is useful in providing facts about HIV testing. The pre- and post-HIV counselling process also requires effective language use. Miscommunication can lead to insufficient use of the healthcare facility (Kravitz, Helms, Azari, Antonius & Melnikow, 2000). Language also provides an opportunity for the HCP to understand patients' beliefs about health and illness. Thus, communication between the HCP and patient is vital for the improvement of the PMTCT programme. The inappropriate use of language when addressing PMTCT clients might impact the PMTCT programme negatively.

Although the relationship between medication non-adherence and language barriers is not well defined (Brach & Fraser, 2000), effective communication on the importance of adherence to ARVs for both mother and child is crucial. Difficulty in understanding the dosage instruction for the ARV medication could lead to treatment adherence challenges (Watermeyer & Penn, 2009). This challenge is brought about by difficulties in communication which have been identified as a possible barrier, especially in the healthcare setting, where the doctor-patient and pharmacist-patient interaction relies on clear understanding.

Cultural and linguistic barriers play a significant role in the management of the HIV epidemic (Penn & Watermeyer, 2012). As such, linguistic factors are critical at all levels of HIV prevention, diagnosis and treatment. According to Penn and Watermeyer (2012), clear communication is needed to facilitate understanding about the disease. Furthermore, Penn (2007) suggested that communication inefficiency may be due to culture and language barriers. As a result, Penn (2007) called for research that would explore challenges of using interpreters especially in the healthcare setting. This suggests that communication ineffectiveness has negative effects on patient adherence to treatment. Research has shown

that communication about HIV could lead to uneasiness which most of the time is demonstrated by patients' use of euphemisms and the avoidance of HIV related terminology (Watermeyer & Penn, 2008; Ware et al., 2009)

Language barriers between patients and HCPs might affect disease incidence, health outcomes or access to care. Certain studies have reported negative associations between language barriers and the number of healthcare visits (Feinberg, Swartz, Zaslavsky, Gardner, & Walker, 2002; Jacobs, Launderdale, Meltzer, Shorey, Levingson, & Thisted, 2001). However, studies exist that do not link the two (Meredith, Stewart, & Brown, 2001). In the context of PMTCT, linguistic barriers could lead to late attendance at antenatal and postnatal care services. Language barriers coupled with community ignorance regarding the PMTCT programme could seriously affect the effectiveness of the programme.

2.10.3.6 HIV Treatment adherence barriers

The importance of adherence to antiretroviral treatment for HIV, such as highly active antiretroviral therapy (HAART), has been documented in the research literature (Chesney, Icknics, Hecht et al., 1999). Studies have found that adherence lower than 95% can be associated with the development of viral resistance to medications (Wahl & Nowak, 2000). Non- adherence in the context of PMTCT could be defined as a mother-infant pair who is not taking Nevirapine (NVP) treatment at stipulated times or a total non-ingestion of the treatment (Delvaux, Elul, Ndagije, Munyana, Roberfroid, & Asiimwe, 2009) by both mother and child. Even when PMTCT programmes are available, women face multiple challenges in adhering to PMTCT services and the ARV prophylaxis, particularly women in rural areas (Bajunirwe & Muzoora, 2005). Several studies have reported a severe loss of follow-up from registration up to delivery in PMTCT programmes (Manzi et al., 2005; Perez, et al., 2004; Stringer et al., 2005; Temmerman, Quaghebeur, Mwanyumba & Mandaliya, 2003). Correlations of non-adherence have been identified from cross sectional studies. For example, Ammassari et al. (2002) found that factors associated with non-adherence include symptomatic disease and the presence of adverse drug effects, psychological distress, lack of family support, an increased antiretroviral regimen, low self-efficacy and inconvenience of treatment. Obtaining PMTCT narratives by using qualitative methods can enrich the understanding of the complex and multifactorial nature of the determinants of adherence (Bartos & McDonald 2000; Bogart et al., 2000; Proctor, Tesfa & Tompkins et al., 1999) in

the PMTCT programme. Increased understanding of the complex dynamics associated with adherence to HAART thus remains important.

Recent studies have shown the beneficial effect of early initiation of ART with a high CD4 count (Braithwaite et al., 2008). Other studies have also shown that provision of HIV treatment to a large number of people in the community could significantly lower or stop the HIV epidemic (Granich, Gilks, Dye, De Cock & Williams, 2009). Studies show that ART adherence in South Africa is influenced by the social, historical, cultural and geographical context of HIV (Gilbert & Walker 2009). Castro and Farmer (2005) suggest that access to ARVs assists in minimizing the visible signs of the disease and helps HIV positive people to reclaim their lives (Mahajan, et al., 2008). This is supported by Pierret (2007) who argued that ARVs normalize life by changing the way in which the illness is experienced.

In a review conducted by Gourlay, Birdthistle, Mburu, Lorpenda and Wringe (2013) on factors that facilitate or prohibit uptake of ART for PMTCT, it was found that individual and community level factors play a significant role. For instance, at an individual level, they identified the following barriers: poor knowledge of HIV/ART/ vertical transmission, lower maternal education and psychological issues. At a community level the barriers included partner support, stigma and fear of HIV disclosure to the partner, community or family. Gourlay et al. (2013) further identified factors that are both facilitators of and obstacles to adherence, such as preference of traditional healers and birth attendants. The health system factors included issues such as staff shortages, service accessibility and lack of deliveries to the healthcare facility (p. 18588).

Various studies have also shown that poor adherence to ARVs in PMTCT is due to a lack of knowledge, and the beliefs that people have about treatment (Peltzer et al., 2010; Mepham et al. (2011; Towle & Lande, 2008). Other studies found that patients doubted the efficacy of ARVs for the prevention of MTCT of HIV (Duff, Rubaale & Kipp, 2012; Levy, 2009). Towle and Lande (2008) also found that women had a belief that the ARVs would harm their unborn child. Other studies have suggested that psychological factors such as fear and shock delayed the initiation of ARVs (Stinson & Myer, 2012; Kasenga, Hurtig & Emmelin, 2010).

Numerous studies have found that HIV stigma exists and fear of HIV disclosure to both partners and the family (mostly grandmothers and mothers-in-law) facilitated non-adherence

to ARVs in PMTCT (Duff et al., 2012; Kasenga, Hurtig et al., 2010). Self-stigma was also mentioned as a barrier to taking treatment in PMTCT (Tinson & Myer, 2012; Kasenga, Hurtig & Emmelin, 2010). Similarly, O'Gorman, Nyirenda, & Theobald (2010) also shown that non-adherence to Nevirapine tablets by pregnant women was due to fear and stigma related to HIV. Furthermore, Gilbert and Walker (2009) explored the social complexity of ART in South Africa and found that the fear of HIV stigma is still dominant, even though the patients believe that ARVs are normalizing their lives. Fear of HIV disclosure has been shown to have negative repercussions for the initiation of treatment and antenatal care (Varga & Brookes, 2008a; Stinson & Myer, 2012; Duff et al., 2012). Fear of HIV disclosure may also lead to non-ingestion of ARVs (Mepham et al., 2011; Kasenga et al., 2010; Laher et al., 2012) as well as the lack of administering and seeking prophylaxis for the infant (Kasenga et al., 2010). A study conducted by Abrahams and Jewkes (2010) on barriers to post exposure prophylaxis (PEP) completion after rape found that PEP adherence was complicated and challenging among women. Adherence to a 28 day PEP was affected by the following factors: "fear of blame, poor knowledge and poor social support and fear of HIV (p475)."

Partner challenges have also been identified as barriers towards non-adherence to treatment for PMTCT (Duff et al., 2012; Stinson & Myer, 2012; O'Gorman, Nyirenda & Theobald, 2010). Other studies showed that lack of support from both family and partners led to non-adherence (Kasenga, Hurtig & Emmelin, 2010; O'Gorman et al., 2010). In addition, studies have shown that the use of traditional medicine takes priority over the use of ARVs for PMTCT because of the cultural beliefs that people have. Stinson & Myer (2012) also found that the use of traditional medicines prohibits the use of ARVs. Theilgaard et al (2011) demonstrated that patients' first point of contact when sick is the traditional healer, especially healers who claim to know how to cure HIV.

Other barriers to adherence to ARV treatment were due to healthcare systems challenges, such as the lack of resources and infrastructure. Numerous studies found that staff shortages led to poor uptake of PMTCT ARVs (Levy, 2009; Chironke, Sundby & Martison, 2009; Theilgaard et al., 2011). Other studies have found that poor treatment of patients by staff, such as the scolding of patients, discourages them from adhering to PMTCT ARVs (Varga & Brookes, 2008a; Duff et al., 2010). The physical location of the clinic was also one of the factors leading to non-adherence to ARVs (Theilgaard et al., 2011). Another barrier to accessing ARVs is the late attendance of antenatal care (Stinson, Boulle, Coetzee, Abrams &

Myer, 2010). A study conducted by Mepham et al. (2011) in KZN, South Africa, found that sub-optimal ARV adherence was due to a number of factors ranging from intrapersonal factors (misunderstandings and misconceptions etc.); interpersonal factors (stealing of ARVs by relatives) and social factors (fear of HIV disclosure). This study only suggested 61% of ARV prophylaxis adherence by women. Murray et al. (2009) further indicated that challenges of ARV adherence are also associated with poverty and illiteracy.

2.10.3.7 Male involvement barriers in PMTCT

Since male involvement could imply different meanings in the health context, for the purpose of this study male involvement suggests male participation in HIV testing, especially during antenatal care (Ditekemena et al., 2012). Byamugisha, Astrom, Ndeezi, Karamagi, Tylleskar, & Tumwine (2011) used the following six variables to define male involvement: "antenatal care services, knowledge of the antenatal care schedule, discussion of antenatal care interventions with the female partner, paying antenatal care fees, knowledge of the antenatal care processes and condom use during pregnancy" (p. 14-43). Although male involvement in PMTCT has been deemed necessary for facilitating acceptance of the PMTCT programme, decreasing infant HIV infection (Aluisio, Richardson, Bosire, John-Stewart, Mbori-Ngacha, & Farquhar, 2011) and facilitating positive decisions related to couple's well-being (Milay, Lugina & Becker, 2008), low male involvement rates have been reported (Homsy el., 2006). Even though many studies have suggested the need for male involvement in the PMTCT programme, in order for it to be effective (Moodley, Esterhuizen, Pather, Chetty & Ngaleka, 2009; Nkuoh, Meyer, Tih et al., 2010; Katz, Kiarie, John-Stewart, Richardson, John & Farquahar, 2009) however, there seems to be a lack of interest by men.

Studies show that when male partners are receptive to HIV testing, women adhere to ARV prophylaxis (Peltzer, Mlambo et al., 2010), attend follow-up care (Nassali et al., 2009) and disclose HIV status (Rujumba, Neema, Byamugusha, Tylleskar, Tumwine, & Heggenhougen, 2012a). Ditekemena et al. (2012) also identified three determinants of male involvement in PMTCT, such as socio-economic factors (level of education; income status); healthcare system factors (hours of operation, health provider attitude, lack of space for male partners); sociologic factors (beliefs, attitudes and communication of men and women). A recent review by Morfaw et al. (2013) revealed a number of barriers to and facilitators of male involvement in PMTCT. They identified societal/cultural barriers which included the following: beliefs

such as antenatal care is a woman's responsibility (Mbonye, Hansen, Wamono & Magnussen, 2010); cultural norms (Mbonye et al., 2010; Tonwe-Gold et al., 2009); societal ridicules of the man (Theuring et al., 2009); conflict between PMTCT and cultural norms, such as views on breastfeeding (Falnes et al., 2011). The review further showed that male individual factors for non-participation in PMTCT were as follows: reluctance to know one's HIV status (Mbonye et al., 2010); no time for antenatal care and PMTCT (Theuring et al., 2009; Mbonye et al., 2010); self-perception of good health (Kizito et al., 2008); observing stigmatising behaviour on other HIV positive people (Abrahams & Jewkes, 2012). Knowledge barriers were as follows: misconceptions that partners infer their own HIV status based on the female partner's HIV result (Mbonye et al., 2010; Parker, 2012); limited knowledge on PMTCT (Homsy et al., 2006). The healthare system barriers included the fact that antenatal care is not male-friendly (Mbonye et al., 2010).

In another study conducted by Rujumba (2012a), men were found to also mirror their own HIV status with their partners' status. This implies that if the female partner is HIV positive, the male partner assumes the same status for himself. This study also revealed that male partners often disappeared after HIV disclosure (Rujumba, 2012a). Abrahams and Jewkes (2012) found that female partners were abandoned by male partners after HIV disclosure. Moreover, female related barriers to male participation in PMTCT included the following: women not involving the male partners due to fear (Kizito et al., 2008); weak relationships (Desgrees-Du-Lou et al., 2005). Others studies cited polygamy (Tshibumbu, 2006) and a fear of HIV testing (Bwirire et al., 2008; Magagula & Mkhatshwa, 2004) as barriers to male involvement in the PMTCT programme.

In a review, Morfaw et al. (2013) further explain the facilitators of male involvement in the PMTCT programme. For instance, the healthcare systems could facilitate male involvement in terms of sending letters of invitation to men, community sensitization activities and ensuring ARV availability in the healthcare facility (Mohlala, Boily, & Gregson, 2011). Furthermore, factors related to relationship dynamics could facilitate increased male involvement in PMTCT by the following: increased partner communication about PMTCT (Katz et al., 2009) and sero-concordance HIV status (Desgrees-Du-Lou et al., 2005). The male individual factors involve giving male partners the time to consider the PMTCT recommendation (Mbonye et al., 2010) and previous HIV testing (Nkuoh et al., 2010).

Other studies have shown the lack of commitment to PMTCT processes even after numerous attempts have been taken to increase the involvement of male partners. For instance, the study conducted by Nkuoh et al. (2010) employed numerous methods employed to encourage male participation in the PMTCT programme, such as encouraging males to accompany their wives to antenatal care, encouraging attendance to PMTCT sessions, one-on-one counselling sessions, provision of tokens as incentives, free HIV testing and provision of invitation letters. This achieved limited success. Thus, obtaining PMTCT narratives of rural women may facilitate an understanding of some of the factors that render male involvement in the PMTCT programme problematic.

2.10.3.8 HIV related stigma and fear

The successful PMTCT cascade completion is also limited by social factors such as stigma and discrimination (Turan & Nyblade, 2013). It has been indicated that non-usage of antenatal services is due to fear of HIV testing, HIV disclosure and stigma (Turan, Miller, Bukusi, Sande & Cohen, 2008; Laher et al., 2012). Other studies showed that HIV positive pregnant women anticipated stigma from the healthcare providers (Nguyen et al., 2008). Stigma has been shown to have a negative impact on health care usage which directly affects patients' quality of life and disease management (Deacon, 2006). Varying theoretical frameworks have shown numerous dimensions of HIV related stigma which affect the quality of life of HIV positive individuals, access to healthcare services and health outcomes (Turan & Nyblade, 2013; Steward et al., 2008; Earnshaw & Chaudoir, 2009; Holzemer et al., 2009; Brickley, Le Dung Hanh, Nguyet, Mandel, Giang le & Sohn, 2009; Turan, Onono, Medema-Winjveen, & Cohen, 2011; Brown, Belue, & Airhihenbuwa, 2010). These frameworks show the HIV-related stigma types which affect the utilisation of health services. The following were mentioned:

- Anticipated stigma which mostly arises from anticipating fear of people who did not know the individual's HIV status.
- Community perceptions of stigma/ normative or felt stigma
- Enacted stigma: this refers to varying acts of discrimination and abuse

- Internalized stigma/self-stigma: this involves internalizing negative experiences that exist in the community.

- **Stigma as a social process**

Deacon (2006) provides a definition of stigma which reflects both the personal and social dimensions of the term. Stigma is defined as a social process whereby:

- "The disease is socially constructed as being preventable or controllable".
- "People identify immoral behaviours which facilitates disease contraction".
- "An association of behaviours with disease carriers is made in certain groups".
- "There is blaming of an individual for disease contraction".
- "There is loss of status because of the social constructions of the disease".

Deacon (2006, p. 421).

Similarly, Weiss and Ramakrishna (2004) defines stigma as a social process which is experienced or anticipated. As a result, such stigma is mostly characterized by negative reactions such as blaming, rejection, marginalisation and being devalued by a person or a group (Weiss & Ramakrishna, 2004).

- **Framework for the effects of stigma on maternal, neonatal and child health**

Turan and Nyblade (2013) developed a framework that shows the effects of stigma on maternal, neonatal and child health, and it was adapted from Kumar, Hessini and Mitchell (2009). This framework shows that stigma and discrimination have psychosocial effects that lead to serious behavioural consequences, which have serious effects on health. For instance, the fear of stigma related to HIV or even the PMTCT programme could lead to delays in utilising healthcare services and that act could lead to adverse health consequences. In the health care setting, Bond, Chase and Aggleton (2002) suggested numerous stigmatising actions by the healthcare staff such as leaving patients unattended, denying patients treatment and breaching confidentiality. These factors therefore, disempower the HIV positive person from seeking ongoing medical care. In understanding the non-utilisation of the PMTCT

services in the Nkangala district, the stigma and discrimination framework offers great assistance.

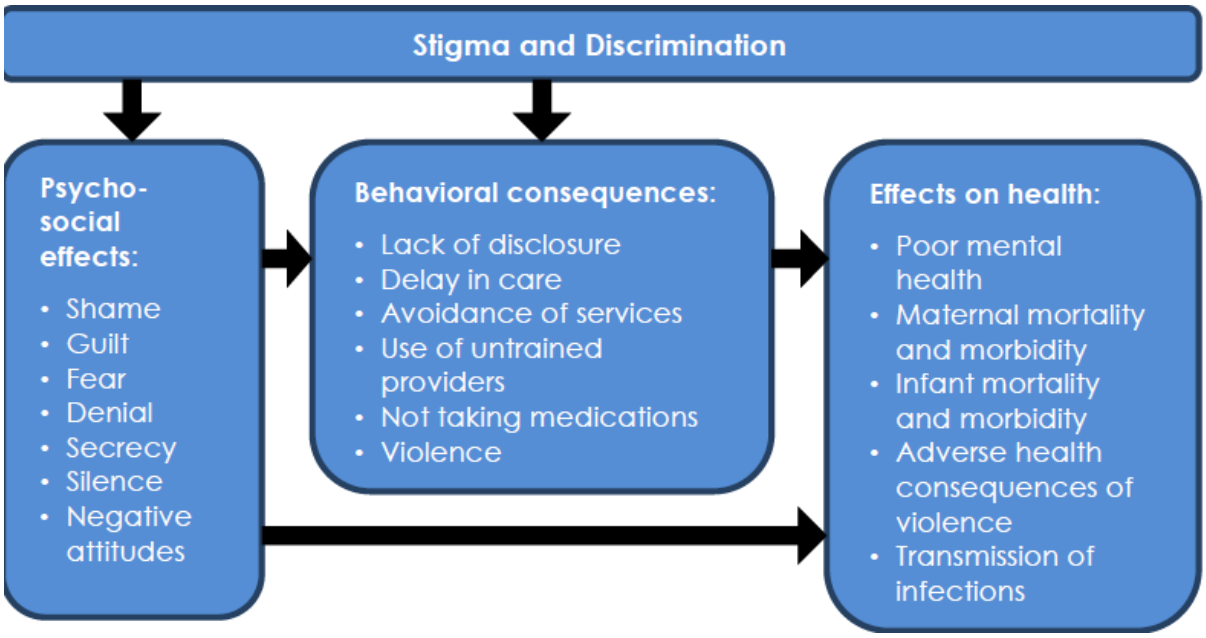


Figure 2.5 Framework for the effects of stigma on maternal, neonatal and child health (Source: Turan and Nyblade, 2013, p.3)

Thorsen, Sundy & Martinson (2008), identified six (6) potential initiators of HIV related stigmatisation which pose challenges to the PMTCT programme 1) routine HIV testing 2) six months exclusive breastfeeding 3) incentives 4) home visits 5) location of the PMTCT programme 6) PMTCT terminology. Bharat, Aggleton and Tyrer (2001) suggested three types of stigma which relate to HIV/AIDS. The first type is self-stigma. This type of stigma involves blaming oneself for the HIV infection and also criticising oneself for being infected. The second type is perceived stigma which mostly involves fear about being stigmatised by the people in the community. This kind of stigma makes HIV disclosure difficult. The third type is enacted stigma. This type of stigma involves being discriminated against because other individuals suspect that you have or know that you have HIV. Enacted stigma involves the act of discrimination against people with HIV.

- **Stigma at community, home and family setting as a source of disempowerment**

Stigma is a source of disempowerment which can be identified at different levels such as community, home and family. Bond et al. (2002) suggest that community stigma may be

demonstrated by individuals distancing themselves from the person that they suspect is infected with HIV. Bond et al., (2002) further suggest that stigma may also present itself in the form of "gossip and name calling" (p. 350). For example, HIV infection promotes two types of stigma related to "sex and death" (Wallman, 1988). When people are morally judged, that is a form of disempowerment for them (Brickley et al., 2009). Such stigmatising behaviour, has the potential to disempower an HIV positive person from seeking medical care, treatment and support which is necessary for the PMTCT effectiveness. Although family has been found to be a facilitator for PMTCT utilisation (Banujirwe & Muzoora, 2005), studies have found that at a household/ family setting, stigma can manifest itself in the form of verbal abuse, rejection, blaming, isolation behaviours (Bond et al., 2002; Brickley et al., 2009; Parker & Aggleton, 2003) and eviction of persons with HIV or not wanting to live or care for an HIV positive person (Szablowniski, 2006). Isolation behaviour can involve separating an HIV positive mother and child in an effort to avoid HIV transmission. In South Africa, Cameron (2013) also argues that stigma affects policies geared towards reducing the epidemic.

2.10.3.9 Social ecological framework for understanding PMTCT barriers

The socio-ecological framework assists in understanding the inter-related relationships between individual behaviours and health outcomes (Wild, Barclay, Kelly, & Martins, 2010; DiClemente, Salazar, Crosby & Rosenthal, 2005). This framework puts individuals experiencing the barrier at the center and shows that the choices they make are found within multiple layers of the framework (Boerma & Weir, 2005). According to Busza et al. (2012) the socio-ecological framework operates at three levels: 1) peer and family influences; 2) community context and 3) socio-cultural environment. The socio-ecological framework recognizes that individuals make healthy decisions based on the many layers of relationships and information which influence the following: breastfeeding, postnatal care and HIV disclosure. A similar framework could assist in understanding the non-utilisation of PMTCT services at the three levels. Figure 2.5 shows the different levels within the framework.

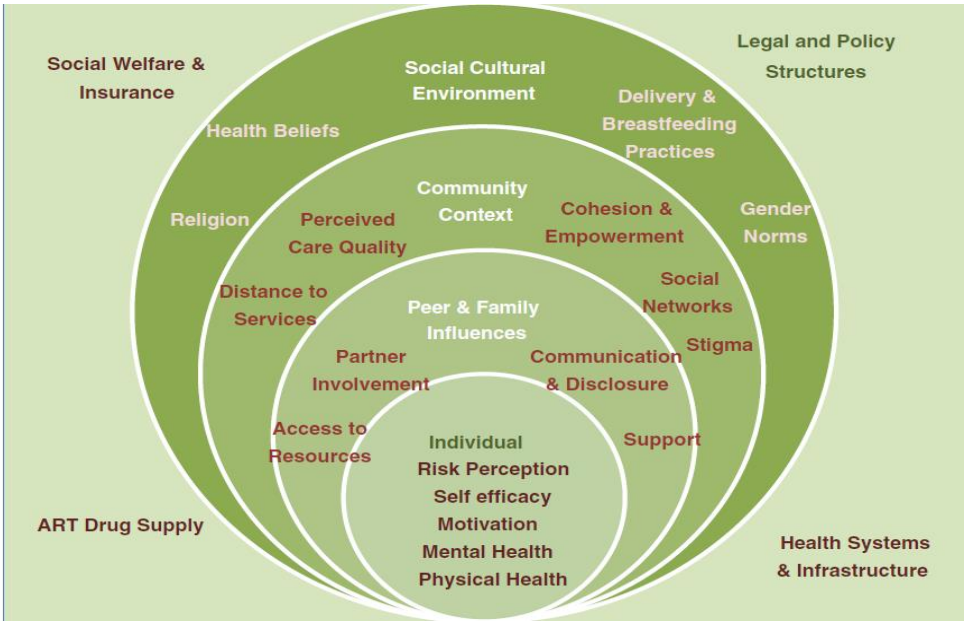


Figure 2.6 Social ecological framework for PMTCT non-utilisation

(Source: Socio-ecological framework for determinants of uptake, adherence and retention in PMTCT adapted from Busza et al., 2012, p. 17376)

2.10.4 PMTCT utilisation facilitators

2.9.4.1 Community involvement as PMTCT utilisation facilitator

Many studies have shown that that there are factors that influence women's ability to navigate within the PMTCT cascade. For example, the studies show that issues such as social support, stigma, disclosure of HIV and partner support cannot adequately be addressed by the healthcare system alone. Community involvement seems adequate in assisting in some of the PMTCT cascade activities (O'Gorman et al., 2010). There are documented community interventions which improved PMTCT outcomes. For instance, in South Africa, mothers2mothers community peer mentoring programme offers support to HIV positive women (Futterman et al., 2010). In Zimbabwe, peer educators conduct community mobilization activities on PMTCT (Orne-Gliemann et al., 2006). In Zambia, there was training of the community motivators and the key counsellors to provide interventions related to vertical HIV transmission (Torpey et al., 2010). Traditional and religious leaders' involvement has also been shown to bring about significant improvement in PMTCT services (Torpey et al., 2010).

In Kenya, partner involvement in counselling showed improvement of the PMTCT services (Faraquhar et al., 2004) whilst in South Africa, community counselling, providing on-going psychosocial and treatment adherence support (Bekker, Myer, Orell, Lawn & Wood, 2006) also improved PMTCT service utilisation. Marcos et al. (2012) argue that community strategies are essential for ensuring access to the full PMTCT cascade by both the mother and child. The review of Marcos, Phelps and Bachman (2012) showed that the integration of facility and community based strategies would improve utilisation of the PMTCT services (Teasdale & Besser, 2008; Futterman et al., 2010; Torpey et al., 2010; Myer, Rabkin, Abrams, Rosenfield & El-sadr, 2005).

2.10.4.2 Existing interventions in rural settings as PMTCT utilisation facilitators

HSRC PMTCT interventions at current study sites

As part of enhancing the existing PMTCT programme at the selected current study sites, PMTCT interventions were implemented which targeted infant follow-up, male involvement in PMTCT, intimate partner violence (IPV), peer counselling and infant feeding, all of which were introduced by HSRC in 2011 (Peltzer, Ladzani, Mlambo, Majaja, Phaweni, Matseke, Shikwane & Rozani, 2010). A brief explanation of each is provided below, together with additional interventions recommended by the other PMTCT literature:

- **Infant follow-up as a PMTCT utilisation facilitator**

This intervention aimed at conducting follow-ups with HIV positive mothers who went through the PMTCT programme and had just given birth, in order to increase early infant HIV diagnosis and early ARV treatment for HIV positive infants. HIV positive mothers are recruited at the maternity hospital wards after birth and are followed up in their respective clinics and homes for a number of sessions. Chetty, Knight, Giddy, Crankshaw, Butler, & Newell (2012) conducted a study in KZN, South Africa and found that interventions for infant follow-up are important because they assist in reducing the transmission of HIV from mother to child.

- **Male involvement as a PMTCT utilisation facilitator**

This intervention aimed to mobilize communities to involve men in PMTCT programmes and to conduct HIV risk reduction and prevention interventions among couples in the PMTCT. Sherr and Croome (2012) also conducted a review on fathers' involvement in PMTCT and found that instead of indirect approaches of involving men in PMTCT (such as inviting men to come to the clinic for HIV testing), provision of HIV testing at community facilities, such as bars, was found to be more effective.

- **Addressing intimate partner violence in PMTCT as a PMTCT utilisation facilitator**

This intervention aimed to assess the extent of partner violence in terms of the severity of abuse and danger risk among pregnant women. It also encouraged the use of community resources by abused pregnant women who test positive for HIV during antenatal care. The women who screened positive for abuse received an intervention session on IPV (Peltzer, Ladzani, Mlambo, Majaja, Phaweni, Matseke, Shikwane & Rozani, 2010). Intimate partner violence interventions could greatly enhance PMTCT services.

- **Peer counselling/ peer mentoring as a PMTCT utilisation facilitator**

This intervention aimed to strengthen the PMTCT programme through a one-on-one peer support intervention for HIV positive pregnant women and to increase the number of HIV positive pregnant women who disclose their HIV status to at least one person (Peltzer, Ladzani, Mlambo, Majaja, Phaweni, Matseke, Shikwane & Rozani, 2010). In support of the PMTCT programme, studies have shown that peer support programmes, such as the mothers2mothers programme that have been introduced to provide education and psychosocial support to HIV-positive pregnant women and new mothers. This programme assists in enabling women to access existing healthcare services. Also, mothers and babies are followed up to ensure that they receive appropriate medical care after delivery (Besser, 2006). Moreover, a study conducted by Futterman et al. (2010) found that combining mothers2mothers peer mentoring and providing culturally-appropriate cognitive behavioural

interventions motivated adherence to PMTCT services and increased HIV knowledge which was primarily indicated by the understanding of PMTCT terminology. Rotheram-Borus et al. (2011) conducted a cluster randomized controlled trial and found that peer mentors significantly increase the support of women living with HIV. Shetty et al. (2008) found that it is feasible to implement a PMTCT programme through the assistance of peer counsellors. As such, they found that peer counsellors are instrumental with regard to the follow-up of infants born to HIV positive mothers.

- **Infant feeding intervention in PMTCT as a PMTCT utilisation facilitator**

This intervention aimed to implement a family-based model of nutrition education in order to empower families (mothers, fathers, caretakers/grandparents) to give nutritious foods to their infants for optimal nutritional status (Peltzer, Ladzani, Mlambo, Majaja, Phaweni, Matseke, Shikwane & Rozani, 2010). Both HIV-positive and negative mothers were selected at the clinics for the family-based intervention (nutrition education). Laar and Govender (2011) conducted a study in Ghana on factors that influence infant feeding choice. Their study recommended that infant feeding interventions focus on socio-economic, cultural and familial barriers when dealing with infant feeding intervention for HIV positive mothers.

- **Combination of community and healthcare systems intervention as a PMTCT utilisation facilitator**

In Zambia, strategies to increase the uptake of PMTCT included factors such as expansion of access to healthcare services, providing daily HIV testing, human resource improvement, HIV stigma interventions, improvement of male involvement in PMTCT, patient confidentiality interventions and providing the follow-up of mother-infant pairs (Torpey et al., 2010). In Uganda, they found that community mobilisation, which involved intervention by people with HIV in PMTCT programmes, could prevent vertical HIV transmission (Mburu, Iorpenda & Muwanga, 2012). Moreover, a review conducted by Marcos et al. (2012), recommended a combination of community oriented interventions to assist with the prevention of vertical transmission. Similarly, Doherty, Chopra, Nsibande and Mngoma, (2009) found that PMTCT coverage in South Africa could be greatly enhanced by the continuous data quality improvement approach. This could be done by the simple

participatory assessment of the PMTCT work done. At the same time, this would encourage the PMTCT managers to improve the coverage of the PMTCT services.

- **Family involvement as a PMTCT utilisation facilitator**

Betancourt et al. (2010) showed that family-centered approached could greatly assist with the prevention of MTCT of HIV. An important component of the family-centered approach is thought to be that of grandmother involvement in the PMTCT programme. In South African societies, grandparents have always played a significant role of raising children (Penn et al., 2010). Grandmothers' involvement comes from the tradition of family togetherness. Foster (2000) indicates that traditionally, the extended family has the responsibility of providing support to other family members without any limits. This implies that life in most traditional societies is characterized by togetherness, which is portrayed by unity between family members (Mudavanhu, 2008). This kind of unity is also portrayed by grandmothers who play the caregiver role for family members. Grandmothers' role of care giving is sometimes not filled by choice, as they are often obliged to care for their grandchildren who are orphaned as a result of HIV (Mudavanhu, 2008). Although grandmothers enjoy caring for their grandchildren, the situation now differs from previous years, as caregiving is now required due to the HIV pandemic which is killing their daughters and children. The grandmothers also play a significant role in illness, whereby sick children are often sent away to be with their grandmothers (Barratt & Penn, 2009). Grandmothers also play a significant role in cases where their children migrate to cities in search of employment (Barratt & Penn, 2009).

Grandmothers have been thought to be the most appropriate caregivers for their grandchildren, because of their experience in raising children. It is thought that they would apply similar measures as the children's parents when disciplining their grandchildren (Safman, 2004). In concurrence with other studies, the grandmothers are mostly recognised for their child-caring responsibility (Boon et al., 2009). Caring for grandchildren is a common practice in South African families. Chen, Liu and Mair (2011) suggested that the common practice of children caring for their parents (filial piety) has now changed into a reciprocal behaviour of grandparents caring for the children. Grandmothers are also considered to be flexible, because they are not occupied by work-related duties. In carrying for their grandchildren, grandmothers also play the role of financial supporter of their

grandchildren. They end up suffering emotional strain from seeing their grandchildren sick and bear the financial burden, because they feel obliged to provide for their grandchildren (Orb & Davey, 2005; Barratt & Penn, 2009).

In Penn et al. (2010), grandmothers were also suggested to be "family and reproductive monitors" (p.13). Hence, in cases where their sons could not impregnate their daughters-in-law, grandmothers would advise their daughters-in-law to fall pregnant by another man in order for the child to carry the family name. In this study, they also explicitly highlighted that grandmothers play the role of shielding families from extra-marital affairs. Grandmothers are also responsible for passing their indigenous knowledge and cultural values to the younger generation (USAID, 2011). Besides the various soul-touching roles played by grandmothers in families, it should be noted that grandmothers also seem to contribute to the practice of mixed feeding, which affect PMTCT effectiveness. Mixed feeding could lead the HIV infection of the child born to an HIV positive mother. Thus, grandmothers' involvement could assist in changing such infant feeding practices.

Numerous programmes exist which are aimed at assisting grandmothers who are caregivers to cope with HIV. For instance, there has been an initiative called Grandmothers against Poverty and AIDS (GAPA) which is aimed at empowering older women from poverty stricken areas to be better equipped to deal with the stresses of HIV (Budaza, Brodrick & Barry, 2012). The GAPA model assists in dealing with grandmothers' needs that occur as a result of being affected by HIV/AIDS. The focus area of this model is on education and providing psychosocial support to grandmothers. The education aspect covers the following areas: HIV/AIDS, human rights, food gardening, business skills, bereavement, parenting skills etc. The psychosocial aspect focuses on the emotional support of grandmothers affected by AIDS. The GAPA model encourages on-going learning and teaching of peers in order to heal the damage caused by the consequences of HIV. This model established that the local clinics are not providing services geared towards grandmothers, and hence, it began to establish health clubs which assist in providing care and nursing for fellow GAPA members. GAPA also provides aftercare services for young school children. Another initiative is the "Go-go grannies" project in Alexandra Township, South Africa, which strengthens the capacity of the grandmothers in dealing with orphaned grandchildren (UNAIDS, 2004). The grandmothers are involved in caring for their own children whom

when they die, they leave their grandchildren. After this, the grandmothers become the caregivers of the children (UNAIDS, 2004).

A study conducted in Uganda showed the negative effects on caregiving caused by HIV (Kamya & Poindexter, 2009). In this study, they found that grandmothers complained of economic destitution, difficulties in caring for the orphans due to poor health and a general concern about what would happen to the orphaned children should they die. This study demonstrated the effects of poverty on grandmothers who are caregivers. Grandmothers' views of the PMTCT programme are thus important in providing an understanding of how they can be involved on the programme. The next section discusses PMTCT HIV disclosure as another PMTCT adherence facilitator.

2.10.4.3 HIV disclosure as PMTCT utilisation facilitator

HIV disclosure is central to the PMTCT programme, because it facilitates adherence to the PMTCT cascade. It is also crucial for the reduction of HIV stigma (Obermeyer, Baijal & Pegurri, 2011). HIV disclosure is considered a proxy measure for stigma (Nyblade et al., 2006). As such, Kasenga (2010) found that women in his study did not disclose HIV status because they feared being discriminated against and labelled as HIV positive. Benefits of HIV disclosure have been noted. For instance, Bii, Otieno-Nyunya, Siika and Rotich (2008) found that partner disclosure leads to better adherence to the infant feeding protocol (Bii et al., 2008). Falnes et al. (2011) found that HIV disclosure leads to increased social support by family members.

- **Understanding when and why HIV disclosure is necessary in the context of PMTCT**

According to Chandoir, Fisher and Simoni (2011), HIV disclosure is one of the most challenging psychosocial factors facing people living with HIV. It is also a critical aspect for people living with a concealable stigmatised identity such as HIV. HIV disclosure is seen as a complex and multifaceted process which is on-going (Chandoir et al., 2011). Zea et al. (2005) showed that HIV disclosure can affect the individual psycho-behavioural well-being, (Broman-Fulks et al., 2007), health (Ullrich, Lutgendorf & Stapleton, 2003), dyadic

outcomes, such as intimacy and trust (Laurenceau, Barrett & Rovina, 2005), and social contextual outcomes, such as cultural stigma (Corrigan, 2005).

Chandoir et al. (2011) proposed a Disclosure Process Model (DPM), which is a framework for understanding when and why HIV self-disclosure is important for people living with a concealable stigmatised disease, such HIV. According to Chandoir and Fisher (2010), disclosing a concealable stigmatised identity could be both harmful and beneficial. Most of the time, the reaction of the confidant determines this outcome.

From the DPM framework point of view, disclosure refers to a situation whereby the discloser verbally reveals a concealable identity which was not previously known by the confidant (Chandoir et al., 2011). DPM sees disclosure as a process which is on-going, because people living with a concealable stigmatised identity found themselves having to disclose their status time and again. It is concerned with communication attributes that happen when the discloser reveals the unknown information to the confidant. The communication attributes involve focusing on the depth, breadth, duration, emotional content of the information and on the confidant's reaction. Thus, reasons that motivate disclosure of a concealable stigmatised identity to others determine when disclosure might be beneficial. According to Chandoir et al. (2011), there are two methods of disclosing a concealable disease, namely the approach goal and the avoidance goal. The approach goal refers to the rewarding or the desired end state after disclosing the unknown news, whereas avoidance goals refer to the undesired or punishing end state after disclosing the unknown news to the confidant. The approach goal as opposed to the avoidance goal brings new insight into the disclosure process. Greene, Derlega, Yep and Petronio (2003) speak about 'testing the waters', for instance, when using the approach goal, the discloser would broach the topic in a round-about way to test the confidant's reaction. People, therefore, disclose for approach goals because they hope for a rewarding/ desired end.

Chandoir and Fisher (2010) found that the people with the avoidance goal are less likely to disclose their concealable identity to others. This is due to fears of rejection and anticipated stigma (Chandoir, 2009). Whilst the approach goals is focused on moving closer to the end point of a relationship, avoidance goals move away from the end point to avoid having conflict or a relationship break-up because of disclosure. Even in the context of PMTCT, the narratives of HIV positive women, grandmothers and HCPs provides an understanding of

factors leading to the approach goal and the avoidance goal of HIV disclosure. Using the framework of Chandoir et al. (2011) the current study creates an opportunity to explore the rural context of HIV disclosure barriers and facilitators.

- **HIV positive women's coping strategies for living with HIV**

There are two types of coping strategies for dealing with stressful situation, namely active and avoidant coping. Active coping refers to behavioural and cognitive attempts to deal with the stressful situation (Lazarus & Folkman, 1984). These authors define avoidant coping as behavioural and cognitive attempts to avoid dealing with a stressful situation. In the context of PMTCT, avoidant coping is presented by factors affecting the utilisation of PMTCT services. This could be in the form of denial, distraction and disengagement from health seeking behaviour. Avoidance coping has been noted to have negative psychosocial and health outcomes, such as an increase in HIV symptoms (Chida & Vedhara (2009), increased symptoms of psychological distress (Kraaij, Van der Veek, Garnefski, Schroevers, Witlox, & Maes, 2008) and non -adherence to ARVs (Vervoort, Grypdonck, de Grauwe, Hoepelman & Borieffs, 2009). Thus, understanding HIV coping strategies is also important for understanding the lived experience of PMTCT in a rural context.

2.10.4.4 Healthcare facility preference as a PMTCT utilisation facilitator

The success of the PMTCT programme depends on patient visits to the healthcare facility in order to receive services. There are some studies that have shown that facilities that offer HIV services which are highly satisfactory for caregivers exist. For example, Watermeyer (2012) study found that factors that drove caregivers to the clinic included satisfaction with services and care, staff treatment and improvement of the child's health. In this study, the following healthcare system recommendations were made in ensuring adequate healthcare facility usage: space improvements, on-going health education, improved provider-patient communication strategies and clinic leadership strengthening. In line with these suggestions, PMTCT facilitators have shown that there are numerous ongoing initiatives to improve the quality of the PMTCT programme in all spheres, ranging from the service recipient level to the policy level. Obtaining the narratives of the lived experiences of PMTCT from the recipients of the PMTCT services is crucial in understanding the facilitating and inhibiting factors to utilisation of the PMTCT programme. Another way of understanding adherence to

PMTCT services is through the narratives of people receiving and providing PMTCT services. Therefore, the next chapter discusses the importance of utilising narrative research in the context of PMTCT, as a way of understanding PMTCT programme needs.

2.11 Conclusion

This Chapter provided a global overview of HIV which was compared with statistics specific to HIV in South Africa. It showed that although PMTCT only started in 2005 in the area of study, it is following most of the PMTCT cascade processes. The literature review points mostly to PMTCT facilitators and inhibitors. The PMTCT facilitators are mostly related to HIV disclosure and community's views about healthcare services utilisation. The PMTCT inhibitors are related to individual, cultural and health factors. The DPM framework was reviewed to understand what disclosure is, as well as when and why disclosure occurs.

CHAPTER 3
THEORETICAL FRAMEWORK

3.1 Introduction

When conducting scientific research, it is crucial to provide a theory or theories which underpin the study, as a basis for understanding the set of beliefs that guide the study. This Chapter thus provides a detailed discussion of the theoretical paradigm used to investigate and understand the intersecting PMTCT narratives of HIV positive women, grandmothers and HCPs participating in and providing PMTCT services. It does this by showing a "net that premises the researcher's ontological (nature of reality in terms of what needs to be known), epistemological (scope and the reliability of knowledge) and methodological views (research process)" of the study (Guba, 1990, p. 17; Fenstermacher, 1994). There are four interpretive paradigms that shape qualitative research namely: positivist and post-positivist, constructivist- interpretive, critical (Marxist, emancipatory), and feminist- post-structuralist (Denzin & Lincoln, 1994). The current study builds on a social constructionist point of view, which is described in full later on in this Chapter. The study also used a phenomenological approach to understand the lived experience of the participants.

To fully comprehend the theoretical underpinnings of the study, this Chapter starts by giving an overview of the phenomenological approach used in the study and also links it to the social construction of reality. This Chapter also discusses the phenomenological approach in relation to multiple realities and gives a description of lived experience. It then provides an overview of social constructionism by linking it to sub-topics, such as social constructionism and reality, social construction of knowledge and social constructionism and language. Finally, this Chapter shows how the narrative approach is positioned within the social constructionism paradigm.

3.2 Phenomenological approach

3.2.1 Understanding phenomenology

Phenomenology originated from the European philosophy of Husserl (1962/ 1970). It rejects modernism and positivism approaches which are concerned with the generation of knowledge

through science. Phenomenology is concerned with individual and personal experiences of human beings and the provision of meaning for the lived experience (Creswell, 1998). It is more focused on the following aspects of the human being: "perceptions or meanings, attitudes, beliefs, emotions and feelings" (Denscombe, 2003, p. 97) about the lived experience. Patton (2002) argues that phenomenology aims to "gain a deeper understanding of the nature or meaning of daily experiences" (p. 104). It requires obtaining detailed descriptions of an experience which involves looking at how the phenomenon is "perceived, described, felt, judged, remembered and sense making" (Patton, 2002, p. 104). Denscombe (2003) further highlights that phenomenology is concerned with how life is experienced by those involved in an experience, without necessarily giving the cause or reason of why things are happening that way It comes in the form of a retrospective reflection of an experience that has already passed (Patton, 2002). In the current study, emphasis is placed on understanding the lived experience of being an HIV positive woman who participates in the PMTCT programme. Moreover, a further aim of the study is to explore grandmothers' views of the PMTCT programme and also understand the lived experiences of the HCPs providing the PMTCT programme services. Obtaining such lived experiences provides an understanding of "attitudes, beliefs, emotions and feelings" (Denscombe, 2003, p.97).

Patton (2002) describes two important concepts in phenomenology which includes describing an experience and interpreting it. Describing an experience means one has lived it and interpreting an experience gives an understanding of an experience. For the people who have a lived experience, the only reality they know is of the experience they have gone through and what it means. According to Denscombe (2003), phenomenology concentrates on "seeing things through the eyes of others" (p. 98) who have been through a particular experience and, as such, it is concerned with presenting the original human experience as it is. It does not analyse or interpret the lived experience of how things happened, but instead, it is concerned with presenting the direct and original lived experience as told by the people who experienced it. Consciousness is central to the lived experience as it is a place where meanings are generated regardless of whether they are "real or fictional" (Patton, 2002: p. 104). Hence, the direct and original lived experiences for the HIV positive women participating in the PMTCT programme entails the following: decision-making for utilising antenatal care services, HIV testing and diagnosis experiences, ingestion of AZT prophylaxis for protecting the child from being infected, infant HIV PCR testing experiences, experiences of HIV disclosure to family/ partners etc. For the grandmothers in this study, the direct and

original lived experiences involved experiences of looking after the HIV infected women and their feelings about the impact of HIV. With regard to the HCPs, the direct and original lived experience involved providing the PMTCT services to the HIV positive women and the observation of different behaviours which accept or reject PMTCT utilisation.

3.2.2 Phenomenology and social construction of reality

The social construction of reality implies that phenomenology makes sense of the world by dealing with the ways in which reality is interpreted socially (Denscombe, 2003). For instance, it argues that the meanings of events are interpreted socially and not individually. Similarly, Huberman and Miles (2002) argued that phenomenology studies the world in which people live. From a phenomenological point of view, this means that people are seen as "creative interpreters of events" which happen in their own world (Denscombe, 2003, p. 99). They are the "agents" who actively participate in interpreting their own experiences (p. 99). As a result, the interpretations of their own lived experiences "bring order in their existence" (Denscombe, 2003, p. 99). This suggests that the individual's ability to interpret their own lived experiences gives them a reason to exist. Thus, the social construction of reality from the phenomenological perspective shows that the lack of social interpretation of events would actually create chaos in the lives of people, as there would be no basis for social life (Denscombe, 2003). In the current study, the social construction of reality involved looking at how antenatal care timing, the HIV testing process, infant feeding and male involvement in the PMTCT programme are interpreted through the eyes of the people in the community.

3.2.3 Phenomenology and multiple realities

Phenomenology is also concerned with multiple realities which are socially constructed. It strongly rejects the idea that there is "one universal reality" (Denscombe, 2003, p. 100). It thus ascertains that there are multiple realities that vary from culture to culture (Denscombe, 2003). Hence, the meaning of a lived experience could be interpreted in "different ways, by different people, in different times under different circumstances" (Denscombe, 2003, p. 100). In the current study, the multiple realities could exist regarding the issue of infant feeding as portrayed by the HIV positive women, the grandmothers and the HCPs. The issue of male involvement in the PMTCT programme could also have multiple realities amongst

the three groups of participants in this study. Multiple realities amongst participants may also exist in terms of antenatal and postnatal care health seeking behaviours. Such multiple views reflect multiple realities of how an experience (such as going through PMTCT, providing its services) can be interpreted by different people in different times and under different circumstances. The next section discusses social constructionism which facilitated understanding of the nature of reality for the participants in the current study.

3.2.4 Description of phenomenology and lived experience

Denscombe (2003) suggested that phenomenologists are concerned with giving the detailed description of a lived experience instead of trying to analyse it into something that is not original. This implies that a detailed lived experience involves providing rich, in-depth descriptions of human experience which are not altered. Such in-depth, rich descriptions may also include information that seems contradictory to the researcher, but should not be changed because it would not reflect the true lived experience. In the current study, the health seeking behaviours were influenced by the social meanings attached to them. The interviews conducted in the current study showed the rich descriptions of the lived experience of participating in the PMTCT programme, as well as the assistance provided to HIV positive women by grandmothers and service provision offered by the HCPs.

3.3 Social constructionism worldview

3.3.1 Understanding social constructionism

Social constructionism came into existence in an attempt to understand the nature of reality. It posits that there is no "single truth" but that there are "multiple truths" although not equal in the construction of reality (Merriam, 2009, p. 10). Social constructionism study multiple realities by looking at how they influence the lives of those who constructed the reality in relation to others they interact with (Patton, 2002). The origins of social constructionism can be traced back to the discipline of Sociology. It emerged during the period of post-modernism which emerged in the 1950s and 1960s within the subjects of "architecture, literary criticism and sociology" (Kvale, 1992, p. 1). Post-modern philosophy does not belong to any single thinker but rather to a "multitude of thinkers" who focused on many aspects of post-modern condition (Kvale, 1992, p. 2). It is also viewed as a family of theories which have elements

of similarity (Slife and William, 1995). Burr (1995) acknowledged that the social constructionists Berger and Luckmann (1967) highly influenced the development of social constructionism. Social constructionism has also been traced back to Mead (1934) who founded symbolic interactionism, which argues that meanings are created through language and that thoughts assist to interpret symbols. The terms constructivism and constructionism are often used interchangeably by social constructionists (see e.g. Lincoln & Guba, 1985 and Gergen, 1985). However, Young and Colin (2004) explain that constructivism refers to individual mental constructions of the world of experience through cognitive processes, whereas social constructionism focuses on the social aspect of an experience. Therefore, the study is built on the same principle of looking at the social aspects of being on the PMTCT programme.

Providing a definition for social constructionism is not easy as this paradigm denotes varying positions of different writers from different disciplines, who do not seem to have anything in common, except that they share some resemblance by virtue of falling under the same category (Burr, 1995). Simply put, the term social construction places emphasis on the dependence on "social selves" in the creation of reality or belief (Boghossian, 2001). This means that reality (including healthcare utilisation) is created by social interactions that people have in a given context.

The social constructionists also believe that in order to understand reality, it is important to know that "knowledge and truth are constructed; they are not just some sort of invention which is made through the minds of people or through what they articulate (Denzin & Lincoln, 1994). Guba and Lincoln (1989) also allude that social construction means that the observer cannot be disentangled from the observed while inquiring constructions. According to them, the findings of a study are an outcome of a construction process. Hence, constructions are part of individual minds which are later articulated, they do not just exist without a person. The explanation below clearly explains the view expressed by Guba and Lincoln (1989, p. 143.)

> "Constructions do not exist outside of the person who create and hold them; they are not part of some 'objective' world that exists apart from their constructors" (P. 143)

Guba and Lincoln (1989) further offer properties of constructions which assist in the ceration of reality:

a) Constructions try to make sense by offering the interpretation of experience and they are mostly "self-sustaining and self-renewing" (p.71). This means that constructions are integral to interpreting the reality of an experience. This is because 'multiple truths' are always acceptable in the creation of reality. Constructions can also renew and sustain themselves.
b) "Quality of construction depends on the scope of the available information to the constructor and the ability to deal with that information" (p.71)
c) "Constructions are often shared and some of those shared are disciplined constructions". This means that there is "collective and systematic attempts to common agreements" about the constructions (p.71)
d) Some constructions are "labelled as malconstruction because they are regarded as being incomplete, simplistic, uninformed, internally inconsistent or derived by an inadequate methodology". (p.143)
e) "Judgment or malconstruction could only be given with reference to a paradigm under which the constructor is operating". Hence, "the condition is framework specific." A construction could thus be judged by looking at the relevant theoretical paradigm such as social constructionism (p.143)
f) Constructions are challenged when new conflicting information emerges from the people who are going through that particular experience.

In the current study, the properties of constructions described above by Guba and Lincoln (1989) imply that women's reality of participating in the PMTCT programme allows them to interpret the lived experience of being in the programme. Even with health-related experiences, constructions of experience could change as new shared constructions are created. In the current study, a change of constructions could be brought about through the discovery of information which was not known before, or was taken for granted by the community. The new conflicting information may include educating the community on healthy living that may go against their social and cultural norms.

3.3.2 Social constructionism and reality

In order to understand social construction and social constructionism, Patton (2002: 96) argue that it is important to raise questions which will provide an understanding of reality in a particular setting. Such questions will focus on the following:

- "How is reality constructed?"
- "What are the perceptions of reality?"
- "What is regarded as truths, beliefs, explanations and worldview?"
- "What are the consequences of behaviour construction of an individual in relation to those they interact with?"

Social constructionism examines the "relationship to reality by dealing with constructive processes in approaching it" (Flick 2009, p. 69). It emphasises that reality is constructed and, thus, meanings are constructed based on experience (Simon, 1996). According to the constructionists, reality is explained in two ways, "pluralistic and plastic". "Pluralistic" in relation to reality means that the reality can be expressed in varying symbols and languages whilst plastic in relation to reality means that a reality can be resized and reshaped to fit the purposeful human actions" (Denzin & Lincoln, 1994, p. 125). In Shkedi (2005), Merriam (1998) importantly stated that:

> "If reality is constructed and the knower and the known are inseparable as it is emphasized by the social constructionist, then all the research participants values are relevant." (p. 6).

Gergen's theory of reality argues that social constructionists believe that the "world that people create in the process of social exchange is a reality" (Gergen, 1985, p. 267). Moreover, the world is understood as consisting of "social articrafts" and products of historically situated interchanges between people (p. 267). Therefore, it is impossible to understand the reality without focusing on the context and interactions between people. In addition to this, Patton (2002) indicates that reality is constructed by focusing on cultural and linguistic factors. This suggests that objective reality it is governed by historical and social elements which shapes it up. Although social constructionism accepts multiple realities in an attempt to understand the nature of reality, historical and cultural factors needs to be treated with caution especially in the context of PMTCT. For instance, infant feeding behaviour which is detrimental to the infants' well-being might need to be "reshaped and resized"

(Denzin & Lincoln, 1994, p. 125) to be inline with the Department of health infant feeding guidelines.

The current qualitative research was guided by the social constructionism paradigm which looks at the "subjective meaning of the experience by linking it to the social world" (Creswell, 2007, p. 20). Social constructivist worldview is concerned with the individual understanding of the world that he or she lives and works in, in order to understand the specific context in which individuals live (Lincoln & Guba, 2000; Schwandt, 2007; Neuman, 2000; Crotty, 1998). The social construction of reality relies very much on the shared views of a particular situation (Creswell, 2007, p. 20). For instance, "the subjective views and meanings of a particular situation are not associated with individuals but they are interpreted by "interaction with the social world" (Creswell, 2007, p. 20). This suggests that meanings are not directed at individuals but that they are constructed by interaction with others (Creswell, 2007). Individual meanings are also interpreted by looking at "historical and cultural norms" that they operate in (p. 20-21). The social constructionist view focuses on different contexts in which people live and work, in order to get a better understanding of the social factors related to the participants (e.g. cultural factors) which might have motivated them to respond in the way that they did. This allows the researcher to interpret the results based on the participants' own cultural, personal and historical experience (Creswell, 2007). Therefore, reality is understood in terms of shared "understandings, practices, language, culture etc." (Denzin & Lincoln, 2000, p. 197).

Social constructionists argue about the importance of a "world of experience as it is lived and can be felt and be experienced by many" (Denzin & Lincoln, 1994, p. 125). In relating this explanation to the current study, it is suggested that the lived experiences of being an HIV positive woman and participating in the PMTCT programme is felt and experienced by many people in the community, where the participants live. Therefore, the feelings and emotions around it, is what shapes reality. Moreover, the grandmothers' lived experiences of looking after HIV positive women is also felt and experienced by many. Social constructionism tries to understand the lived experience from a point of view of those who have lived the experience "emic" and not from the researcher's point of view (Schwandt in Denzin & Lincoln, 1994, p. 118; Merriam, 2009). Hence, in this study, interest is focused on understanding the lived experience of participating in the PMTCT programme as constructed by the participants who are influenced by the community views on health issues. In this

study, meaning was thus constructed based on the shared experiences of the participants which are influenced by their social contexts. This suggests that although most of the social constructionists conduct textual analysis of experience, they also "immerse themselves in the social context and minds of the participants" in order to understand what they say (Sciarra, 1999, p. 43).

In trying to understand reality, social constructionists never seek to find correlations between variables, as positivist do, but rather study a particular situation in order to allow the events to dictate the way that experience is interpreted. The interest of social constructionists is in "words, actions and records", in order to understand people's contexts and how they construct reality (Patton, 1980, p. 43). In this study, understanding how reality is constructed by focusing on words that participants utter was important in constructing meaning through themes. Social constructionists interpret reality by focusing on what people say about their own worlds (Maykut & Morehouse, 1994).

Social constructionism emphasises the development of broad open-ended questions to allow for the construction of meaning (Creswell, 2008). Crotty (1998) mentioned several assumptions of constructionism, such as:

a) Human beings are responsible for constructing meanings as they are engaging with the world that they are interpreting (p. 42).
b) Historical and social perspectives influence the meaning that individuals construct about phenomena. Researchers construct meaning by first understanding the context or setting in which the experience is taking place. Thus, an interpretation is shaped by the experiences and background (p. 42-43).
c) Generation of meaning is socially influenced by the involvement with the human community (p. 42-43).

3.3.3 Social construction of knowledge

As already indicated, the social constructionists argue that human beings do not just discover knowledge, they construct it. As such, concepts, models and schemes are invented to make sense of experience. This suggests that information keeps on changing based on the new

experiences that emerge (Denzin & Lincoln, 1994, p.126). Schutz (1962) described knowledge from a constructionist point of view as follows:

> "All our knowledge of the world emanates from common sense…which involves constructs of abstractions, generalizations, formalizations and idealizations specific to relevant level of thought organisation" (p. 5)

Maykut and Morehouse (1994) appear to agree with this thought:

> "If knowledge could be divided in parts and examined individually, it follows what the knower understands apart from what he or she is examining. On the other hand, if the knowledge is constructed, then the knower cannot be totally separated from what is known" (p.11).

According to Schutz (1962), knowledge is constructed through selection and structuring. Moreover, knowledge is constructed in the process of "social interchange" (Gergen 1994, pp. 45-50). This implies that knowledge is constructed through the social interactions between people. Burr (1995) argues that knowledge becomes fabricated through social interactions that take place in the community, between people. Therefore, the role of language is important in such relationships. This suggests that knowledge is socially constructed in a communicative practice, as part of the social process of constructing reality. Construction of knowledge elicits varying actions from human beings (Burr, 1995). In the current study, new infant feeding guidelines require action from the HCPs, HIV positive women and grandmothers to enforce messages and adhere to the proper feeding procedures respectively.

In addressing the social construction of knowledge, the social constructionists argue that there is no unique "real world that pre-exists before the human mental activity and human symbolic language" (Bruner, 1986, p. 95). They believe that the mind is active in the construction of knowledge. Social constructionism does not look at the individual minds and cognitive processes. However, it looks at what is said as part of the social construction of meanings and knowledge (Denzin & Lincoln, 1994). According to Gergen (1985, p. 267), knowledge is just one of the many attributes that individuals possess. As such, it is bound to the same processes that characterise human interaction, such as "communication, negotiation, conflict, rhetoric amongst others". Gergen and Gergen (1991) explain it as follows:

> "Accounts of the world…take place within shared systems of intelligibility usually a spoken or written language. These accounts are not viewed as the external expression of the speakers' internal processes (such as cognition, intention) but as an expression of relationships among persons" (p. 78).

3.3.4 Social constructionism and language

Social constructionists focus on the shared generation of meanings that are shaped by other social processes, including language. They posit that one is born into a social and cultural environment which has different contexts that are acquired through language (Burr, 1995). The constructionist emphasises that in order to understand the social world, an interpretation should be provided. Interpretation involves a deep look into the meaning of the language and action of actors. Social constructionists are particularly concerned with knowing and being and not necessarily with method. According to Wolcott (1992), the method gives a full understanding of the purpose of inquiry. Gergen (1986, p. 143) suggested that "there are no independently identifiable, real world referents to which the language of social description are cemented".

Language is seen as a vehicle used for negotiating agreements in the world (Gergen, 2009). The social constructionists depend on two characteristics of language conventions: metaphors and narratives. Metaphor convention suggests that words on their own cannot be compared, therefore, there are no words that reflect the world better than those others. Words are only regarded as metaphors when they are taken out of context of their normal use (Gergen, 2009). Narrative convention suggests that language can be used to narrate events that provide an explanation to facilitate an understanding of what is being said. Narratives assist in the exploration of construction of life issues. Narratives also often attempt to give voice to the unheard and marginalised, by promoting the sharing of first-hand experience (Gergen, 2009). In the current study, language allowed a narration of PMTCT lived experiences by the three groups of participants. Through the use of language, the context of the lived experience is comprehended.

3.4 Narrative approach positioned within the social constructionism paradigm

The narrative inquiry approach was influenced by the social constructionist paradigm, which shows the perspective that meanings from individual experience are explained through

interaction with others (Creswell, 2008). According to Bruner (1985), narratives provide a way of knowing the reality about the world. In agreement with this, Lieblich et al. (1998), argued that narratives openly explore the construction of life issues. Unlike the positivists who claim that narratives are value-free, social constructionists claim that narratives are value-laden. This is because narratives are used as a "heuristic device which allows the ordering of facts in a particular order" (Gudmundsdottir, 1996, p. 296). In the current study, the narration of people's stories (both big and small stories) shows how reality is perceived (Gudmundsdottir, 1996). Narratives are thus an end product which demonstrates what individuals wish for others to know about himself or herself. Narrative inquiry has to do with the reconstruction of a person's experience in relation to the social environment (Clandinin & Connelly, 2000).

Shkedi (2005) mentioned an important point that experiences do not exist on their own. They are experienced temporally and, therefore, are also interpreted in relation to the totality to which they belong. Clandinin and Connelly (2000) suggested that narratives provide quality of structure for an experience. From a social constructionist point of view, narratives are interpretive tools which assist in the way that the world is perceived. This point is clearly explained by Gudmundsdottir, (1995):

> "Narrative functioning always involves interpretation and reinterpretation, the structuring of experience and the act of telling someone something. (p. 29).

Narratives are not "scientific truths as positivists say, they are rather narrative truths" which are not open to proof and "therefore cannot be judged as true or false" (Bruner, 1990, p. 111). According to social constructionist, the 'narrative truth' is shown by giving specific location in space and time (Jovchelovitch & Bauer, 2000). The 'narrative truth' for the current study is shared as a lived experience of participating in the PMTCT programme, supporting those receiving PMTCT services and providing services to those in the programme, which includes sharing the experience from a rural point of view. The 'narrative truth' is told by the participants in terms of how they see or perceive the truth. This truth would include the influence that the surrounding factors have on how participants view it. It is important to note that narratives are an interpretation. They are not straightforward copies of the world (Gudmundsdottir, 1995). The interpretation of a narrative is guided by the paradigm of

analysis. In the case of the current study, narratives are interpreted using the social constructionism paradigm. Another interesting point is that narratives are linked to life. Life has a meaning because it is "lived according to a script" (Widdershoven, 1993, p. 5). Therefore, it provides stories that are lived because they are interpreted within a temporal dimension of past, present and future and within a particular context. In the current study, the lives of participants who are HIV positive assisted them to tell a lived experience of being diagnosed with the HIV disease, disclosing the HIV status and the social constructions of living with HIV while participating in the PMTCT programme.

3.5 Narrative research in the context of PMTCT

3.5.1 The narrative canon

This section provides an overview which serves as a prelude to a broader discussion of narratives of HIV and PMTCT research. The words narration, narrative and narrate originate from Latin background and are often used interchangeably (Jovchelovitch & Bauer, 2000). In studies related to Linguistics, the narrative canon may be traced back to Labov (1972) who had a great influence on the "structure of the narrative" (Georgakopoulou, 2007, p. 31). It is important to note that narratives encompass three aspects: firstly, the structure of a story, secondly, the knowledge of plot and action and thirdly, the skills of constructing a story (Gudmundsdottir, 1996). The desired structure suggests that the quality of a classic narration should be well-structured and that it should have a beginning, middle and an end (Labov, 1972). Similarly, Ochs and Capps (2001) argued that "a plotline that encompasses a beginning, middle, and an end, conveys a particular perspective and is designed for a particular audience who apprehend and shape its meaning" (p. 57).

In accordance with this structure, Labov (1972; 1982); Labov and Waletzky (1967) presented the six common elements of the narrative structure in terms of the following key elements: abstract (summary of narrative); orientation (time, place, situation, participants); action (sequence of events); evaluation (significance and meaning of action); resolution (what finally happened) and lastly, coda (returns perspective to present). The narrative canon "emanates from the communicative event such as research interviews" (Georgakopoulou, 2007, p. 32) which also focus on "personal, past experience on oral narratives (p. 3).

Similarly, Burke (1945) argued that the narrative structure may be understood by raising the following key questions: what was done (act)? When or where (scene)? By whom (agent) was it done? How was it done (agency)? And why was it done (purpose)? Moreover, Gee (1986) argued that narrative structure involves looking at how the story is presented in terms of the oral features rather than the written representation. The oral presentation of narratives involves focusing on changes in the pitch, pauses and other punctuations. Shifting from the narrative structure, the second and third aspect of narratives focuses on the knowledge and the skills of constructing a story, which provides rich descriptions of human events and thoughts (Carter, 1993). This implies that the focus is on giving prolific narrative accounts of people's stories. The next section discusses the importance of narrative inquiry approach.

3.5.2 Why a narrative inquiry approach

> "Narrative does not belong to any scholarly field, they are interdisciplinary by nature and they assist with data interpretation (Riessman, 1993, p. 217)" and "they require interpretation because they do not speak for themselves" (Personal Narratives Group, 1989a, p. 261).

According to Riessman and Speedy (2007), the field of narrative inquiry has a "realist, modernist, post-modern and constructionism" element which causes scholars to disagree about its origins (p. 428). However, scholars generally concur that stories are the center of people's daily lives, because of their ability to provide an explanation about the past (Riessman & Speedy, 2007). Defining narrative inquiry has brought about considerable disagreement, as shown by literature. As on the above section, Labov (1972) defines narratives as stories about past events which all have common properties. Other scholars see narratives as discrete units with clear beginnings and endings. They all agree that sequence in a narrative is imperative (Cronon, 1992; Polanyi 1985). For Labov and Waletzky (1967), a narrative always poses this question: "and then what happened?" (p. 13). Young (1987) came up with a different view of consequential sequencing and emphasised that the meaning of one event causes another to happen, even though there is no chronological order. Others have argued for thematic sequencing, where they emphasised that a narrative is stitched together by a theme and not necessarily time (Michaels, 1981). Although some believe that narratives are defined in terms of the temporally sequenced plots (Riessman, 1987), they have admitted that stories told in research are rarely clearly bound in a sequence and, therefore, putting them

in a sequence is a complex interpretive process (Riessman, 1993). The narratives for the current study are, therefore, stitched together by a theme and not time because the lived experiences of the participants did not follow a bound sequence.

Literature has shown that there is no compulsory narrative theory and that there is a great deal of conceptual diversity (Langellier, 1989; Martin, 1986; Mishler, 1986; Riessman, 1993). Narratives are seen as both the "phenomena and the method" (Connelly & Clandinin, 1990, p. 2). Hence, this implies that narrative inquiry "as a methodology looks at varying views of the phenomenon under study" (Connelly & Clandinin, 2006, p. 375). The current study employed a narrative research approach (falling under the social constructionism view), whereby the participants shared their stories of participating and rendering PMTCT programme services. The current study utilised the narrative inquiry method because it always "explores the phenomena of experiences rather than doing comparative analysis" (Clandinin & Connelly, 2000, p. 128). Moreover, this method allowed the participants to freely narrate their experiences of a phenomenon. It focused on people's individual life stories (Marshall & Rossman, 1995) of being in the PMTCT programme, supporting and providing PMTCT services to those in the programme. The narrative inquiry approach was used because it gives an opportunity to study a situation according to culture specific settings, and attempts to make sense of phenomena in terms of the meaning people that bring to them (Denzin & Lincoln, 2000). It also assumes that people live "storied lives" and, therefore, "telling and retelling those stories" provides a better understanding of an individual (Marshall and Rossman 1995, p. 115).

One of the advantages of this method is that the narrative inquirer keeps the "narrative view of experience in the fore front as their methodological frame of analysis" (Clandinin & Connelly, 2000, p. 128). Clandinin and Connelly (2000, p. 20) also describe narrative inquiry as a "way of understanding the experience" or "the study of understanding experience as a story" (Clandinin, et al., 2006). Importantly, narratives require interpretation because they are a representation of experience (Riessman, 1993). Within the qualitative framework, there are many approaches which are not necessarily in a narrative form but are in the form of question and answer exchanges (Riessman, 1993). This study is built on the premise that an experience makes sense when it is cast in a narrative form (Bruner, 1990; Gee, 1985; Mishler, 1986). Therefore, narrative inquiry is more than just narrating stories, it is also about understanding the experience (Clandinin et al., 2006; Paokeng & Rosiek, 2003;

Polkinghorne, 1988). The relevance of the use of the narrative approach in the current study stems from the fact that story telling is a means of gaining insight of a person's life (Greenhalgh & Calman, 2006; Riessman, 2008). The aim of narrative research is to come as close as possible to the meaning of subjective experience (Riessman, 1993).

Participants narrate stories using a variety of narrative genres (Riessman, 1993). For instance, there are "habitual narratives whereby events happen over and again without peak of action" (Riessman, 1993, p. 230). There are also" hypothetical narratives which focus on events that did not happen" (p. 230). Lastly, there are "topic-centered narratives which focus on snapshots of the past that are thematically linked (p. 230). Therefore genres of narratives are representations that the narrators choose (Riessman, 1993). The next section discusses the broad functions of narratives and also highlights the use of narratives as an interpretive tool.

3.5.3 Narrative functions

- **Narrative as human expression**

According to Riessman (1993), autobiographical narratives occur when individuals tell stories about their lives, hence, human beings are essentially story-telling animals (Connelly & Clandinin, 1988, 1990; Lieblich, Tuval-Mashiach, & Zilber, 1998). According to Widdershoven, (1993), people carry out various activities in a narrative way, which is seen as a human expression. For example, people night dream in narratives, day dream in narratives, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, learn and hate in a narrative way. Similarly, Grimmet and Macknnon (1992) argued that human life, social life and all human interactions encompass constructing and reconstructing personal and social stories. Such constructions and reconstructions would also be prominent in the lived experiences of the participants in this study. As such, the narration of the lived experience would involve remembering how PMTCT services were rendered to them, how they felt about being HIV positive (hope, despair, fear) and having negative and positive feelings about the PMTCT programme (doubt, angry, criticize, hate, hope) etc. Therefore narratives are human expressions that reflect a lived experience of a particular issue, and they are developed through a dialectical relationship between self and society (Howarth, 2006; Jovchelovitch, 2007). Human expressions assist in developing, constructing or

reconstructing personal and social stories. Thus, narratives create an environment for human expressions which are constructed socially and personally.

Narratives are not just a way of describing events, they are also a part of the events (Carr, 1986). This implies that narratives allow for a better interpretation of language, as events are described using language. In the study of Linguistics, narratives have been one of the major areas of research (Ozyildurm, 2009). Moreover, Polkinghorne (1988) arguesd that language brings reality to human experience. This suggests that a language is the device to bring to the fore, experience in a narrative manner. Human beings react to certain issues in life on the basis of meanings attached to language. Language is responsible for the meaning provision of a narrative. Therefore, understanding human behaviour means understanding the language used (Seidman, 1991). Jorgensen (1989) indicated that in order to understand reality and social world, language and culture are crucial for conveying meaning. This point is clarified by Spradley (1979):

> "Language is more than a means of communication about reality. It is a tool for constructing reality. Different languages create and express different realities. They categorise experience in different ways of thinking and perceiving."
>
> Spradley (1979, p.17)

People use language to communicate their lived experience which they convey through narration. This gives them the ability to make decisions about how to use language to communicate their experiences. In the current study, the narration of participants' lived experiences of being in the PMTCT programme, supporting those in the PMTCT programme and providing services to HIV positive women, reflects how the PMTCT programme is interpreted. The narration is, therefore, executed in a way that is desired by the participants. According to Seidman (1991) every word used by participants in a story shows an understanding of an issue. Therefore the participants' narratives of behaviour towards utilisation or non-utilisation of PMTCT shows how they perceive and understand it.

- **Narrative as an interpretive tool in health research**

There is ample literature available on narrative research methods to understand and describe health related issues (Overcrash, 2003). Narratives have been found useful in studying

quality of life (Bowling, 1995; Gill & Feistein, 1994 and Leplege, 1997). In the healthcare setting, narratives are used to investigate how patients feel about a certain practice or treatment (Overcrash, 2003). In the current study, narratives have been used to understand the experiences of HIV positive women regarding participation in PMTCT together with grandmothers and healthcare providers' views of the programme. According to Gale, Mitchell, Garand and Wesner (2003), narratives are subjective personal experiences told to others as stories, and have played a crucial role in all areas of healthcare for a long time. The use of narrative research allowed subjective stories regarding the utilisation of the PMTCT services, which includes experience of HIV testing and diagnosis, HIV disclosure experiences and the general dynamics that participants experienced in the context of PMTCT. The next section deals with HIV narratives in the context of PMTCT.

3.5.4 Importance of narratives in HIV research in South Africa

The narrative of HIV positive women provide an opportunity for voicing feelings about being HIV positive and being in the PMTCT programme, whilst the grandmothers' and HCP's narratives demonstrates their views on the PMTCT programme. This suggests that the narratives provide an opportunity for these women's voices to be heard, although they had been previously silenced, suppressed and sidelined (Gergen, 1997; Reinharz, 1994). Narratives are thus seen as a powerful tool of expression for these voiceless women because they become empowered by expressing their lived experiences (Gergen, 1997). Narratives are also social constructions of reality, which is constructed through language. As summarized in the section below, there is ample research that has been conducted on HIV in South Africa, including topics such as: HIV lived experiences and narratives of poor women, narratives of PMTCT programme failures, narratives of teaching about HIV in schools, media narratives of HIV and masculinity, narratives of truth and reconciliation, narratives of HIV disclosure and infant feeding narratives.

3.5.5 Narratives of the HIV lived experience

A lived experience is better described through narratives. Soskolne (2003) conducted a study on narrative analysis of life stories of women living with HIV in Khayelitsha and found that HIV/AIDS was socially constructed as a death sentence. The women in this study incorporated the experiences of the HIV illness into their accounts and shared how HIV

disease was framed. A lived experience of HIV has also been shared by Savage (2010) in Higgins and Norton, who is an AIDS activist. He indicated that the narratives of HIV are important in order to understand the experiences of those living with the disease. Furthermore, Savage (2010) argued that as a person openly living with HIV, he sees a lived experience as a form of healing for the person narrating the story of living with HIV and for those who have "misconceptions, misunderstandings, fears and stigmatization about the disease" (p. 30). He argues that freedom of fear comes from disclosing one's HIV status. Stadler, Delany and Mntambo (2008) conducted a qualitative study in Soweto, South Africa, to obtain women's perceptions and experiences of HIV prevention trials. In this study they found the key dominating narrative themes to be related to "AIDS fatalism and denial" (p. 197). Participants in this study conceptualised AIDS as part of reality in their lives and as something that cannot be controlled by an individual. Their perceptions of HIV/AIDS encouraged non-testing behaviour. This is in line with the findings of Balshem (1991) who demonstrated the repercussion of fatalism as avoidance. Brandt (2008) conducted a narrative analysis of the poor and HIV infected South African women. In this study, she found that disruption of poor women's lives was associated with their initial HIV diagnosis. The narratives from the study further revealed that a "denial-based coping" strategy was used and as a result, the HIV and misunderstanding about HIV was marginalised. The women's experiences were mostly filtered through poverty which dominated their narratives. Other similar studies which addressed the narratives of poor, HIV infected women in South Africa include that by Soskolne (2003). In another study conducted by Rohleder and Gibson (2006), HIV positive, poor women found themselves in a different position, of constructing a positive identity regardless of their negative views about living with HIV. These studies on narratives of HIV provide an understanding of the context of a lived experience, which is also important in understanding the context of PMTCT. The next section discusses some of the existing literature on PMTCT narratives.

3.5.6 Narratives on factors affecting the PMTCT programme

Numerous studies have been conducted in South Africa showing the failures of PMTCT. Laher et al (2012) found that the reasons for vertical transmission were "inadequate PMTCT ARV regimens" (p. 93) which were against the national guidelines, mothers' refusal of treatment; preterm delivery, delayed antenatal care attendance, fear of stigma and challenges with infant AZT administration and infant feeding. Varga and Brookes (2008a) conducted

narrative research which examined the intersection of socio-cultural and programmatic factors in relation to PMTCT service usage. In this study, they found that power differences determined PMTCT service utilisation. For instance, the counsellor's profile that included traits of poor education, impoverishment and at high risk for HIV transmission facilitated a non-threatening interaction. These finding suggested that initial contact with counsellors could facilitate adherence to PMTCT cascade activities such as HIV testing (Varga & Brookes, 2008a). The results of this study further revealed high levels of "psycho emotional stress" by nurse counsellors, was due to high HIV counselling loads (p. 798). This study showed that the use of narratives assists in developing case study stories of adolescents. Narrative methodology thus allows for the narration of a story from the point of decision making regarding HIV testing to post-enrolment in the PMTCT programme. The study described above further revealed perceived ethical misconduct by the healthcare workers. The adolescents in the study saw healthcare workers as gossipers, because they divulged the HIV positive status of the adolescents. The youth participants in this study opted to attend antenatal care services in other clinics where they were not known or opted to delay the initiation of antenatal care. Contracting HIV was also portrayed as a death sentence by the nurses in this study. The narratives in this study assisted in identifying some factors that show the facilitators and inhibitors of PMTCT enrollment. The next section provides a summary of narratives in relation to HIV education.

3.5.7 Narratives of teaching about HIV

Baxen (2008) used a narrative approach to understand life histories of teaching about sexuality and HIV in schools. The use of narratives in the teaching context allows for an understanding of "how and in what way the teachers understand themselves in relation to HIV and their work in a classroom" (p. 318). In the context of PMTCT, the participants' lived experiences of being part of the PMTCT programme, are important to understand the areas of capacity building needed in a rural context. The PMTCT programme is for women of all ages, including school going children. The lived experiences of the three groups of participants could provide narratives that are directly linked to teaching about HIV and PMTCT in a rural context.

3.5.8 Narratives of media representations of masculinity and HIV

There is a growing body of literature which explores the relationship between media, narratives and HIV. There has been global research exploring media representations of masculinity and HIV (Gibbs & Jobson, 2011). Newman and Persson (2009) suggested that some media representations of masculinity focus on socially and economically marginalised groups of males such as groups that were at high risk of contracting HIV. The newspapers have been identified as effective in positioning and forming dominant views regarding masculinity issues (Gibbs, 2010; Jacob & Johnson, 2007). Studies have shown that the media is central to collection of narratives about HIV. For instance, Gibbs and Jobson (2011) explored multiple narratives of masculinity which were dominant in the Daily Sun Newspaper in South Africa. This study explored how masculinity narratives enable/ hinder health behaviour in relation to HIV. Gibbs and Jobson (2011) shared community narratives about masculinity which are mostly constructed in public domains. This study found three global masculinity narratives namely: masculinity and work, violence and crime; masculinity and HIV.

In terms of masculinity and work, Gibbs and Jobson (2011) found that media narratives portrayed "men as workers" (p. 177). For instance, men are involved in activities such as "sport, singing, business and entrepreneurship" (p. 177). This suggested that the media portrayed that masculine success stems from working (Gibbs & Jobson, 2011). According to Walker (2005), failure to attain masculine success through work, leads to a masculinity crisis (of not having work). As result, men resort to indulging in risky sexual behaviours (multiple partnerships) as another way of boosting their masculinity and as such, they become at risk of contracting HIV (Hunter, 2005). Regarding masculinity, violence and crime, Gibbs and Jobson (2011) found that media representations show men as being susceptible to death. This study suggested that the media presents men as being violent, and therefore, subjected to violence. Because of the high possibility of death, they engage in risky sexual behaviours which place them at risk of contracting HIV (Gibbs & Jobson, 2011). This study also found that men's narratives of HIV are limited. It thus suggested that the limited masculine narratives on HIV/AIDS, undermines HIV prevention strategies.

Other studies which explored the relationship between media representations of masculinity and HIV/AIDS looked specifically at how the media has constructed male HIV risk groups

(Newman & Persson, 2009). In South Africa, some research has been conducted on how the media represents HIV/AIDS (Campbell & Gibbs, 2008; Gibbs, 2010). Jolly (2010) looked at public narratives of the "Truth and Reconciliation Commission (TRC) in South Africa, whereby community and individual narratives explored gender-based-violence and human rights in the HIV/ AIDS context. The current study also assists in understanding issues pertaining to masculinity issue in the context of PMTCT.

3.5.9 Narratives of HIV disclosure and masculinity

Mfecane (2012) conducted a study on narratives of HIV disclosure and masculity in a South African village and found that HIV disclosure restored men's social respect. The narratives of these men who participated in a support group also showed that HIV disclosure by men elicited a positive response from community and that looking healthy, because of ARV use, facilitated disclosure. This suggests that physical improvement in health is linked to HIV disclosure. Furthermore, a study conducted in South Africa (Dageid, Govender & Gordon, 2012) on masculinity and HIV disclosure among HIV positive heterosexual men indicated that HIV disclosure was influenced by "HIV status acceptance, support by others and having healthy relationships" (p. 925). The narratives in this study suggested that masculinity issues served as an obstacle to HIV disclosure and seeking healthcare services. Another study also argued that the social constructions of masculinity, which portray men as not vulnerable and not emotional, perpetuate their non-health-seeking behaviour (Lynch, Brouard & Visser, 2010). These studies imply the importance of narratives in unpacking issues related to masculinity and HIV.

3.5.10 Infant feeding narratives

Varying concerns regarding infant feeding continue to exist in the countries of SSA. For example, a narrative review conducted in West Africa found that breastfeeding is considered an essential aspect of motherhood, by mothers and the general community (Samuelsen, Norgaard, & Ostergaard, 2012). Another narrative study showed that breastfeeding for the first six months is an acceptable practice and non-breastfeeding in the first months leads to stigmatising behaviour towards mothers (Abiona, Onayade, Ijadunola, Obiajunwa, Aina, & Thairu, 2006). Narratives of infant feeding are an important component of the current study, as they bring into light the perspectives of rural women related to how an infant is supposed

to be fed. Although narratives are important in understanding the lived experiences of women, this study also examined the lived experience beyond the narrative canon, in order to fully understand rural women's experiences of the PMTCT programme. The next section discusses small stories which focus on the context of the lived experience.

3.6 Beyond the narrative canon

3.6.1 Small stories

In trying to understand the lived experiences of HIV positive women participating in the PMTCT programme and the role played by grandmothers and HCPs in relation to PMTCT, the current study looked beyond the narrative canon. This section provides a justification of looking beyond the narrative canon by also concentrating on the other non-canonical, underrepresented narratives, such as small stories. In understanding the origin of the small stories, it is important to begin by defining a small story and continue by providing a summation of prototypical narrative data, called big stories (which mostly represent autobiographical narratives).

3.6.2 Understanding the small story paradigm

The term 'small story' was originally coined by Bamberg (2004a and 2004b) and later adopted by Georgakopoulou, who initially referred to it as "formulations (storylines, on-going narratives)" (Georgakopoulou, 2007, p. 36). Small story research serves as a "new narrative turn with more emphasis on the lived and told experiences" (Georgakopoulou (2007, p. 154). The small story is a framework of narrative and identity analysis (Georgakopoulou, 2007). Rampton (2006) in Georgakopoulou (2007, p. 60) argued that small stories find parallels in late modern theory, which emphasises the importance of the "communication contexts" in which the stories occur. Small stories assume that "language performs specific action in specific environments and therefore is part of social practices and it is shaped by them" (Georgakopoulou, 2013, p. 6; Bauman & Briggs 1990; Hanks, 1996). Small stories allow for the shifting of the analytical lens from the well-structured canonical stories to the "small, hidden, unofficial stories that are either in the fringes of official or non-official sites" (Georgakopoulou, 2007, p. 60). Hence, the small stories genre refers to the data that is between the naturally occurring data and research interview. For this reason small

stories are termed naturalistic research conversations (Sools, 2012). The above explanations suggest that small stories study narratives in contexts, rather than studying the narratives as text. The small stories assist in unpacking the context in which events occur. Culture and community guided the analysis of context in this study (Georgakopoulou, 2006). The small story paradigm aims to showcase the importance of the interactional paradigm of talk in narrative analysis (Georgakopoulou, 2007). One of the distinctive features of small stories is that they are literally small and that their structure is different from the traditional narrative canon, because they do not always have a beginning, middle and an end. Moreover, because they are interactional small stories that happen in daily conversations, they might not have significant meaning, that is they may "denote absolutely nothing" (Georgakopoulou, 2007). This implies that small stories may be easily excluded from narrative analysis because they are small in nature. However, their smallness provides the context in which they are taking place.

Small stories depart from the conventional formalities of the narrative canon which thrives on having "one active teller as opposed to multiple tellers, highly tellable account as opposed to low tellability, detachment from surrounding activity at the expense of embeddedness in local context, [and] closed temporal and causal order over the open-endedness" (Ochs & Capps, 2001, p. 20). Thus, the introduction of the small story in narrative inquiry points to a shift in focus from the structural properties of narrative to the process of narration (Sools, 2012).

Typically, small stories were dismissed in narrative inquiry. They were regarded as non-stories and appeared to be a nuisance, especially as a result of bad interviewing. They were regarded as incoherent descriptions (Georgakopoulou, (2007). As a result, only big stories were catered for. Big stories refer to the prototypical kind of stories that show the past experience of non-shared events (Georgakopoulou, 2006). They point to the prototypical data collection method used in narrative research, whereby there is minimal researcher interruption during the interview that leads to autobiographical stories. The big stories focus mainly on what the story is about, whereas small stories focus on how the story is told (Riessman, 2008). Big stories fit the description of narrative quality provided by Ochs and Capps (2001):

> "A coherent temporal progression of events that could be ordered for rhetorical purposes and be located within the past time and place. They must also consist

> of a plotline that has a beginning, middle and end. It should convey a certain perception to a certain group of audience who would capture and shape its meaning."
>
> Ochs and Capps (2001, p. 57)

This suggests that big stories are structured in a way that reflect the past time and place. They are also organised according to plotline, which follows the sequence of beginning, middle and end, whilst small stories look beyond narrative structure. Ochs and Capps (2001, p. 19) argued that stories that arise spontaneously in ordinary conversation are not structured neatly. On the contrary, Georgakopoulou (2007) argued that small stories from ordinary conversations which are interactional provide the context of the story. Therefore, the current study also focused on small stories to understand the context of a lived experience of participating in the PMTCT programme.

3.6.3 Types of small stories

Georgakopoulou (2007) suggested that there are four types of small stories. This means that non-canonical narratives could be analysed according to these small story types. The proposed four types reflect the kinds of stories that are normally told in daily conversation. They are part of a trajectory of interactions rather than a free-standing, self-contained unit (Georgakopoulou (2007).

Table 3.1 Small story types

#	Small story type	Description
1	Stories to be told/ future telling stories	Stories are deferred for future telling
2	Breaking news	Involves telling stories right away as they are unfolding
3	Future projections of storytelling.	This type of story involves telling future projections. It involves a lot of planning of actions for events.
4	Shared stories.	This refers to the retelling of stories, be it a past or future projection story

3.6.4 Small story significance

In each and every narrative research interview, there are stories which are more or less connected to the narrative canon. The main reason for focusing on small stories in this study was to locate the non-canonical narrative data provided by the participants in order to make the subjectivities and contexts visible Ryan (2008) portrayed in interactional exchanges. Hence, focusing on small stories allowed the researcher to gain insight into the subjective views and positions of the participants (Ryan, 2008). One of the advantages of the use of the non-canonical narratives (small story) is that they report events that show some kind of immediacy, a relevant past or near future. They also assist in establishing the link between past, previous and future interactions.

Moreover, the small stories provide an opportunity to look at the small details of the discourse which could easily be missed out by the analytic lens which mainly focuses on fully fledged stories (Georgakopoulou, 2007). Therefore, the small story analysis allows for the inclusion of data that is regarded as redundant (Bamberg, 2004b). It covers day-to-day conversations which are the main mode of communication. It is the small elements of the story which bring about the bigger picture of an experience. Small stories show how people tell their personal past event experience in a conversation.

3.7 Conclusion

Chapter Three presented the theoretical paradigm guiding the current study. It explained that the use of the phenomenological approach provides a clear understanding of participants' lived experiences of participating in the PMTCT programme. The study is conducted from a social constructionism point of view, which looks at the subjective meaning of experience by linking it to the outside world. This study also discussed the narrative approach by positioning it within the social constructionism paradigm. The use of canonical and non-canonical narratives is important in capturing the true lived experience of service users and service providers.

CHAPTER 4
RESEARCH METHODOLOGY

4.1 Introduction

This Chapter provides a bird's eye view of how this study was conducted. It provides a full corpus of information on the processes followed to carry out the study and gives a comprehensive description of the research methodology employed. Furthermore, this Chapter outlines the study design, sampling method, participants selection procedure and data collection technique employed. The ethical considerations in relation to data collection for the study are also discussed. The approaches to data analysis that were utilised in this study (thematic analysis and small story analysis) have also been outlined. It is on the basis of these discussions that a conclusion is drawn at the end of this Chapter.

4.2 Theoretical underpinning of the research methodology used

- **Why a qualitative research method?**

The current study utilised a qualitative research approach guided by the social constructionism paradigm. As discussed in Chapter Three, it employed the narrative research strategy as the method of research inquiry. This study used a qualitative research framework because it is a naturalistic, interpretative approach which is concerned with the meaning of how people understand the world and the experience they encounter in that world (Merriam, 2009). It mainly assists in describing, exploring and explaining the phenomena under study (Marshall & Rossman, 1995; Silverman, 2010). It also explores in-depth information about the opinions, experiences and feelings of individuals who are producing subjective data (Hancock, 1998).

Qualitative research was deemed appropriate for the current study because its focal point is on the "socially constructed nature of reality" (Denzin & Lincoln, 1994, p. 4). It focuses primarily on exploring the "relationship between the researcher and what he or she is studying as well as the context which shape the inquiry" (Denzin & Lincoln, 1994, p. 4). Exploration and understanding of HIV positive women's lived experiences of participating in the PMTCT of HIV programme, healthcare experiences of providing PMTCT services and

grandmothers' views of PMTCT showed the social constructions that participants produced about the nature of the reality and the context that they live in. Nelson, Treicher and Grossberg (1992) define qualitative research as:

> "An inter-disciplinary, trans-disciplinary and sometimes counter-disciplinary field. It crosscuts the humanities and the social and physical sciences. Therefore, it is many things at the same time. It is multi-paradigmatic in focus. Its practitioners are sensitive to the value of the multi-method approach. They are committed to the naturalistic perspective and to the interpretive understanding of human experience" (p. 2)

The above definition shows that qualitative research is accommodative to many other disciplines and that it consists of many theoretical paradigms which offer interpretive solutions to social and human problems. Qualitative research encompasses a variety of methods which attempt to understand social phenomena (Brewer & Hunter, 1989). For instance, it uses research methods or approaches such as participant observations, in-depth-interviews, focus group discussions etc. (Creswell, 2008). It also utilises multiple techniques such as "ethnomethodology, phenomenology, hermeneutics, feminism, deconstruction, ethnographies etc." (Nelson et al., 1992, p. 2 in Denzin & Lincoln, 1994, pp. 3-4).

The use of qualitative research for this study was advantageous in that it enabled the researcher to understand the views of participants through the interviews and observations carried out during data collection (Denzin & Lincoln, 1994). In other words, the researcher was able to examine the everyday life constraints of participants and obtain rich descriptions of PMTCT articulated in the data. It produced invaluable information for understanding the phenomena in terms of how HIV as a disease and PMTCT as a programme are socially constructed. As such, the "aspects of human behaviour" regarding the determinants of health and sickness were revealed (Ulin, Robinson, Tolley, 2005, p. 6). This suggests that qualitative research leads to new research questions which assist in understanding why phenomenona happen the way they do (Ulin et al., 2005). It could thus be deduced that qualitative research always "adds new dimension to the on-going search for answers" (Ulin et al., 2005, p. 6). It assists in "building theories, concepts or hypothesis" instead of deductively developing hypothesis to be tested as it is done in positivist research (Ulin et al., 2005, p. 5). The next section gives a description of the setting in which the study took place.

4.3 Description of study setting

The study was conducted in the Nkangala district of Mpumalanga Province which is ranked the 3rd most rural province in South Africa, with 60.9% of its population living in rural areas where 86.7% of households have access to water (IDP Nkangala District Municipality, 2011). Nkangala district has a population of 1 308129 people and an HIV prevalence of 32.1% (National Department of Health, South Africa, 2013 and Statistics South Africa, 2012). Nkangala district is at the economic hub of Mpumalanga Province and is rich in minerals and natural resources. The district's economy is dominated by electricity, manufacturing and mining. These sectors are followed by community services, trade, finance, transport, agriculture and construction (IDP Nkangala District Municipality, 2011). Figure 4.1 below shows that Nkangala District is made up of the following six sub-districts: Delmas, Dr J.S. Moroka, Emalahleni, Emakhazeni, Steve Tshwete, and Thembisile. The current study was conducted in Dr J.S. Moroka sub-district. Below is a map showing where the six sub-districts are geographically situated:

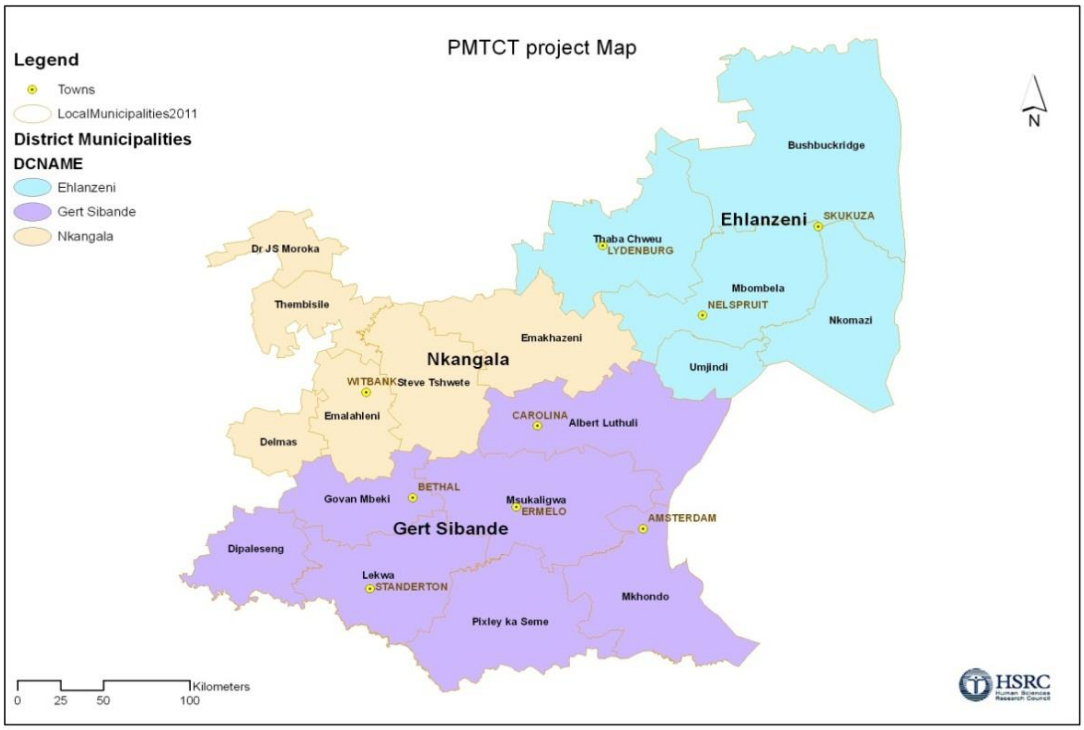


Figure 4.1 Geographical map of Nkangala District Municipality and its sub-districts (Source: Map developed by HSRC GIS)

4.4 Healthcare facility location and services provided

The study was conducted at the three healthcare facilities (two health centres and one hospital) of the Mpumalanga Province, which fall under the jurisdiction of the Dr JS Moroka sub-district. The researcher chose to conduct the study at the healthcare facilities of the Dr JS Moroka sub-district, because of the groundwork that had already been laid (Glesne, 2011) during the implementation of the PMTCT interventions by the Human Sciences Research Council (HSRC). Also the situational analysis conducted by the HSRC in 2010 (Peltzer, Ladzani, Mlambo, Majaja, Phaweni, Matseke, Shikwane & Rozani, 2010) showed a high prevalence of late attendance of antenatal care by the pregnant women in this area. The distance between the two healthcare centers is approximately 20kms and the hospital is situated between the two. Below is information about each healthcare facility:

Table 4.1 Healthcare facility information

Healthcare facility information	**CHC A**	**CHC B**	**Hospital**
Number of supervisor visits per month	Once	Once	Once1
PMTCT staff members	6	13	10
Number of doctor's visits per month	Once	Twice	N/A
Clinics with 2 or more lay Counsellors	Yes	Yes	Yes
Clinics have a counselling room	Yes	No dedicated counselling rooms, converted consulting room	Yes
Rooms that are private or with layout conducive to HIV testing	No	No	Yes
Services provided by the clinic	Antenatal care Postnatal care (immunization) Chronic diseases Mental illnesses Pap smears etc	Antenatal care Postnatal care (immunization) Chronic diseases Mental illnesses Deliveries Pap smears etc ARV initiation	Maternity services ARV provision Referrals to PHC

Healthcare facility information	CHC A	CHC B	Hospital
Days for facility services **Monday** **Tuesday** **Wednesday** **Thursday** **Friday**	Family planning Chronic illnesses Antenatal care Postnatal care Collection of PCR test results and TB sputum results	Family planning Antenatal care Chronic illnesses Treatment issue Postnatal care	
Working hours	8 hours	24 hours	24 hours

4.5 Access to study setting

The healthcare facilities where the study was conducted were in an "open/ public setting where access to community members is freely available" (Silverman, 2010, p. 203). The researcher used "overt research" access which involved informing participants about the study and obtaining their agreement through the healthcare professionals (Silverman, 2010, p. 203; Marshall & Rossman, 2006). Access to the healthcare facilities was made easy by the researcher's previous involvement in a study which entailed implementing a HSRC PMTCT infant follow-up intervention in some of the healthcare facilities falling under the jurisdiction of the Dr JS Moroka sub-district. Steps that were taken as part of gaining entry to the study site included introducing the study to the healthcare professionals. Topics that were discussed during site visit included, amongst others, reasons for choosing the site, activities to implement during data collection, emphasis on non-disruptiveness of the study and reporting of results and benefits of the study (Bogdan & Biklen, 1992). The peer counsellor's role of recruiting study participants and taking notes during data collection was also accentuated by the researcher.

4.6 Familiarity with the site

The researcher has been working for the HSRC for five years in a unit which deals with HIV, sexually transmitted infections and TB (HAST) related projects. The PMTCT project at the HSRC entitled: "Programme to improve the implementation of PMTCT services in Mpumalanga Province" was led by the researcher. The project was first implemented in the

Gert Sibande district and was later implemented in the Nkangala district. In the Gert Sibande district, the researcher managed a PMTCT family based intervention which aimed to (i) encourage early participation of pregnant women in the PMTCT programme (ii) emphasise HIV primary prevention messages to HIV negative women (iii) encourage male partner involvement in the PMTCT programme (iv) encourage family member involvement in the PMTCT programme. Through this intervention, a large number of pregnant women who never went to the clinics for antenatal care services were recruited to start attending antenatal care services early. Their partners and other family members were also tested for HIV. Nkangala district is where a PMTCT intervention with a special focus on infant follow-up for babies born to HIV positive mothers was undertaken. This project aimed to reduce the number of children infected with HIV as a result of the lack of proper follow-up. It is in the interest of the researcher, with her wealth of experience in social surveys in Mpumalanga healthcare facilities, to conduct these types of studies as in the process, local experience is gained. As a result of previous experience in managing PMTCT projects in the area of study, the researcher authored and co-authored eight articles (relating to the PMTCT services in the two districts) which were published in peer reviewed journals (**See Appendix A**).

4.7 Study design

A narrative qualitative research design was used to conduct this study. Data were collected using semi-structured interviews which are commonly used in narrative research (Murray, 2008). The interview method assists with understanding the experience of other people and the meaning that they attach to their experiences (Seidman, 1991). Interviewing is not simply about questioning and providing answers, it is about understanding the experience together with its meaning (Seidman, 1991). The telling of a story is a meaning-making process (Seidman, 1991, p. 1). In the current study, the interviews were more focused on the details of experience. This meant that participants had to construct details of the experience (Seidman, 1991)

4.8 Sampling and study procedure

Using a purposive sampling procedure, two PMTCT community health centres (CHCs) and one hospital were selected to recruit women participating in the PMTCT programme,

grandmothers and HCPS (Patton, 2002). Purposive sampling is defined as a sampling method in which participants are chosen based on particular features of the study (Strydom & Delport, 2002). It allows the researcher to select relevant, rich cases which provide in-depth information (Patton, 2002). Women were recruited at the CHCs, during antenatal and postnatal care services (at 3 days visit post-delivery, at six weeks during infant HIV PCR testing and during infant HIV PCR result collection). The PMTCT clients who came from the catchment areas surrounding the two local primary healthcare facilities in the Dr J.S. Moroka sub-district participated in the study. Four focus group discussions (FGDs) were also conducted with grandmothers who came to the two CHCs for their monthly check-ups. Healthcare providers from the three healthcare facilities (two CHCs and one hospital) also participated in the study.

4.8.1 Inclusion and exclusion criteria for the HIV positive women

Participants were eligible to be part of the study if they were HIV positive women aged 18 years and above. The women aged 17 years and below could not participate in the study since they would need parental consent before participating. Only women coming for their second antenatal care or subsequent antenatal and postnatal care visits could be included. The reason for this was because women were required to share their experience of the previous healthcare visits in order for the PMTCT experiences of HIV positive women to be comprehensively realised.

4.8.2 Data collection

4.8.2.1 Individual narrative interviews with HIV positive women

In total, the sample for this study consisted of 66 participants who were divided into three groups: 29 HIV positive women, 32 grandmothers and 5 HCPs (see figure 4.2 below). With regard to the first group of participants, 31 women were recruited to participate in the study based on their HIV positive status. Of the 31, only 29 women agreed to be interviewed. Of the remaining two women, one could not participate due to language challenges, as she only spoke non-native language (Shona, from Zimbabwe). The other participant was in a hurry to do household chores. In order to elicit information about what these women understood and how they made decisions to participate in the PMTCT programme, semi-structured interviews were conducted with the five categoriess of women who were at different stages

and at different points within the PMTCT programme (see Figure 4.2). Conducting individual interviews were relevant for the HIV positive women because of confidentiality issues around their HIV positive status. Individual interviews also allowed them to freely share their experiences without any fear of stigmatization. Due to the nature of the study, individual interviews allowed the HIV positive women to freely narrate their journeys of being on the PMTCT programme. The HIV positive women were recruited by the peer counsellor during the antenatal or postnatal care PMTCT services. The interviews took approximately one hour per participant. All the interview sessions were scheduled to coincide with processes in the PMTCT programme that were offered at the healthcare facilities. The interview schedule followed women through their experience of the PMTCT programme and health services at each stage, in order to examine the changing meaning of PMTCT in relation to self, family and community.

4.8.2.2 Focus Group Discussions (FGDs) with grandmothers

The second phase involved conducting FGDs with grandmothers. In order to get more insight into the lay understanding of the PMTCT programme, the researcher conducted four FGDs with grandmothers who came to the healthcare facility for monthly chronic illness check-ups. For confidentiality purposes and to ensure stigma avoidance, the grandmothers were not directly related to the HIV positive women who were interviewed. Hence, their HIV statuses were not obtained, as the researcher was only interested in getting their views of the PMTCT programme. They were randomly chosen during the clinic visits to participate in the FGDs. The FGDs consisted of 6-10 participants, in order to allow participants' to express their wider norms, values and opinions (Ulin et al., 2005). The FGDs lasted for 1-2 hours, to allow for longer discussion, as the subject was intense. This method discouraged early leavers and late joiners in the group (Morgan, 1997).

The FGD was employed to get more information that could not be easily obtained by individual narrative interviews (Welman, Kruger & Michell, 2007; Morgan, 1988). Using FGDs for grandmothers instead of indepth interviews helped the researcher to understand the social context and explore what a group of grandmothers knew about HIV (Richie & Lewis, 2003). The FGDs further allowed grandmothers to freely share information collectively on the cultural views of infant feeding and the general understanding of the PMTCT programme (Ulin et al., 2005) without any fear of stigmatisation. The FGDs were also used to "validate

the data" that were collected from the other groups of participants to promote "data triangulation" (Creswell, 1998, pp. 201-203). Focus group discussions are useful in getting varying and fresh opinions from a group of participants all at once. This is clearly pointed out by a sociologist, Blumer (1969) who stated that:

> "A small number of…individuals who are acute observers and who are well informed…are brought together as a discussion and resource group, is more valuable many times over than a representative sample" (p. 41).

The inclusion of grandmothers in the current study was necessitated by the central role that grandparents have always played in their respective families (Penn et al, 2010). Grandmothers have played a central role in bringing up children and caring for sick children (Penn et al, 2010) especially in the era of the HIV pandemic. Forrest et al. (2003) indicated that grandmothers have been regarded as knowledgeable about the illnesses and the traditional treatment that they might require. In particular, maternal grandmothers are known for caring for sick children who are then sent back to their parents when they are in good health (Barratt & Penn, 2009).

Grandmothers' involvement was also important in the current study in determining their knowledge of PMTCT and in understanding the critical areas of intervention that are needed for grandmothers, as they play a pivotal role within their families. The HIV pandemic in South Africa has left many children orphaned. It is for this reason that the current study (especially the FGDs) allowed grandmothers to shed some light on their experiences of dealing with children and grandchildren who are HIV positive. Obtaining grandmothers' views on infant feeding in the context of non-curable diseases like HIV was also of interest.

4.8.2.3 Individual narrative interviews with healthcare providers

The third phase of data collection involved conducting in-depth narrative interviews with the five health care professionals at the three healthcare facilities (two interviews at each of the CHCs and one interview at the hospital). Due to the PMTCT study being conducted at different sites, it was convenient to conduct individual interviews instead of FGDs. The HCPs individual interviews allowed them to share their individual experiences of providing

PMTCT services in a rural context. It was also done to assure trustworthiness of the data collected from HIV positive patients and grandmothers'.

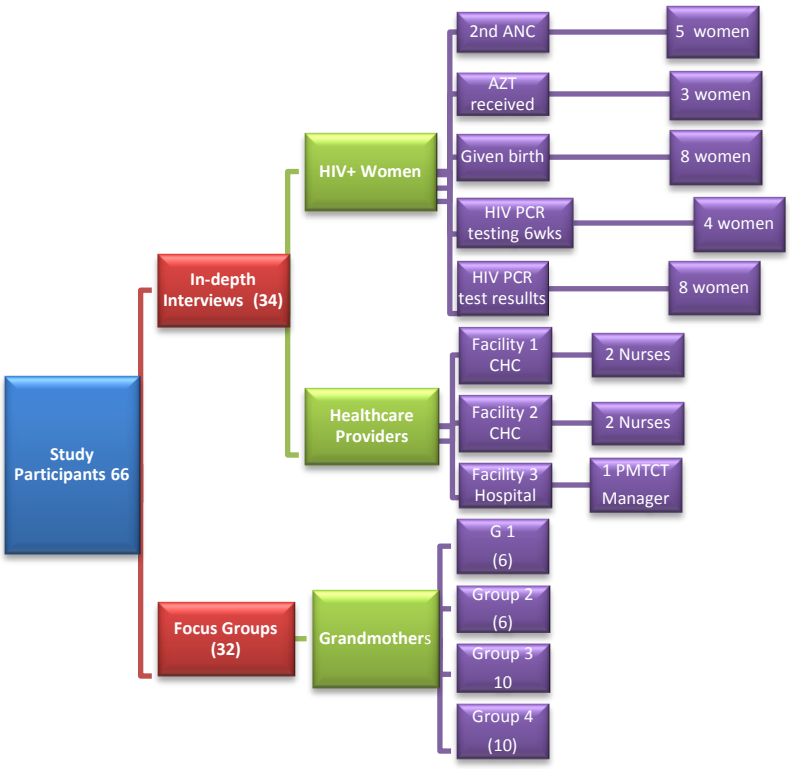


Figure 4.2 Study participants

4.8.3 Participants' demographic characteristics

4.8.3.1 Demographic characteristics of the HIV positive women

Table 4.2 below shows the demographic characteristics of the HIV positive women who participated in the study. Individual interviews were conducted with the five categories of women, who were at different points of the PMTCT programme. The categories were as follows: women at the 2nd antenatal care visit (5 women), pregnant women on AZT (3 women), women who had just given birth (8 women), women at the stage of infant HIV PCR testing or waiting for infant HIV PCR test results (5 women) and women who had received infant PCR test results (8 women). In terms of marital status, table 4.2 shows that most women were single, with the exception of two who were married and one who was divorced. The ages of the participants ranged from 18-43 years. Most of the participants had a high school educational qualification. The lowest educational level achieved was grade 4 and the highest level was a tertiary (post matric) qualification. Most of the participants were native speakers of the Setswana language, with just less than a handful being speakers of the Sepedi

language. Table 4.2 also shows that most of the participants were unemployed and the majority of them had more than one child. A few participants (eight) were on ART for life treatment.

Table 4.2 HIV positive women demographic characteristics

# of Participants	Type of PMTCT service	Sex	Age	Marital status	Education	Language	Employment status	# of children	On treatment
1	2nd antenatal care attendance	Female	22	Single	Grade 11	Setswana	Unemployed	No children	No
2	2nd antenatal care attendance	Female	19	Single	Grade 12	Setswana	Unemployed	No children	No
3	2nd antenatal care attendance	Female	27	Single	Grade 10	Setswana	Unemployed	2 children	No
4	2nd antenatal care attendance	Female	18	Single	Grade 9	Setswana	Unemployed	No children	No
5	2nd antenatal care attendance	Female	27	Single	Grade 12	Setswana	Unemployed	2 children	Yes
6	Pregnant woman on AZT	Female	32	Single	Grade 10	Setswana	Unemployed	1 Child	Yes
7	Pregnant woman on AZT	Female	30	Single	Grade 12	Setswana	Unemployed	1 Child	Yes
8	Pregnant woman on AZT	Female	33	Single	Grade 11	Setswana	Unemployed	2 children	Yes
9	Mother who had just given birth	Female	41	Divorced	Grade 12	Sepedi	Unemployed	5 children	No
10	Mother who had just given birth	Female	39	Single	Grade 4	Setswana	Unemployed	6 children	No
11	Mother who had just given birth	Female	24	Single	Grade 12	Setswana	Unemployed	1 Child	No
12	Mother who had just given birth	Female	21	Single	Grade 11	Setswana	mployed	1 Child	No
13	Mother who had just given birth	Female	43	Single	Grade 5	Setswana	Unemployed	4 children	No
14	Mother who had just given birth	Female	26	Single	Grade 9	Setswana	Unemployed	2 children	No
15	Mother who had just given birth	Female	21	Single	Grade 12	Setswana	Unemployed	1 Child	No
16	Mother who had just given birth	Female	36	Married	Grade 11	Setswana	Unemployed	1 Child	No
17	Infant HIV PCR testing/ Waiting for infant HIV PCR test results	Female	23	Single	Grade 9	Setswana	Unemployed	2 children	Yes
18	Infant HIV PCR testing/ Waiting for infant HIV PCR test results	Female	24	Single	Grade 8	Setswana	Unemployed	1 Child	No
19	Infant HIV PCR testing/ Waiting for infant HIV PCR test results	Female	25	Single	Tertiary	Setswana	Unemployed	3 children	Yes
20	Infant HIV PCR testing/ Waiting for infant HIV PCR test results	Female	30	Single	Grade 11	Setswana	Unemployed	2 Child	No
21	Infant HIV PCR testing/ Waiting for infant HIV PCR test results	Female	26	Single	Grade 11	Setswana	Unemployed	3 children	No
22	Infant HIV PCR test results received	Female	25	Single	Grade 9	Setswana	Employed	2 children	Yes
23	Infant HIV PCR test results received	Female	26	Single	Grade 8	Sepedi	Unemployed	2 children	
24	Infant HIV PCR test results received	Female	35	Single	Grade 9	Setswana	Unemployed	3 children	Yes
25	Infant HIV PCR test results received	Female	33	Single	Grade 11	Sepedi	Unemployed	3 Children	No
26	Infant HIV PCR test results received	Female	28	Married	Grade 7	Setswana	Unemployed	3 Children	No
27	Infant HIV PCR test results received	Female	23	Single	Tertiary	Setswana	Unemployed	1 Child	No
28	Infant HIV PCR test results received	Female	43	Single	Grade 11	Sepedi	Unemployed	6 Children	No
29	Infant HIV PCR test results received	Female	26	Single	Tertiary	Setswana	Employed	3 children	Yes

4.8.3.2 Demographic characteristics of grandmothers

Table 4.3 presents the demographic characteristics of the grandmothers who participated in the FGDs. In total, four FGDs were conducted, each having a varying number of the participants. Group one and two had six participants each, while group three and four had ten members each. The number of participants in each group was determined by the availability of grandmothers during the time of the FGDs. Table 4.2 further shows that the ages of the grandmothers in the study ranged from 40-74 years. In terms of the grandmothers' educational qualifications, just over a handful had no schooling background, whilst the rest had achieved secondary school qualifications (grade 8-12). The number of grandchildren of each grandmother ranged from 1-15.

Table 4.3 Grandmothers' demographic characteristics

Grandmother FGDs	Total # of participants	Age Range	Education	Pensioner/ non-pensioner	# of grandchildren (Range)
Group 1	6	40-74 years	No schooling=2 Primary=1 Secondary= 3	Pensioner=2 Non-pensioner= 4	1-6
Group 2	6	57-73	No schooling=1 Primary=2 Secondary= 3	Pensioner=5 Non-pensioner= 1	1-9
Group 3	10	45-73 years	No schooling=1 Primary=2 Secondary= 7	Pensioner= 2 Non-pensioner= 8	1-12
Group 4	10	52-81 years	No schooling=2 Primary=4 Secondary= 4	Pensioner= 7 Non-pensioner= 3	1-15

4.8.3.3 Demographic characteristics of HCPs

Table 4.4 portrays the demographic characteristics of the HCPs, who participated in individual interviews. In total, five HCPs were interviewed to gain understanding of their experiences of offering the PMTCT services. The ages of the HCPs varied from 43-56 years and they were all married females. All the HCPs had children, with the total number of children ranging from 1-4. Three HCPs were the managers of the healthcare facility while. The other two HCPs were professional nurses (PN) responsible for the provision of PMTCT services. All HCPs had 2-10 years of PMTCT experience.

Table 4.4 Demographic characteristics of HCPs

Interview #	Age	Gender	Marital status	# of children	Position	PMTCT experience	Language
1	47	Female	Married	3	Facility manager	8	Setswana
2	43	Female	Married	1	Professional Nurse	3	Setswana
3	49	Female	Married	4	Facility manager	10	Setswana
4	51	Female	Married	2	Professional Nurse	2	Setswana
5	56	Female	Married	1	Maternity Manager	5	Setswana

4.8.4 Interview guide

The semi-structured interview questions were used in a flexible way and there was no pre-determined order in which participants had to respond to questions (Merriam, 2009). The participants were probed to elaborate more on the points of interest (Denscombe, 2003). The interview guide ensured coverage of all the relevant topics during the interview (de Vos et al., 2002). The selected interview questions were framed using the processes in the PMTCT cascade, adapted from Marcos et al. (2012). The FGDs guiding questions were generalised to give some of the community opinions on the PMTCT programme. In the current study, the semi-structured interviews yielded narratives which were in the form of small story and big story narratives. The semi-structured questions for each group of participants are provided below:

Table 4.5 Interview guide

HIV positive women	Grandmothers	Healthcare Providers
1. REPRODUCTIVE HISTORY - Please tell me about how your reproductive history and how do you feel about your current pregnancy (the later part is for pregnant women) - How does your family feel about your current pregnancy? 2. ANTENATAL CARE & HIV TESTING - Please tell me how do you feel about your HIV positive diagnosis? - Can you tell me about your experience of the first antenatal care visit to the clinic to date? - What do women in your community understand about the importance of antenatal care and HIV testing? - What do women in your community say about the	1. What do women in your community understand about PMTCT? 2. How do you feel about the PMTCT programme? 3. If your daughter or daughter in law was found to be HIV positive while pregnant, how will you feel? 4. What do women in your community think of HIV testing? 5. What do women in your community think of HIV treatment? 6. What do women in your community belief is the right time to start antenatal care? 7. What do women in your community think of home deliveries? 8. What do women in your community understand by ARV adherence?	1. Since the accreditation, how is the PMTCT programme going in general? (What are the challenges?) 2. What, in your view, have been the most important benefits of implementing PMTCT? 3. What challenges (if any) have you had in implementing PMTCT? 4. What steps could be taken to improve the running of the PMTCT programme in this clinic? 5. Why do you think some women do not come for antenatal care. 6. Why do you think some women come late for antenatal care? 7. How can we improve early ANC uptake? How should the community

termination of pregnancy? How do you feel about their views?

3. PMTCT Knowledge and PMTCT Barriers
- What do women in your community say about the PMTCT programme?
- How should the community be involved in the PMTCT programme?
- What do women in your community say about the language used in the PMTCT programme?
- How do you feel about having someone you can talk to at the clinic?
- How do you feel about involving family members on the PMTCT programme?

4. INFANT FEEDING
- What do women in your community say about infant feeding?
- How do you feel about infant feeding method?

5. TREATMENT
- What do people in your community say about ARVs?
- How do you feel about the ARV treatment?
- How do you feel about having friends who are also taking ARVs?

6. SOCIAL SUPPORT AND HIV DISCLOSURE
- How do you feel about participating in a support group?
- How do you feel about HIV disclosure?
- How do you feel about having someone to support and guide you?

9. How do women in your community feel about the language used in the PMTCT programme?
10. How do you feel about involving men on the PMTCT programme?
11. How do you feel about the involvement of grandmothers in the PMTCT programme?
12. How do you feel about infant feeding?
13. How do you feel about HIV disclosure?

be involved? Explain.

8. What are the reasons for dropping out of the PMTCT programme?
9. What do people say about the terminology used in the PMTCT programme?
10. How can PMTCT messages be improved?
11. What impact will the participation of other family members have on the PMTCT programme?
12. What are barriers to ARV non adherence and/or adherence by women?

4.8.5 Selection of research assistants for fieldwork

A total of three HIV positive women working at the CHCs as HIV peer counsellors who had been through the PMTCT programme and openly disclosed their HIV status were recruited as research assistants for the study. The researcher used research assistants who were involved in the HSRC PMTCT infant follow-up intervention implementation. Their role in the current study was to screen and recruit HIV positive women who came to receive prenatal and postnatal services. The research assistants were also responsible for recruiting grandmothers for the study at the healthcare facilities.

The research assistants were recruited based on the following attributes: residing in the community where the study was conducted; knowledge of Setswana or Sepedi languages; knowledge of the area of study; possession of a matric qualification; aged 18 years and above and a good understanding of what the women are going through. The research assistants who were selected were subsequently trained by the researcher on basic HIV/AIDS, PMTCT and the current study content. Because the researcher has vast experience in training community

health workers on basic HIV/AIDS and PMTCT which she did before in the HSRC PMTCT project, she conducted the training herself. Upon training, the research assistants were employed for the duration of the data collection period which lasted for three months between September and November 2011. The research assistants were trained on the following aspects which were critical for the success of the study, as suggested by Bickman & Roy (1998):

- Contact with participants for recruitment. The research assistants were trained on different ways of approaching the participants. For example, having good listening skills, effective dialogue, eye contact, body movements etc.
- Handling participant refusals. The research assistants were trained not to force any participants to be a part of the study. However, they were also trained to avoid outright refusals. They were expected to document participants' reasons for refusals.
- Interview content. This was done to allow the research assistant to be able to explain the objectives of the study to participants.
- Recording the main points of the interview in order to ensure that no data is lost.

4.8.6 Selection of research assistants for transcription

In total, there were two research assistants who were responsible for transcribing the interviews in the original native language and later translating the interview transcript from the native language to English. As with the fieldwork research assistants, the research assistants for transcription were recruited according to the following criteria: aged 18 and above, possession of a post matric qualification, native speaker of local language (Setswana and Sepedi), and a good understanding of English. The research assistants were employed for a period of six months between December 2011 and May 2012 to complete the transcriptions. In order to check the truthfulness of the data, the researcher also transcribed all of the recorded interviews using the original language of the interview and later translated data into English. The researcher monitored the work of the research assistants daily by conducting regular checks of their transcribed work, comparing it with the tape recorded information. In cases where there were disagreements between the data transcribed by the research assistants and the researcher, an effort was made by all the team members to repeatedly listen to the original tape of the recorded information. This allowed the research team to reach consensus on the audio or written data.

4.8.7 Use of an audio-tape

An audio-tape was used to record all of the participants' narrative interviews. The researcher also wrote notes when and where it was felt necessary to do so. The research assistants did the same as a back-up control measure. According to Creswell (2008), notes are taken as a back-up mechanism in case the audio-tape recorder fails to function due to technical reasons. The written notes were also later used to verify some of the recorded information that was not clear.

To ensure the quality of audibility, individual interviews with patients took place in a private room allocated by the healthcare facility manager. The same was done for FGDs with grandmothers, except in one case where a FGD took place outside under a tree due to the lack of space in the healthcare facility. Each participant was given an opportunity to hold the audio-tape whenever they wished to respond to the topic that was discussed. Interviews were conducted between 8am-4pm (healthcare facility hours of operation), three times a week, on healthcare facility antenatal and postnatal care days. The interviews were conducted in Setswana (native language in the area of study), and Sepedi in cases where the participants spoke this language.

4.9 Researchers' Reflexivity

- **Researcher as an insider**

As already indicated on section 4.6 of this Chapter, my insider knowledge comes from prior involvement on the HSRC work which involved implementing PMTCT interventions over a five year period in the area of study. Furthermore, I share similar characteristics with the participants such as language, race and ethnic background. Although originally, I do not come from the area of study, there are similarities between my place of birth (Limpopo province) and the study area. These similarities are in terms of rural setting, poor infrastructure, poor roads etc. As an insider, I had greater understanding of participants' perceptions of healthcare use and their culture. My insider role was mostly known by the healthcare providers whom I have worked with during the implementation of the HSRC PMTCT interventions. As such, during data collection phase, I shared my biography with both the HIV positive women and grandmothers to allow them to see some similarities

between myself and them. Part of the biography involved sharing with the participants my original place of birth, age, marital status, number of children, employment and where I currently reside. Sharing my biographical data was touching, as it involved highlighting how my parents were affected by the World War II, and had to vacate from their original abode. Due to the minimal age difference between myself and some of the participants, most HIV positive women felt comfortable and could relate with me as equals. Also sharing the information about where I grew up, made them to see me as coming from a similar situation as theirs. The same biographic data was shared with the grandmothers. The grandmothers were very much interested in my ethnic background and geographical home districts, because it seemed to make them think of their own roots and the eventualities that unfolded when they were getting married, especially related to cultural practices, for example, dowry (commonly referred to as 'lobola' in the native communities).

After some biographic revelations, the discussion was switched to the topical issues of the study. There were no languages or cultural differences as I could relate and converse well with the participants within their locus. My ability to speak Setswana and Sepedi allowed the participants freedom to communicate their experiences. Fontana and Frey (1994) indicate that the sexual difference of the researcher might have a significant impact on the outcome of the interview. In this study, the interviewed participants, who are all women, were free to relate their practical situations without any fear of doubts that their confidentialities may be compromised as the researcher is also female.

According to Griffith (1998), an insider position also focuses on deeper issues such as having similar beliefs, education, work and lifestyle with the participants. Although I was an insider because of sharing similar geographical setting and language factors, I did not have similar beliefs with participants about healthcare utilisation. I also did not have the same educational level, work experience and lifestyle as the participants. But these differences, made the younger participants (HIV positive women) to believe that coming from an almost similar background such as mine, they also have a potential to have a good life. The challenge that I experienced as a researcher was with regard to over familiarity with the place of study. Instead of getting deeper into issues of poor healthcare utilisation some participants would say "as you know culturally this is acceptable…" The supervision meetings, brown bag meetings with colleagues and post-graduate seminars allowed me to think aloud about my

findings which in turn created a balance between insider and outsider positions that I occupied. Coghlan and Brannick (2005) indicate that this is useful for the doctoral student.

- **Researcher as an outsider**

As an outsider, during the data collection phase, I would arrive at the healthcare facility between seven and eight o'clock in the morning and observe the HIV peer counsellors providing health education on different topics to the patients. For instance the peer counsellor would share her HIV positive status first and then talk about the benefits of HIV testing. The patients were observed to listen attentively, showing a high level of interest in the subject matter, particularly because the peer counsellor publicly disclosed her HIV positive status, with balanced emotions. One morning I witnessed many school girls participating in the health talks. I also observed a young boy listening to the talks. This made me realise that although the messages were meant for pregnant women and mothers, anybody could actually listen to them. In this case, it was a young boy who was perhaps waiting for the girlfriend to be assisted at the clinic.

The HCPs' willingness to be part of the study made the research process even easier. The good relationship that I built with the peer counsellors, also made the recruitment of HIV positive women successful. The peer counsellors at one healthcare facility were observed to attempt unceasingly to recruit grandmothers, who showed a lack of interest in being part of the FGDs. The use of my personal biography encouraged the participants to trust me almost immediately, and as a result, they seemed to feel free to discuss their experiences. As an outsider, during the interviews, I encountered HIV positive participants who seemed generally comfortable with describing their experiences. However, some participants were noted to be a bit reserved. This had been anticipated, as some of the participants had been diagnosed as HIV positive as recently as at their previous healthcare visit. The different personalities of the participants seemed to influence how each of the participants responded during the interviews.

As an outsider, most participants did not have a problem of me interviewing them. Starting by giving my biographical background helped them to locate my previous and current socio economic status, culture, language and how I might fit in their context. Although I did not find any problems, one participant asked me about my HIV status. I want to admit that as an

'outsider', the question caught me off guard especially because I did not want to provide an answer that would suggest that there is a distinction between myself and the participants. Although I knew very well that I was HIV negative, I found myself struggling to say so without offending the participant who was HIV positive. I decided to phrase my response this way: "For now I am HIV negative…" Although I do not wish to contract HIV in the future, when I said "for now", this response showed that I was not ruling out the future possibility of contracting it. My response made the participant to see me as her equal. At the same time, my response reflected openness and honesty.

4.10 Description of the pilot study

Prior to the actual data collection, the researcher conducted a pilot study in one of the healthcare facilities in the Dr JS Moroka sub-district (which does not form part of the study) with two HIV positive antenatal clients. This was done to ascertain whether the participants would clearly understand the questions posed in the main study. The pilot study was useful as some of the questions were rephrased to yield improved narration by the participants. Through the pilot study, shortcomings in the design of the proposed procedure were addressed before hand. As noted in Shkedi (2005, p. 40), the pilot study assisted with the following:

- "Development of clear research questions"
- "Knowledge of the missing link between what is already known and gaps in literature".
- "It directed the researcher to new body of literature".
- "Technical way of data collection and techniques to be used either when introducing the study or re-phrasing the manner of asking questions".
- Understanding what questions to ask, who to ask, and how and when to interview (Seidman, 1991).

4.11 Ethical considerations and procedure

The researcher was responsible for gaining entry to the site. Ethical clearance to conduct the study was obtained from the University of Witwatersrand (**See Appendix B**) and the Mpumalanga Department of Health **(See Appendix C)**. When at the facility, permission was obtained from the healthcare manager (**See Appendix D).**

4.11.1 Informed consent

All the participants were approached to provide informed consent for participating in the study **(See Appendix E-J)**. Participants had the right to refuse to take part in the study or to withdraw their participation in the study at any stage without any consequences. Participants were told that they may refuse to answer any questions that they were not comfortable answering. The researcher explained and tailored the information on the consent form to the level of the participants in the study (Watermeyer & Penn, 2008).

With regard to the individual interviews, confidentiality and anonymity were strictly adhered to. However, confidentiality could not be guaranteed with the FGDs. This is due to the fact that, although the researcher might promise the participants that all the interview information will be kept confidential, this cannot be guaranteed as information may be divulged by fellow group members. Confidentiality is very much aligned with the human privacy principle (Gregory, 2003). However, van den Hoonard (2002, p. 8), argued that 'promises of confidentiality are easier to make than to keep". This shows that the notion of confidentiality in research is very contentious because it means that information should not be divulged (Wiles, Crow, Heath & Charles, 2006). This is contradictory to what the research does because researchers have a mandate to report the findings (Wiles et al., 2006). In the current study, confidentiality and anonymity meant non-disclosure of participant names when reporting the findings. For the participants in the study it meant non-disclosure of both the discussions that took place during the interviews and the real names of participants who raised particular issues. Therefore, as a precautionary measure, the researcher had a brief discussion about the importance of maintaining confidentiality and anonymity due to the nature of the study prior to commencing the FGDs. Moreover, participants were encouraged to use pseudonyms to protect their real identity. The importance of respect and anonymity was emphasised even at the end of the FGDs. It is, however, worth mentioning that in FGDs for the grandmothers, some grandmothers used their real names due to the fact that the researcher also used her real name. Their real names are not used in this thesis.

4.11.2 Protection of participants

All data presented in this thesis was anonymised. The tape recorded information does not include the names of the participants, except the names of the few grandmothers who

mistakenly mentioned their names during FGD introductions. Transcribed information was number coded to facilitate the organisation and management of the data but no names or other similar identities linking individual participants to the responses they provided were collected. The only place where names appeared was on the informed consent form (**See Appendix E-J)**, indicating participants' agreement to take part in this study. These were kept in a locked filing cabinet, which was kept separate from the interviews and were excluded from the appendices of this study. Codes were used to protect the identity of the participants.

Potential risks to the participants in this study were negative consequences that they could suffer if the confidentiality of the information obtained in the study were infringed. Referrals were made to counsellors within the facility in situations where participants asked for further counselling, as counselling fell outside the scope of the study.

4.11.3 Confidentiality of data

The raw data (transcribed information) will be retained for a minimum of two years in a locked file in the researcher's office.

4.12 Credibility, transferability, dependability and confirmability

The principle of trustworthiness in qualitative research data has been interrogated by positivist theories (Shenton, 2004). Therefore, ensuring data trustworthiness is something that occurs throughout the research process for qualitative researchers. The use of the terms "validity and reliability" in qualitative research does not carry the same connotations as in quantitative research (Creswell, 2008, p. 190; Shkedi, 2005; Arksey & Knight, 1999, p. 49). In every research study, there is a need to know whether the "findings of the study can be trusted or not" (Arksey and Knight, 1999, p. 49). Lincoln and Guba (1985; 2000) suggest the use of credibility instead of validity, transferability instead of external validity or generalisation, dependability instead of reliability and confirmability instead of objectivity. All these terms attempt to address the trustworthiness of the qualitative research data. To ensure credibility of the current study, the triangulation principle was used. This study adopts the definition of triangulation by Bryman (2003) who refers to triangulation as more than one method of examing a research question to ascertain credibility of findings. Bryman (2003) indicates that Denzin (1970) extended the understanding of triangulation method beyond its

convetional meaning by classifying it according to four types which are as follows: data triangulation, investigator triangulation, theoretical triangulation and methodological triangulation" (p. 1142). Therefore, the current study employed multiple data collection methods (in-depth interviews and FGDs) and "data collection sources" (HIV positive women, grandmothers and healthcare providers) (Creswell, 1998, pp. 201-203; Creswell, 2007 and 2008) in order to ascertain findings credibility. Theoretical triangulation was also used whereby the researcher interpreted the findings in two different ways by using both thematic and small story analysis (Denzin, 1970). For credibility purposes, the researcher compared the emerging themes between the different sources of information to establish triangulation (Creswell, 2008). The researcher also used in-depth detailed descriptions to convey the findings of the study. This was done by ensuring that the categories and themes identified during data analysis were direct quotations from participants' interviews (Graneheim & Lundman, 2004). The in-depth detailed descriptions of the findings would enable transferability of the information to other settings (Lincoln & Guba, 1985; Merriam, 1988).

The credibility of the findings was also enhanced by the qualities of the researcher. For instance, the researcher is a female of child-bearing age, a native speaker of the participants' language and has implemented a number of PMTCT interventions at the healthcare facility level in the Mpumalanga. The researcher also comes from an under-privileged background which brought her to the level of the participants. This description links to the description of researcher biasness by Creswell (2008). As a result of possessing similar characteristics to participants, the researcher was able to interpret the findings from participants' lens. As far as the credibility of data analysis and interpretation is concerned, the thematic and small story analysis frameworks that were used, are credible as they have previously been utilised by numerous researchers (Glesne, 2011; Creswell, 2008; Georgakopoulou, 2004; 2007; Bamberg 2004b) and have been proved to produce credible results. Data analysis was further enhanced by the researcher's self-reflections, which involved asking four key questions as a way of ensuring credibility on the data analysis (Holloway & Jefferson, 2000, p. 5). For instance, throughout the process of data analysis, the researcher asked herself: "What were the only prominent observations noticed in the data"? and "why were those observations prominent to her"? This dealt with subjective reflections as being alert to one's own biasness and theoretical dispositions aids the credibility of interpretations. Thirdly the researcher asked "how could she interpret what she was noticing"? Related to this question, the researcher looked at the importance of time, such astime spent at research site, time spent observing and

time spent interviewing), which all lead to data interpretation credibility. Lastly the researcher asked, "how she would know if her interpretation is the right one" (Holloway & Jefferson, 2000, p. 5)?

As previously stated, the researcher had full insight into the area of study as she spent three years implementing a PMTCT intervention. This led to a better understanding of the phenomenon under study (Creswell, 2008) and therefore lent credibility to the narrative account. Even though multiple and subjective realities exists (Sandelowski, 1998), in order to enhance the credibility of the findings, peer, mentor and supervisor debriefing sessions were conducted to explain how data were analysed, how particular themes were generated and how the final stage of data analysis was concluded.

Another principle of trustworthiness is shown by dependability. Lincoln and Guba (1985) argued that dependability "seek means for taking into account instability and phenomenal factors or design induced changes" (p. 299). This implies that dependability looks at the extent to which data meaning changes over time, and the data alterations made by the researcher during the data analysis processes. Hence, showing the similarities and dissimilarities between participants' data, when doing the analysis, could achieve dependability (Granehein & Lundman, 2004).

Trustworthiness may also be reflected by transferability. Transferability refers to the "extent to which the study findings can be transferred in other settings" (Polit & Hungler, 1999, p. 717). To ensure transferability, the participants' characteristics, culture and context were explained in detail (Granehein & Lundman, 2004). Transferability was also ensured by providing rich descriptions of the data, which included direct quotations of the participants.

4.13 Data analysis

Two data analysis methods were employed for this study. Firstly, thematic analysis was used, which displayed data thematically in a category focused narrative form (Shkedi, 2005). Secondly, "small story" analysis (Georgakopoulou, 2007) was used, which involved analysing the underrepresented narratives which are always part of interviews. Prior to the application of the two pronged data analysis method, data were transcribed and translated. The transcription and translation processes are described below.

4.13.1 Transcription and translation processes

As part of data analysis, the interviews were transcribed as soon as data collection was completed (Ulin et al., 2005). Early transcription allows for immediate recall of verbal and non-verbal behaviour (Ulin et al., 2005). The information was transcribed in such a way that the original meaning of the language was retained (Ulin et al., 2005). This was done by first transcribing the recorded interviews in the original native language (Setswana & Sepedi) and then later translating it into English. Transcription and translation took place concurrently in order to stay as close as possible to the original meaning (Ulin et al., 2005). This was an intense activity, as it involved both the researcher and the two research assistants. Discussions about what the researchers heard on the tape were ongoing (Silverman, 2000). Some of the transcription problems encountered related to the poor quality of the sound on the recorded interviews. Other participants spoke quietly and in some instances there was background noise (Bucholtz, 2000) from the other patients who were queuing outside the room and waiting to be assisted by other peer counsellors. Some of the translation dilemmas identified were the recorded talk was not always clear because of people talking simultaneously or noise outside. Another translation dilemma was that the participants spoke in overlapping sentences which sometimes incorporated a number of issues which did not necessarily link up. Also, the "intonation emphasis and accents used in speech were hard to depict" in a transcript (Denscombe, 2003, p. 185).

The transcription process involved repeated listening to recordings in order to understand and become familiar with the stories (Atkinson & Heritage, 1984). As such, a number of steps were followed during the transcription process: firstly, the interviews were transcribed and translated verbatim, and the interviews were read many times to gain familiarity with the data and ensure consistency between Setswana and English language (Riessman, 1993). The second step involved an in-depth period of reflection on each individual interview. Thirdly, the researcher reflected about each individual interview comparing it with other interviews. Fourthly, all the interviews were contrasted and compared and units and codes were identified and attached to the transcript (Riessman, 1993). The challenges with translation were that some words could not be easily translated (Ulin et al., 2005). These included idioms and metaphors that are embedded in cultural connotation (Ulin et al., 2005), especially when talking about rituals done on babies and the HIV diagnosis. However, the meanings of such words were easily translated, because the researcher is familiar with the languages used

by participants. Hence, words that were as close as possible to meaning of the original words were used (Ulin et al., 2005).

One of the translation dilemmas mentioned by Temple and Young (2004) is that of translation from one language to another being influenced by how the translator sees their social world and not necessarily how the participant views it. In the current study, as already mentioned, the two research assistants and the researcher were fluent in the Setswana, Sepedi and English language, hence, quality translation was achieved. Translation process involved one research assistant translating from the original language to English and the other research assistant translating from the English language to the original language. The researcher played a dual role of the researcher, transcriber and a translator, in order to check the credibility of the transcriptions and translations carried out by the research assistants. Eloquency in both languages and the familiarity with both cultural meanings and interpretations of the participants, made the translation process to be manageable (Temple and Young, 2004).

4.13.2 Thematic analysis

Thematic analysis was used, in order to gain an overall understanding of the data that emerged from the three groups of participants (HIV positive women, grandmothers and HCPs). Thematic analysis assisted with the generation of categories, sub-categories and theme patterns from data (Glesne, 2011). The thematic categories and sub-categories were generated by first coding participant answers into different groups (Silverman, 2000; Gibbs, 2007). According to Saldana (2009), coding is the initial step towards a more rigorous data analysis and, therefore, is regarded as heuristic (meaning a problem solving technique with no specific formula). Moreover, coding involves "transforming raw data to form an idea" which in the end, implies that all data relates to that idea (Richards & Morse, 2007, p. 137). A descriptive coding (Wolcott, 1994) method which involved summarising a word or short phrase of the topic was useful for this research. Hence, through coding, data are summarised into interpretive categories without really reducing its original meaning (Saldana, 2009).

The coding process requires that the researcher pay meticulous attention to words that are said by the participants, as part of the analysis process. However, how the content of data are perceived and interpreted "depends on the type of filter that covers that lens" (Saldana, 2009,

p. 6). Importantly, "all coding is a judgment call" since "we bring our subjectivities, our personalities, our predispositions and our quirts" to the process (Sipe & Ghiso, 2004, pp. 482-3). The coding process also assists in reducing data into manageable chunks. Miles and Huberman (1984), define "data reduction" (p. 21) as a process of "selecting, focusing, simplifying, abstract and transforming…..raw data" (1984, p. 21). The coding process also involves making decisions about which data chunks will provide the initial focus of analysis.

To this end, numerous codes were generated in order to highlight salient features of the data (Saldana, 2009). The coding process thus involved systematically grouping the similarly coded data into categories (Saldana, 2009). As suggested by Lincoln and Guba (1985), the researcher used her "tacit and intuitive sense" to determine which data "look alike" and "feel alike" when grouping them together" (p. 347). The researcher had to code and recode and categorise and re-categorise, in order to obtain emerging patterns and meanings of human experience (Saldana, 2009). Themes were later generated based on the outcome of the coding process.

A theme is an "outcome of a code, categorisation and analytic reflection" (Saldana, 2009, p. 13). Through descriptive coding (Wolcott, 1994), intra-thematic and inter-thematic participant experiences were explored (Owen, 1984). Intra-thematic analysis considers the themes identified for a particular participant. An inter-thematic analysis was done by comparing themes emerging from the three groups of participants. These are referred to intersecting PMTCT narratives which overlap or coincide among the three groups of participants. The intersections in this study were brought about by participants raising similar issues, which cut across their PMTCT lived experiences. The theme intersetions were discussed from a social constructionist point of view.

4.13.3 Small story analysis

Another type of analysis used in the current study was small story analysis. The justification for looking beyond the narrative canon is provided in Chapter Three of this thesis. The small story analysis primarily focuses on four aspects namely: analysis of the small story by type, small story analysis according to levels of positioning, small story composition analysis and interactional features of the small story. All of these four aspects are discussed in full in below sections.

4.13.3.1 Analysis of small story by type

As explained in Chapter Three, there are four types of small stories. Hence, the first part of the small story analysis was done based on the following four small story types as proposed by Georgakopoulou (2007): stories to be told, breaking news stories, future projection of story-telling and shared stories. The proposed four types of stories reflect the kinds of stories that are normally told in daily conversations. They are part of trajectory of interactions rather than a free standing self-contained unit (Georgakopoulou (2007).

The following steps were followed in undertaking the small stories analysis according to the four story types: Firstly, the researcher selected and categorised the participants' interview excerpts according to the type of small story. Secondly, the small story extracts were analysed according to the specific features of each of the small story type. For example, in analysing the "**stories to be told"**, the researcher looked at specific excerpts which had elements of stories to be told or stories that were deferred for future telling. In the context of PMTCT, such stories may include HIV disclosure to the partner, family, friends etc. When analysing the "**breaking news**" stories, the focus was on extracts that showed eagerness to tell the stories right away as they were unfolding, instead of waiting for future telling. The analysis of the "**future projections of stories**" involved focusing on extracts that showed lots of action planning for events. The analysis of the "**shared stories**" involved focusing on participants' extracts where stories were retold continuously and encompassed past or future projection stories. Lastly, the researcher identified the additional small story types which did not fall within Georgakopoulou's small types described above. The newly identified small stories were also analysed according to their specific features which were outlined according to their type. Additional sub-small story types were also identified benchmarking on Georgakopoulou's small story types.

4.13.3.2 Small story positioning levels analysis

The second part of the analysis involved analysing the small stories according to positioning levels. This kind of analysis was done using steps delineated by Georgakopoulou (2007; 2013) and Bamberg (2006). The small story analysis according to positioning levels included firstly looking at how characters are positioned within the story, secondly, how the speaker positions himself or is positioned within interactive situation, thirdly, how the

speaker or narrator positions a sense of self or identity with regard to dominant discourses. Bamberg (2006) asserts that people use small stories in their conversations and that these create a sense of who they are. Moreover, subjectivities are shaped by their individual positions in relation to the contexts from which they arise.

4.13.3.3 Small story compositions analysis

The third part of the small story analysis in the current study was done by examining the composition of the story. In doing so, the analysis focused on three separate but interrelated levels, namely: "ways of telling the story, sites of the story and tellers of the story" (Georgakopoulou, 2013). The three small story compositions are discussed below.

- **Ways of telling the story**

The small stories were analysed by looking at the ways in which the stories were communicated by the teller. This required attention to the type of stories and the narration of participants' experiences. In the current study, ways of telling the story focused on the sequence of the story, in terms of how it was introduced and how it exited the conversation.

- **Sites of the story**

The small stories were further analysed by looking at the sites of the story. This refers to the spaces where the experiences took place. The spaces in which experiences took place differed. Hence, this allowed for the analysis of different interactional regimes of small stories. In the current study, the sites of the story involved varying places where the experiences took place, for example, the healthcare facility, the home environment, the community environment etc.

- **Tellers of the story**

Lastly, the analysis focused on the tellers of the story. This refers to the actual participants in the communicative activity. These are the individuals with specific "biographies and self-projects" (Georgakopoulou 2013, p. 8). Self-projects are ways in which tellers see

themselves through the stories they tell. As such, they may see themselves in various ways which reflect both negative and positive personal attributes. Participants' stories could reflect them as having certain "capacities, habitual practices, likes, dislikes, desires, fears, commitments, [or] social status" (Rampton 2007, p. 3). The tellers in the current study are the three categories of participants, namely the HIV positive women, the grandmothers and the HCPs. The small stories obtained from these categories of participants would reflect how they perceive themselves in relation to the PMTCT programme. Their biographies would be reflected by their actual perceptions of the PMTCT programme.

4.14 Conclusion

Chapter Four outlined the methodologies applied in implementing this study. A full description of the study setting was provided. Furthermore, Chapter Four presented a full account of the selection criteria for the study participants. The role of the researcher in conducting the study was clearly described. This Chapter also showed that data credibility and dependability are possible and can be transferred to similar contexts. The ethical procedures were discussed. This demonstrated that although confidentiality is possible to maintain, it cannot be guaranteed in the case of FGDs. Transcribing and translation dilemmas were also discussed. Finally, this chapter described data analysis triangulation that was used, where the initial analysis was done using thematic analysis and small story analysis. This process allowed for findings to be understood from different angles of the method of inquiry.

CHAPTER 5
RURAL HIV POSITIVE WOMENS' LIVED EXPERIENCES OF PARTICIPATING IN THE PMTCT PROGRAMME FEAR OF HIV DISEASE AND FEAR OF HIV STIGMA

5.1 Introduction

This Chapter is the first of the three Chapters that present findings of this study. Based on the theoretical and methodological frameworks discussed in the previous chapters, this Chapter presents a detailed description of the thematic analysis which arose from the semi-structured narrative interviews conducted with HIV positive women participating in the PMTCT programme. Whilst this Chapter is solely devoted to the presentation, analysis and discussion of findings related to the HIV positive women, an analysis of the other results obtained from the grandmothers and HCPs' narratives will be provided in subsequent Chapters Six and Seven. Thematic analysis was conducted to attain an overall understanding of the lived experiences of HIV positive women participating in the PMTCT programme. At the end of this Chapter, a conclusion is drawn.

5.2 Thematic analysis narrative descriptions and discussions

The overall narrative for this Chapter is structured according to the thematic sequence of steps on the PMTCT cascade which are supposed to be followed by the HIV positive women in order for the PMTCT programme to be effective. Therefore the narrative thematic sequence of the HIV positive women's lived experiences in this Chapter is presented according to their past behaviour of utilising antenatal care services, present behaviour of receiving PMTCT services and future intentions and recommendations for PMTCT services enhancement. The presentation of the main story for this Chapter using the thematic sequence of PMTCT cascade steps allows for the identification of challenges at each phase of health seeking. At the same time, it allows for a deeper infiltration into participants' lived experiences which addresses the objectives of the study. Figure 5.1 shows the seven key themes presented according to a sequence of PMTCT cascade stages discussed in Chapter Two of this thesis. The themes are as follows: 1) fear affecting decision and action taking for PMTCT use, 2) HIV testing perceptions: acceptance and fear of HIV stigma, 3) fear and

HIV treatment perceptions, 4) Fear causing a dilemma to remain voiceless, 5) Infant feeding practices influenced by fear of HIV stigma, 6) PMTCT obstructions and 7) PMTCT programme enhancement.

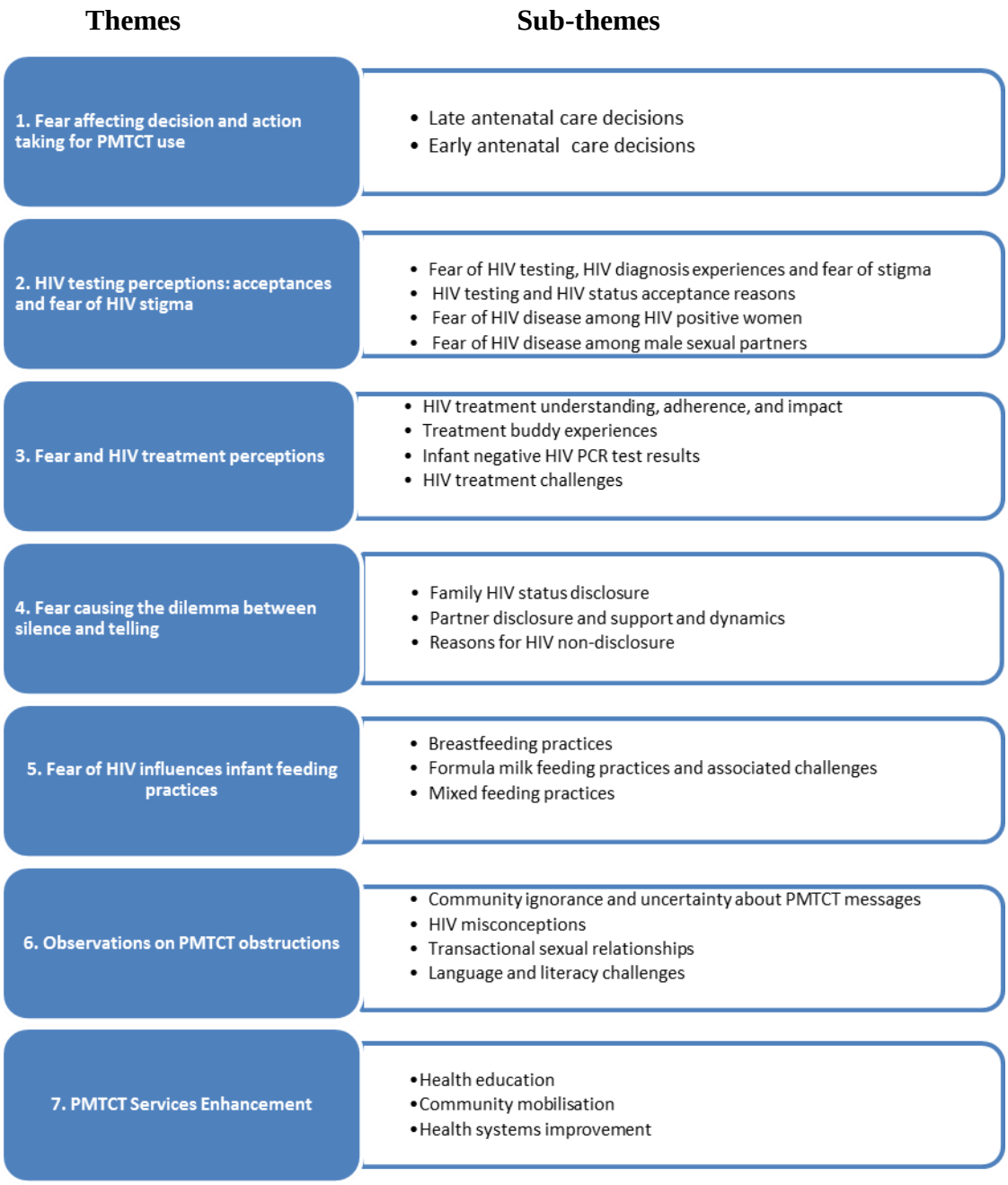


Figure 5.1 Seven themes and subthemes providing an account of PMTCT lived experiences by the HIV positive women

Although the narratives of the HIV positive women are presented according to the steps of the PMTCT cascade, they reflect two key aspects which dominate this Chapter: fear of HIV disease and fear of HIV stigma. The findings are presented according to each theme and sub-

theme showing illustrative excerpts from interviews with the participants. The selected excerpts reflect participants' general views of the PMTCT programme. Both dominant and non-dominant lived experiences were selected to illustrate the narratives of PMTCT. Analysis of themes emerging from individual participants (intra-thematic) and a comparison of themes between participants (inter-thematic analysis) was performed. The illustrative excerpts from individual interviews with HIV positive participants were selected based on their in-depth, detailed description. The results are further described and discussed.

5.2.1 Theme 1: Fear affecting decision and action taking for PMTCT use

Theme one begins by providing the narrative account of the lived experiences of rural HIV positive women's decision-making and action-taking concerning their utilisation of the PMTCT services. Decision making is an initial step prior to the engagement on the PMTCT cascade processes. This is explored by obtaining narratives from the HIV positive women about facilitators and inhibitors of antenatal care attendance. As such, theme one consists of two sub-themes which demonstrate that decision-making and action taking in this Chapter, focuses on the 1) late antenatal care attendance and 2) early antenatal care attendance by the women in this study context. The section below provides narratives of factors that influence the decisions for late antenatal care utilisation.

5.2.1.1 Late antenatal care attendance decisions

"Others come and others don't, we are used to it, others don't come at all, they come on the last day [of baby delivery]"

The HIV positive women in this study shared their past experiences and thoughts on the factors that contribute to their late antenatal care attendance. Results reveal the individual factors which lead to late attendance of the antenatal care services, this include exhaustion due to long periods of antenatal care attendance, time defer (postponement of action-taking), previous child-birth experiences and pregnancy medication myths, fear of healthcare providers and non-preference of the healthcare facilities.

- **Avoidance of long periods of antenatal care attendance**

Varying reasons were provided by the HIV positive women for making decisions to utilise antenatal care services late. The first reason for avoiding early antenatal care attendance was due to the perception that it is exhausting because of long periods of attendance. For example, one woman shared her observations around what makes other women in her community to not start antenatal care early.

> *"Most of the women in this area prefer to come [to the clinic] when they are 7 or 8 months [pregnant]. They say they get tired of travelling to the clinic. I don't know, they say it becomes a very long time. Uhm, she [a woman] knows that if she comes at 8 months [to the clinic], the next month she will give birth"* ***(Mother who received Infant HIV PCR test, 26years, single, two children****).*

Their tiredness appears to stem from the thought of having to attend antenatal care services for many months of pregnancy until delivery. This study reveals that the number of trips to the healthcare facility during antenatal care discourages timeous attendance. This point is supported by another woman who includes herself as one of the people who have a tendency to start antenatal care late. This woman said "*Sometimes we have this thing of saying that when you go to the clinic early, you will be going there for long periods… Sometimes one would say, I do not want to have many trips to the clinic, that is the perception we have about many trips to the clinic, even though it is important [to go to clinic]…"* This narration seems to indicate that the comfort of not having many trips to the healthcare facility supersede the importance of receiving health services timeously. There are other studies which also found that the majority of women started antenatal care late because of not wanting to attend the many sessions included in the antenatal care programme (Mrisho et al., 2009; Tann et al., 2007). The current study also confirms that antenatal care attendance was generally perceived to be important by the HIV positive women even though action-taking for utilising antenatal care services was poor (Mrisho et al. (2009). The analysis of data further confirms what has been observed that pregnant women in South Africa generally utilise antenatal care services relatively late in their pregnancy, and that less than 40% actually attend antenatal care services before 20 weeks gestation (Barron et al., 2013).

- **Deferring time or postponement of action-taking**

Besides the avoidance of long periods of antenatal care attendance, some participants deferred time by indicating that they needed "*more time to think*" about antenatal care initiation. For instance, a 24 year old mother waiting for infant HIV PCR test results said "*I knew that I was pregnant when I was three months, I just told myself that I should stay a bit while thinking about it* [starting antenatal care attendance]*". But at home they kept on saying I should go* [to the clinic] *but I kept on saying I am not yet ready, I will go* [when I am ready]". Like other studies, the current study shows that the late utilisation of the PMTCT services is influenced by individual factors which may be due to community barriers such as stigma (Busza et al., 2012; Bajunirwe & Muzoora, 2005) and social barriers (Merten et al., 2010; Selin et al., 2007; Nam et al., 2008; Obermeyer et al., 2009) relating to the utilisation of the healthcare services. A need for time to 'think' about receiving healthcare services that are beneficial to both the mother and baby is a reflection of other external factors which are blocking such action to be taken. Besides the long periods and deferring time for antenatal care attendance, participants' narrative accounts did not emphasise that late antenatal attendance is an old tradition which was used to avoid other women having to estimate the gestational age of a woman. Late antenatal attendance would mean that you are delivering anytime, but an exact delivery date would not be that obvious. Hiding gestational age could also be due to fear of witchcraft which might lead one to experience miscarriage.

- **Pregnancy experience and myths about pregnancy medication**

Another individual factor that contributed to HIV positive women's decision to attend antenatal care late was having already had the experience of motherhood (or having given birth before). A few women indicated that because they had been pregnant more than once, they did not see a need to start the antenatal care services early. Although expressed differently by these women, the excerpt below illustrates common feelings about antenatal care attendance in this rural context.

> "…*"No it was just me, most of the time I was coming on time. The first one [child]I came when I was 3 months, with the second born I came when I was 2 months, with this one I came when I was 8 months pregnant. I just stayed at home (laugh…)…I then stayed a bit and said I will go to the clinic later. [If I go*

> *early] I will be taking those tablets that make the stomach bulge and then I decided that I will go later. When I take those tablets, my stomach becomes so big, then it hit 8 months, I said eish, let me go to the clinic, the child might be coming anytime…" (**Mother waiting for child's HIV PCR test results, 25 years, single, 1 child**).*

This participant seemed at peace with her behaviour of late antenatal care attendance. But more than that, she demonstrates that late antenatal care attendance is associated with having two or more children (Hanh, Gammeltoft & Rasch, 2011). This portrays an example of how some women in a rural context reach a point where they think that they are fully equipped with health information and, therefore, do not have to carry out some of the procedures that they were previously taught at the healthcare facilities. Importantly, this kind of behaviour seems to undermine the lessons that women are taught at the healthcare facility. Not being sick causes them to feel no urgency or pressure to seek medical help. Mepham et al. (2011) found that having a disease symptom improved the health seeking behaviour of participants in their study. Furthermore, recent studies have identified additional barriers to participation in the PMTCT processes such as long waiting hours, lack of comprehensive information about HIV and PMTCT, stigma and partner dynamics leading to a lack of participation in PMTCT processes (Homsy, King, Malamba, Opio, Kalamya, & Mermin, 2007; Thorsen et al., 2008; Larsson et al., 2012; Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2011).

The above excerpt further revealed another individual factor that instigated the late attendance of antenatal care services. This was pregnancy myths that experienced mothers seem to have regarding pregnancy medication. A common view by some participants as indicated on the above participant excerpt was that medication given during pregnancy makes their stomachs bulge "*When I take those tablets, my stomach becomes so big."* Over and above the belief that pregnancy medication bulges the stomach, one woman also shared what other women in her community believe: "*other women say this medication is not fine, it causes dizziness…*" This data seems to suggest beliefs that perpetuate late antenatal care attendance by women in this rural context. It also suggests that a lived experience of prior utilisation of healthcare services seems to delay participation in subsequent antenatal care services. This may also form an example of how community factors influence individual behaviour when it comes to health-seeking behaviour (Busza et al., 2012; Bajunirwe & Muzoora, 2005).

- **Fear of healthcare providers**

HIV positive women further revealed that their decision to utilise antenatal care late was influenced by factors such as fear. Some participants suggested that their non-utilisation of PMTCT services was due to fear of the HCPs because they shout at them for being pregnant and ask them too many questions. One woman shared her reasons for starting antenatal care late which points to fear as the cause.

> *"I came to the clinic late. I was not able to come to the clinic [early], I was afraid; I am told that they [nurses] shout [patients] at the clinic. I was afraid, they [community people] say they shout at people at the clinic. They ask too many questions about the pregnancy. The … [stammering], I don't know how to explain it, but they do shout. They shout at you for being pregnant, it's like when you are a school child coming for family planning, they shout and ask as to why do you want to prevent [do family planning]. That is why I tested late. Others come and others don't, we are used to it, others don't come at all, they come on the last day…[to still do it]" (**Mother who had just given birth, 21 years, single, one child**).*

The above excerpt suggests that the fear expressed by this participant is mostly instigated by the community's negative beliefs about the utilisation of healthcare services. Because of the belief that the HCPs shout, some pregnant women were reluctant to utilise the antenatal care services early. As expressed by the participant on the above excerpt, the practice of late antenatal attendance is common in this setting. Therefore, early antenatal care attendance practice is often viewed negatively (or is seen as a surprising act) as shared by one mother who had just received infant HIV PCR test results *"... at first, many* [women] *asked me, why did you go* [to the clinic] *so early? It is too early, people* [in this community] *often go* [to the clinic] *when they are 9months pregnant*." The results seem to suggest that late antenatal care attendance practice is normalised in this context and as a result, the effectiveness of PMTCT is affected.

Another important finding of this study concerns poor communication between patients and HCPs. As shown by the above excerpt, this participant felt that she was being interrogated about her sexual life by the HCPs. This demonstrates that any miscommunication between

the patient and a HCP can lead to non-utilisation of the healthcare services (Kravitz, Helms, Azari, Antonius & Melnikow, 2000; Penn & Watermeyer, 2012; Penn, 2007; Feinberg et al., 2002; Jacobs et al., 2001). Jewkes, Abrahams and Mvo (1998) also found that nurses shouted patients for various reasons such as "talking softly", "slow movements" to consulting room, pregnant teenagers etc. (p. 1785). In the current study, some participant felt ill-treated by the nurses. An example of such ill-treatment is given by one mother who had just given birth. She stated that "*…you can arrive in the healthcare facility feeling very very very sick. The nurses would see you seated there on the chair and* [they could see] *that this person is very sick. However, they would just pass you just like that and help other patients who are not very sick*." This illustrates some observations by the participants when it comes to the management of patients by the healthcare providers. It is the actions such as these that seem to encourage late antenatal care attendance.

In another account of having a lived experience of not being treated well by healthcare providers, one mother aged 35 years said "*At the doctor they forced her to do hysterectomy*." The fear of healthcare providers seems to also be instigated by poor communication about family planning issues. Studies have shown that HIV positive women are coerced to sterilise without their consent and that this is a typical scenario for women who are poor or socially disadvantaged (International community of women with HIV/AIDS, 2010; 2011). A study conducted in Namibia also found that women were sterilised without their knowledge (Dumba, 2010). This finding differs from what the HIV positive women in the current study reported, as the HCP did discuss sterilization with the participants, although they were forcing them to undergo it.

Another participant shared the details about the conversation that she had with one pregnant woman in the community about her reasons for fearing the HCPs. This is what this 24 year old woman said "*So previously I met one lady who said [name of participant] you know what, I am pregnant. Although I'm pregnant, I am scared of going to the clinic because they might say I'm like this [HIV positive], do you see?* This excerpt seems to suggest that the fear of HCPs could also be brought by anticipating HIV positive results. Such negative anticipation seems to affect the timeous utilisation of PMTCT services. As pointed by another 23 year old mother who had just received her infant HIV PCR test, the fear is also brought by not knowing your HIV status while pregnant "*…At first I was scared, to tell the truth, I was scared indeed. Isn't I did not know my situation [HIV status], I did not know, I was scared…"* Not knowing one's HIV status

while pregnant seems to be another factor that delays timeous antenatal care utilisation. Similarly, a study conducted in Botswana showed that barriers to participation in the PMTCT programme included fear of knowing one's HIV status, fear of stigma, lack of support and negative attitudes of the HCPs (Kebaabetswe, 2007).

The current study further revealed that in some cases, women just have fear of antenatal care attendance. One participant who had also just received infant HIV PCR test results gave a scenario about her cousin sister saying that "*Women do not want to come to the clinic, they have fear and I do not know what they fear. Like my cousin…she would not come for antenatal care, if she does come, she would shout at the nurses and leave the clinic…"* On the other hand, healthcare workers in other countries have also been found to have negative attitudes towards HIV positive pregnant women (Schaan, Taylor, & Gungquisa, 2010). Moreover, studies have shown that HIV stigma reduces the quality of care of HIV positive patients. Numerous studies have also shown that people living with HIV have actually been refused services by HCPs (Mahendra et al, 2006; Thi et al., 2008).

- **Non-preference of healthcare facility and healthcare system an agent of HIV stigma for HIV positive women**

Another individual factor that influenced the late antenatal care utilisation was that the HIV positive women in this study perceived the non-preference of the healthcare facility as a result of the manner in which services are provided to the patients. For instance, as illustrated on below excerpt, some participants felt that the HCPs were judging them based on their HIV positive status. As a result they were no longer comfortable to receive services at the healthcare facility.

> *"Eish this clinic, sometimes I don't prefer it but if you do not have a choice, there is nothing you can do. At this clinic maybe when you are sick, is like they take you like THIS ONE is sick. Nurses now, nurses of nowadays, eish I do not know, I do not know how to describe them. A clinic is a clinic, because you are sick, you are supposed to get help from there, the clinic is supposed to accept each and every patient without judging that so and so has this and that. Because at this clinic, is like after leaving [the consultation room], when they [nurses] are seated they say [to each other] have you seen that one, I am the*

> *one who was helping her and she is like this and that, hey I do not prefer coming to this clinic" (**Mother Waiting for infant HIV PCR test results, 23years, single, two children**).*

The above excerpt is an example of perceived stigma which seems to be the underlying reason for certain behaviours such as late antenatal care. As found in other studies, data for this study showed that some HIV positive women had a lot of anticipated stigma (Turan & Nyblade, 2013). The data from this study seem to suggest that some participants anticipated negative reactions from HCPs about their HIV positive status. A mother waiting for infant HIV PCR test results provides a rationale for always anticipating stigma "…*I am not free in this clinic [facility name], they gossip a lot…*" Another participant also supported the gossiping issue by saying "*You will find them gossiping saying this person has this and that, without discussing the important services that are provided by the clinic*." This is an indication that the healthcare facility in this setting is seen as a threatening environment.

Similarly, Thorsen et al. (2008) identified one of the stigma initiators as the location of the PMTCT programme. Some studies have suggested evidence of stigmatising behaviours at healthcare facilities (Holzemer, Uys, Chirwa, Greeff & Makoae, 2007). They have argued that HIV stigma may be experienced by both the HCPs and the HIV positive patients. For the HCPs, stigma results from the fact that they work with HIV positive patients, whereas, for the patients stigma results from the fact that they are living with HIV. Another study found that patients were not assisted when the HCPs discovered that they were HIV positive (Asia Pacific Network of People Living with HIV/AIDS, 2004). Other studies have suggested that a positive attitude of HCPs could greatly improve the participation of women in the PMTCT programme (Bresolin, Rinalds, Enning, Hendee & Schwarz, 1990; Gerbert, Macquire, Bleeker, Coates & Mc Phees, 1991). Moreover, certain studies have indicated that a supportive and non-threatening healthcare environment is essential for HIV positive women to adhere to and attend healthcare services (Lamping, Sewith, Clark & Ryan, 1990; Gee & Kimbal, 1987). In a study conducted by Nguyen et al. (2008), it was found that stigma and discrimination were cross-cutting. This implies that women experienced stigma and discrimination at all points in seeking services for PMTCT. Similar to the current study, this led most women to not desire the utilisation of PMTCT services at their local healthcare facility. Nguyen et al. (2008) found that pregnant women changed antenatal care sites because they wanted to confirm their HIV statuses at the other healthcare facilities. In line

with the current study, Rothpletz-Puglia et al. (2012) also expressed that one of the concerns for HIV positive women was the belief that HCPs have negative attitudes towards them because of their HIV status. The stigma in this study was also presented in the form of gossips (Abrahams & Jewkes, 2012).

- **Other factors influencing late utilisation of antenatal care services: prolonged disease symptoms, religious beliefs, culture and laziness**

The current study further reveal additional factors for late utilisation of PMTCT services such as prolonged disease symptoms, religious beliefs, culture and laziness. With regard to prolonging disease symptoms, the current study shows that, prior to the action of health-seeking, a few participants suffered a number of illness symptoms which necessitated that they seek medical help. One pregnant woman on AZT treatment said:

> *"I missed my periods…I went to the clinic, they said I am not pregnant…I stayed and stayed and then when I had a toothache, they said I am 6-7months pregnant" (**Pregnant woman on AZT, 32years, single, 1 child**).*

The above excerpt is an example of late reaction towards illness symptoms which in the context of HIV, seems to disturb the effectiveness of PMTCT. A few participants waited until they were very sick before they were diagnosed with HIV. An example of this was provided by a 26 year mother waiting for infant HIV PCR test results who had a recurring STI until she had a baby. This is what she said: "*At home they thought its drop [sexually transmitted disease like gonorrhea] … I then went to the hospital, they gave me tablets to stop it, that is when I had a child. Since then, I have been having burning urine, discharge was coming out, now it is just the smell* [from the vagina], *it is not coming out [discharge.* Data from the pregnant HIV positive women also indicated that similar behaviour is practiced by the mothers in seeking health for their children. For instance, one mother in this study was only prompted by severe illness symptoms to take her child to the healthcare facility to be tested for HIV "*Today I had to come and test her [the child], she is always coughing…I want to know where she stands [HIV status*."

Levy (2009) also found that health-seeking behaviour was mostly influenced by prolonged disease symptoms. In a study conducted on women's experiences of HIV testing, they found

that the majority of women who tested negative sought HIV testing because they practiced unprotected sex, whereas women who tested HIV positive were only identified when they started experiencing HIV-related symptoms (Beervor & Catalan, 1993). Kasenga et al. (2010) also found that women obtained medical help as a result of the symptomatic experience of illness. For example, they experienced diarrhoea, coughing and swelling of the body.

The current study also found that additional factors for the late antenatal care attendance were due to religious beliefs. One mother who had just given birth shared what seems to be the problem when it comes to antenatal care attendance *"Many [women] are putting their trust on churches…they would rather start at church to be seen by the pastor before they go to the clinic*." Other reasons for late antenatal attendance were due to pregnancy that is not showing "*…it [stomach] was not showing, then I came before the end of seven months…that is when I found out I am HIV positive."* One woman mentioned the attachment to tradition as the cause. This is what she said:

> *"…many people who follow tradition, you will find that they say you must drink this [traditional medication] and it will cleanse your blood, meaning that when you go to the clinic you will not find it [HIV]. Or maybe when you find that it is there, perhaps drink those things, when you go again you will find it is not there…they say it is medication for cleansing the blood"* ***(26years, infant HIV PCR test results, 2 children.***

Another 33 year old woman who had come for second antenatal care attendance mentioned laziness as another cause *"People in this community are lazy to come to the clinic, you will find that the person wait for the months towards the time when she is almost done, they do not want to go to the clinic…many people still have fear…"* This study shows that the fear of utilising antenatal care services early is interpreted as laziness or due to pregnancy stomach not showing. The "laziness" and waiting for the "pregnancy to show" could be due to wanting to avoid exhausting periods of antenatal care attendance as discussed earlier on this section. Finally, an alternative view was related to witchcraft. Although this particular had participant accepted that she is HIV positive, she also believed that she had been bewitched by her in-laws. The 28 year old mother who had just received infant HIV PCR test results said "*…they are the kind of people who practice witchcraft. And then I got sick and when they checked [me] that*

side [traditional healers] we found that they have a plan about me." This excerpt shows some of the beliefs that women have about their ailments. In this case, being HIV positive was linked to witchcraft. The data suggest that instead of seeking medical help first, some women go to a traditional healer as a first point of treatment. This appears to indicate that medical help is sought as a last resort. Similarly, Sibeko et al. (2009) found a high preference for traditional medicines by mothers. The narratives provided above by the HIV positive women, shows that individual factors caused by the fear of stigma and fear of HIV influences decision making for late antenatal care utilisation in this rural context. The next sub-theme discusses factors influencing decision making for early antenatal care utilisation in this context.

5.2.1.2 Early antenatal care attendance decisions

"They do not make people to feel guilty of their sicknesses or blame them for what happened"

Analysis further revealed the facilitating factors that influence decision making for early antenatal care utilisation. The participants' experiences reflect that both individual and healthcare facility related factors seem to influence decision making regarding early antenatal care utilisation.

- **Self-drive and knowledge of HIV status**

The analysis of data further revealed diverse factors for early antenatal care attendance expressed by the HIV positive women. For instance, the decision for early antenatal care attendance was practiced by some women who had already been diagnosed of HIV and thus, had self-drive that was mainly influenced by their desire to ensure that their child would not be infected with HIV. A 33 year old mother who had just received her infant HIV PCR test results for her third child said:

> *"With the second one, I started when I was two months, isn't with the first one they told me the importance of starting antenatal care early in order to prevent the child from getting what I am suffering from [HIV] and to get the treatment. With this third born, I came when I was 3 months. I got the treatment and kept on coming for check-ups, there was no problem until the end when I gave birth…"*

Again, the decision to commence early antenatal care attendance was mostly taken by second or third-time mothers. This is because they had been through antenatal care services before and they understood the importance of early initiation of antenatal care services. The self-drive to utilise PMTCT services was a result of the good education provided during antenatal care, and the information given was accepted by the women because they were already HIV positive. The lived experiences expressed by HIV positive women further shows that women who initiated HIV testing accepted their HIV status with greater ease than those who were caught off guard by the outcome of an HIV positive test results. Msellati (2009) suggests an important interpretation of this, that having self-drive to go for HIV testing implies that the person has thought about it and processed the thought of being tested. However, those caught off guard by the request to perform HIV testing would have never thought of the possibility of being HIV positive. The HIV positive women's lived experiences showed that participation in antenatal care services is prompt when HIV status is already known. Moreover, PMTCT messages seem to be well understood by women who have already been diagnosed as being HIV positive. The behaviour of utilising antenatal care services only when the HIV status is known seems to defeat the objective of keeping the child alive and the mother healthy (UNAIDS 2011; UNAIDS, 2012). The women's experiences indicated that self-drive is crucial at all levels of participation in the PMTCT services.

- **High compassion, non-judgmental and good reception**

Another decision which prompted early antenatal care attendance by women was due to empathy received from the HCPs. Although there were HIV positive women in this study who were not impressed with the HCPs and the healthcare facility, some participants praised the behaviour practiced by the HCPs, which does not seem to suggest that they are discriminating against the women. As indicated below by a 41 year old mother who had just given birth, HCPs do not seem to blame women for their HIV positive diagnosis *"Uhmm the service that I am getting at the clinic is good, they know how to work with people. You know even when you are sick, feeling very sick, you are at home, they do not make you to feel guilty… They do not make people to feel guilty of their sicknesses or blame them for what happened. You feel free they know how to speak to people…"*

One participant emphasised the beautiful feeling that she had when she went to the healthcare facilities and she also mentioned that she felt free when utilising the healthcare facilities "*I come feeling free knowing that they know how to speak to us, then they are able to explain what the problem is or if there is no problem..."* This finding is unlike that of Nguyen et al. (2008) who found that women changed antenatal care sites after testing because they did not comprehend the information provided at their clinics.

Analysis reveals that when the HCPs give good service to the patients, they feel free to participate in all the PMTCT processes. Participants perceived not being treated well at the healthcare facility as being a result of HIV stigma. According to the participants, the manner in which the HCPs talk to the patients encourages acceptance of services they provide. This implies that when the HIV positive women feel free in the PMTCT programme, they would not doubt that there confidentiality. Similarly, in a study by Hardon et al. (2012), most of the participants indicated that HCPs respected their right to confidentiality regarding their HIV status. This positive feeling might only occur if HIV positive women in the PMTCT programme are made to feel respected by the HCPs. The lived experiences for some HIV positive women in the current study thus show that high compassion and a non-judgmental attitude by the HCPs facilitates utilisation of PMTCT services. This suggests that when HIV is normalised, even within the healthcare facility, PMTCT services would be adhered to.

- **PMTCT language comprehensibility**

The results further highlight another facilitating factor for making a decision of utilising antenatal care services early by HIV positive women was the understanding of language used in PMTCT. For participants who believed that language used in PMTCT is comprehensible, the one clear message that they understood was that PMTCT assists with preventing the child from being infected with HIV. The data seemed to indicate that HIV positive women in this study did not care so much about the terminology used in the PMTCT programme. They assumed that the healthcare professionals knew exactly what they were doing. As shown by the data, communication seemed to be one important factor for understanding the terminology used in the PMTCT programme. For example, some HIV positive women understood PMTCT messages because the HCPs took time to explain what the PMTCT programme does. Two participants said *"They were treating me well, you know they were explaining each an everything saying that I should not feel down. I should be open and happy just*

like that..." Therefore, according to some HIV positive women, comprehension of antenatal information is a predictor for utilisation of PMTCT services. In support of this, another two participants said *"Language used on PMTCT things is understandable because they explain, they explain from the beginning. They take time, they sit down and explain nicely what to do, its understandable).* This implies that communicating PMTCT messages in a clear and precise way could lead to better comprehension of PMTCT, which may also increase utilisation of services by the community. Data further revealed that media such as television (TV) and radio, was also found to be an effective information provider of PMTCT. A few participants said "*Even on TV, they sometimes talk and explain all over…*[about PMTCT]*."* According to these women, understanding the messages conveyed by the PMTCT programme certainly assisted in improving the behaviours of the women participating in the PMTCT programme and of the community at large. This suggests that if messages are well understood in terms of PMTCT content, and language which is specific to the women's level, then it is possible for vertical transmission of HIV to be reduced (National Department of Health, South Africa, 2010). After making the decisions to utilise antenatal care services, the next step that takes place on the PMTCT cascade process is the HIV testing. Therefore, the next section discusses the perceptions of HIV testing and HIV diagnosis among HIV positive women in a rural context.

5.2.2 Theme 2: HIV testing perceptions: acceptance and the fear of HIV stigma

"…if you test after a long time, it [HIV] would have already eaten your blood…"

Theme two gives an account of HIV testing perceptions among HIV positive women. The narratives about HIV testing are discussed by focusing on the four sub-themes falling directly under this theme namely: HIV diagnosis fear and fear of stigma, HIV testing and status acceptance reasons, fear of HIV disease among HIV positive women, and fear of HIV disease among male sexual partners.

5.2.2.1 Fear of HIV testing, HIV diagnosis experiences and fear of stigma

The first sub-theme under HIV testing perceptions relates to fear of HIV testing, diagnosis experiences and fear of stigma. Following the early or late decision making for antenatal care attendance, the next step described by all the participants was that of accepting to be

tested for HIV and being diagnosed HIV positive. This Chapter reveals that the HIV positive diagnosis for some participants involved moments of fear and thoughts of stigma. One mother aged 27 years and had just received infant HIV PCR test results, expressed her fear of testing saying "*…I was scared of testing, but when you are pregnant you are forced* [to do so]." Some participants found it difficult to accept their HIV status. For instance, a 26 year old mother who had also just received infant HIV PCR test result indicated how devastating it can be "*to discover that you are pregnant and also HIV positive*", she continued to say she "*almost miscarried and ended up having premature birth*". This shows some of the consequences of non-acceptance of HIV diagnosis. Fear of how people will respond to ones' HIV status could also affect HIV status acceptance. One participant in the current study also indicated that even girls in the community fear HIV testing. As illustrated by below excerpt from one participant, the fear of HIV testing reveals varying perceptions between girls and boys about its relevance and meaning.

> "*…they [girls and boys] are afraid of testing, girls say they do not want to test if they are not pregnant, boys say they do not want to have AIDS" (**Pregnant woman attending second antenatal care, 19years, single, no children**).*

This excerpt shows that HIV testing is believed to be beneficial only when one is pregnant. Therefore, this illustrates perceptions of HIV testing which might be detrimental to community's health. It seems to suggest that health-seeking behaviour is influenced by the belief that such action would be beneficial or not (Rosenstock, 2005). Therefore, the perceived susceptibility leads to better usage of health services. Demonstrating this, a study conducted in South Africa found that people who were at less risk of contracting HIV showed interest in knowing their HIV status (Mwamburi, Dladla, Qwana & Lurie, 2005). Another study in South Africa also found that women who were not interested in participating in antenatal screening had no interest in their HIV status, and about 44% of them were found to be HIV positive (Mseleku, Smith & Guidozzi, 2005). The above excerpt further suggests that HIV testing is perceived by boys to be an HIV transmission strategy in this context. This seems to suggest some stereotypical behaviour by men when it comes to health seeking. This point will be elaborated on in section 5.2.2.4.

Numerous studies have shown that poor participation in healthcare services is due to stigma and discrimination (Painter et al., 2004; Rogers et al; 2006). Similar to the current study,

other literature has shown that fear of HIV stigma delay HIV testing (Nguyen et al., 2008; Pai et al., 2008; Sinha, Dyalachend, kulkarni, Vasuderan, Bolinger, 2008; Mitra, Jacobsen, O'Connor, Pottie & Tugwell, 2006). Bwirire et al. (2008) found that the reasons for poor follow-up among mothers in PMTCT were due to the fear of HIV testing, stigma, discrimination, non-partner support and challenges with infant feeding stigma.

5.2.2.2 HIV testing and HIV status acceptance reasons

- **HIV testing acceptance, freedom to live and HIV stigma rejection**

The second sub-theme under HIV testing perceptions relates reasons for HIV testing and HIV status acceptance. Chapter Five indicate that a number of women accepted HIV testing because they thought "*it is obvious that when you are pregnant you need to go through that…*" About nine other women also indicated that it is better to have knowledge of one's own HIV status than to be "uncertain" This shared view is reflected by one mother who had just given birth who acknowledged the importance of knowing ones HIV status in order to be able to enjoy life. She emphasised that the uncertainty about HIV status seems to be a barrier for enjoying life *"One needs to know his or her own status in order to be able to live life. If you do not know your status, it means you cannot enjoy life because you will always worry about what if [I have HIV]…"* In support of the above excerpt, another participant who was waiting for infant HIV PCR test results considered knowledge of HIV status as a means of giving one a freedom to live "*... when you have tested [for HIV] it is better than if you had not. If you have tested and they tell you that you are [HIV] positive you are able to be free."*

Although most of the participants have accepted their HIV status, their lived experiences reveal that some found it easy to do so whilst others did not. An easy acceptance of HIV positive status was reflected by a 25 year old mother who had just received a negative infant HIV PCR test results who indicated that "*after being counselled, she just accepted that she is HIV positive*", whilst four other participants accepted their statuses because they believed "*they were not the only ones living with HIV*". HIV status acceptance for some HIV positive women was determined by the factor of time. As shared by one participant, although she has accepted her HIV positive status, "*that did not happen the same day*", she goes on to say, "*in their eyes* [healthcare providers] *she had accepted but deep down, she had not*." This suggests that the HIV

positive women's continuation of the other PMTCT cascade processes is affected by the HIV acceptance period. For instance, if the mother takes long to accept her HIV positive status, this delays the seeking of health interventions for herself and her child. The current interventions related to utilisation of the PMTCT processes do not necessarily address this challenge from the point of view of a rural context. Therefore, understanding context barriers is important in addressing PMTCT non-utilisation barriers (Thompson et al. (2012). Studies have shown that HIV testing lowers risky behaviour among HIV positive people (Denison, O'Reilly, Schmid, Kennedy & Sweat, 2008). The current study shows that knowledge of HIV status also frees HIV positive women from engaging in risky behaviours, which implies that knowledge of HIV status acts as a protective measure (Sweat et al., 2011). Other studies show that HIV testing provides an opportunity for one to know their HIV status early (Njunga & Blystad, 2010) in order to be able to make informed choices about life (Kasenga, 2010).

Although stigmatising behaviour is often presented in the form of gossips (Abrahams & Jewkes, 2012), a few participants indicated that acceptance of HIV status is key. As illustrated by below except if one has accepted her situation, issues such as gossips should not affect them.

> *"… Yes people will talk saying why is so and so [like this]… without them knowing their own situation, but they gossip about you saying they have heard something about so and so. But as long as you have accepted it, even if someone is saying something, they can say it as long as you have accepted that I am like this. You are not supposed to be stressed by an outsider, you are not supposed to give stress a chance to affect you, you have to forget about it…"* ***(Mother who received infant HIV PCR test results, 25 years, single, 2 children)***

This indicates that fear of stigma is often there among HIV positive people (Abrahams & Jewkes, 2012) however, HIV status acceptance is a good way of fighting the HIV stigma. According to some participants, another facilitator for HIV status acceptance is the adjustment of personality traits. Besides the time it takes for HIV status acceptance, some HIV positive women in this study indicated the importance of adjusting some of their personality traits as another strategy for facilitating HIV acceptance. Having personality

traits such as self-love, becoming patient and gaining the ability to deal with community perceptions of people who are HIV positive was deemed necessary. These traits are employed by some HIV positive women participating in the PMTCT programme as strategies to avoid HIV stigma and discrimination concerns. Turan and Nyblade (2013) assert that stigma and discrimination affect the implementation of the PMTCT processes. Similarly, Hardon et al. (2012) found that HIV stigma is still a challenge among HIV positive pregnant women, however, unlike the current study, Hardon's study did not express strategies employed by the participants. Similar to findings of other studies, HIV positive women in the current study suggested that HIV stigma may be presented in the form of gossip (Bond et al., 2002; Abrahams & Jewkes, 2012). As such, HIV stigma could lead to a change in behaviour during antenatal care. Some HIV positive women in the current study suggested that the lack of love for self is shown by not participating in the PMTCT processes (such as HIV testing), in order to avoid stigma and discrimination. Msellati (2009) indicated patient movement during antenatal care and found that women with a known HIV positive status prefer using other health facilities if they fell pregnant again. This was done to avoid the embarrassment of falling pregnant a second time while HIV positive.

Some HIV positive women in the current study indicated that self-love could assist in reducing the effects of stigma and discrimination on themselves. A mother aged 41 years and had just given birth said "*… those who are in the same situation as hers should have a patient heart, and they must have love, meaning they must start by loving themselves."* She goes on to say, "*loving self will encourage other people to love you. They will love you, they will not be pointing fingers at you…….if you feel ashamed of yourself, they will also feel ashamed of you…"* This Chapter shows that some HIV positive women in this study believed that stigma and discrimination affect people because they lack self-love. As such, they believed that having self-love would stop people from paying attention to the negative remarks made by fellow community members. According to these women, self-love means caring about oneself, positive thinking and self-acceptance. It also involves having the belief that one has value and is a worthy person. One participant appeared to believe that self-love would automatically allow her to receive appreciation and love from others. This suggests one of the powerful strategies for dealing with HIV infection in the context of PMTCT in a rural setting.

- **Child protection**

Analysis further shows the narratives given by women for HIV testing acceptance. Most HIV positive women were found to be generally knowledgeable about the benefits of HIV testing, which were mostly for the protection of the unborn child. A 25 year old woman waiting for infant's HIV PCR test results shared the repercussions of HIV testing avoidance in this way:

> "*It is painful to give birth being [HIV] positive and the child becomes positive because of you not wanting to test. In the end, that child will leave [die] you and then you will start having a sore heart...*"

As shown above, this participant believed it would be upsetting to avoid HIV testing intentionally, whilst aware of one's own HIV positive status. This is a shared view by most women in the study which seem to suggest that participants knew about the pros and cons of not being tested for HIV especially if one is pregnant. This Chapter also demonstrates an important factor that HIV positive women in this study seemed to lack the knowledge that HIV testing may also be beneficial to the mother. They emphasised the importance of HIV testing in order to avoid giving birth to a child who is also HIV positive. Similar results were found in other studies where the majority of participants acknowledged the importance of HIV testing for pregnant women because of the high possibility of transmitting HIV to the child if not tested (Adedimeji, Abboud, Merdekios & Shiferaw, 2012; Boyd, Simpson, Hart, Johnstone & Goldberg, 1999; Rothpletz-Puglia & Storm, 2012). This indicates that HIV testing is generally acceptable as a form of child protection (Etiebet, Fransman, Forsyth, Coetzee, & Hussy, 2004; Hardon et al., 2012; Levy, 2009). However, unlike the HIV positive women in the current study, Levy found that participants showed knowledge that HIV testing would also preserve the mother's health. This is because once the mother is aware of her HIV positive status, she may receive the required intervention on time, for both herself and her child (Levy, 2009). Again, unlike some HIV positive women in the current study, who indicated that HIV testing acceptance was for the child's protection, Bajunirwe and Muzoora (2005) found that the demographic factor of age was the highest predictor of acceptance of HIV testing. The current study does not reflect participants' knowledge of global efforts to reduce the spread of HIV by keeping both mother and child healthy and alive

(UNAIDS, 2011; UNAIDS, 2012). Therefore, this seems to suggest a lack of PMTCT knowledge by the HIV positive women.

- **Peer HIV counselling**

"Her counselling me now made me feel like a person again because I didn't feel like it…"

The results further reveal the reasons for HIV status acceptance. A number of participants shared their lived experiences about the peer counselling services they received from the healthcare facilities, upon receiving their HIV positive diagnosis. This study revealed the importance of using peer counsellors to support HIV positive women in the PMTCT programme, as an initiative that was well appreciated by all the participants. Knowledge of HIV status was seen as a vehicle for receiving the necessary support from the community and healthcare providers. This is reflected by one woman who urged other women to "*go and find out about their HIV status so that they can get all the necessary support from the [community] people, clinic and peer counsellors."* The fact that the participants were counselled by a person who is also HIV positive made them feel comfortable and encouraged to open up about their lived experience of being HIV positive. One of the participants articulated the peer counselling in this way *"Sister [name of counselor] counseled me and told me about herself [that she is also HIV positive], so I was happy and I became open when she explained to me…*" Most of the HIV positive women in this study indicated a number of factors that suggests the effectiveness of peer counselling in the PMTCT programme. For example, the peer counsellors were regarded as being instrumental in HIV disclosure to family, HIV acceptance and a change in mindset of how participants perceived being infected with HIV. A 35 year old mother provides a good example of how peer counsellors make some HIV positive women feel in this study context as shown on below excerpt.

> *"… Her counselling made me feel like a person again because I didn't feel like it, I was thin, but after her counselling she reminded me of my importance in the world, [and that] children need love. She said I must get counselling so that the baby growing inside me must not get any complications and come to the world in a good condition… It [peer counselling]made me realize that I can live my life… this person [peer counselor] has told me that she is like this[HIV+] and living her life, so why can't I. When I came back from the hospital ….. I told her*

[name of counselor] that I am going to tell them [my family about my HIV status] because I have to get their love."

Throughout their experiences of being counselled by the peer counsellors, the participants developed self-worth and felt a desire to live their life again. The above excerpt shows an example of trust that some HIV positive women had towards the peer counsellors. They had no fear as they did with the healthcare nurses. Interesting is that peer counselling is also seen as a weapon that leads to acceptance of physical appearance. Therefore, this Chapter seems to suggest that the interaction between peer counsellors and HIV positive women allowed the women to better understand the PMTCT messages given by the nurses through peer counselling exposure (Agadjanian & Hayford, 2009). Chapter Five therefore shows participants' preference of knowing their HIV status (Levy, 2009) for care and support (Hardon et al., 2012; Department of Health, South Africa 2009). The data for the current study further revealed that because the peer counsellors were also HIV positive, participants understood them better. A study conducted in Malawi showed high antenatal service utilisation rates of 98% and postnatal utilization service rates of 97.5% by mother-infant pair through the PMTCT cascade, when peer counsellor services were utilised (Kim et al., 2012). In this study they found that community health workers reduced disparate clinic services and improved the retention and utilisation of PMTCT services. A study conducted in Zimbabwe in a resource-limited setting also found that using peer-mentors was feasible in the PMTCT programme (Shetty et al., 2008). A pilot study conducted in South Africa also showed that the involvement of mentors, who were also HIV positive, augmented PMTCT service utilisation because of information and emotional support provision to HIV positive women (Futterman et al., 2010). The lived experiences of the HIV positive women in the current study support the findings from previous literature that peer counselling is key to the utilisation of PMTCT services in any setting. The narratives provided above by the HIV positive women, provides an understanding of HIV testing perceptions in this rural context.

5.2.2.3 Fear of HIV disease among HIV positive women

The third sub-theme under HIV testing perceptions shows that some HIV positive women highlight the 'fear' of HIV disease. For instance, this fear is shown by one participant who sees HIV as a disease that is very scary and that non-timeous HIV testing would consume the blood of human beings. This woman believes that *"...if you test after a long time, it would have*

already eaten your blood." This is an example which shows that HIV is sometimes humanised and equated to something that consumes the blood, as a way of conveying the negative repercussions of not knowing ones HIV status timeously. The fear that HIV consumes the blood seems to reflect the societal and cultural beliefs that women in the rural communities have about the disease. Furthermore, one participant reflected on some cultural beliefs that people in the community have about HIV and she said "*Many people say they have been bewitched, or they have been exposed to some demeanors, whilst suffering from this same disease [HIV].*" In concurrence, Thompson et al. (2012) argued that it is important to understand context specific barriers in dealing with interventions for reducing HIV, whilst Busza et al. (2012) argued that understanding health, religious beliefs and cultural norms is equally important. Cultural norms could include the belief that HIV is caused by witchcraft. Other studies found that beliefs relating to witchcraft or religion lead to seeking alternative treatments which are more aligned with such beliefs (Roura et al., 2010; Wanyama et al., 2007). In this context, witchcraft beliefs might also delay utilisation of PMTCT services, therefore future interventions needs to consider this.

Some participants' fear of HIV was also revealed by their past experiences of HIV testing, as well as the emotions that they felt when collecting their HIV test results. An example of that is shown by below excerpt from one participant.

> *"They tested me. Isn't at that time you would be afraid to come and get the results, you would think how will people perceive me, do you understand? [So] I did not fetch my results [and because of that, I did not] know what my situation was. But with the second one, I was even starting to say, when you are like this [HIV positive], you have to do that, when you are like that [HIV positive], you have to do this. I [have] accepted [my status]. I [have] accepted and I have started taking my treatment."* ***(Mother who had received infant HIV PCR test results, 33 years, single, 3 children).***

As part of the antenatal care lived experience, some HIV positive participants highlighted their past perceptions of the HIV disease. An example presented above showed a woman being afraid of collecting her HIV test results the first time when she was pregnant. However, this feeling changed after she was diagnosed with HIV and received information about the importance of HIV testing. This scenario reflects some behaviour in this study

context that might negatively affect the goal of PMTCT. It seems to suggest that some HIV positive women in the study context take HIV testing seriously only after they had been diagnosed as HIV positive, implying a difference in health seeking behaviour in the absence of the HIV diagnosis. This suggests that the state of well-being leads to utilisation or non-utilisation of healthcare services. Msellati (2009) indicated that there are many studies which show that a high number of pregnant women "fear and refuse HIV testing" (p. 838). Even though women fear HIV testing, studies have shown that they often change their minds during the follow-up consultation. Homsy et al. (2007) found that fear of testing for HIV was due to feeling that, knowing that one is HIV positive would accelerate the HIV disease. Other studies showed that a fear of HIV testing is likely to be minimal once the testing programme has existed for a longer time (Urban & Chersick, 2004). In concurrence, other studies found that testing rates often start off low and increase over time (Igumbor, Pengpid & Obi, 2006). Despite the sense of fear associated with HIV testing, other studies have found that routine pre-natal HIV testing is generally acceptable to the women attending antenatal care (Podhurst, Storm & Dolgonos, 2009); Chou, Smits, Huffman, Fo & Korthuis, 2005; Chandisarewa et al., 2007).

The fear of HIV is shown again by the participants' fear of mentioning or saying the word 'HIV'. It is worth mentioning that all HIV positive women in the current study referred to HIV positive diagnosis as "positive", they refrained from using the word 'HIV', and they opted to rather use pronouns such as "it, this and that" to refer to HIV. An example which reflects all participants' non-use of the word 'HIV' is shown below.

> *"After discovering that I am like this [HIV+], I went to her [my friend] and disclosed my status because she was also able to come to me and tell me that she has that kind of a problem [also HIV+]. So when I found out that she was like that [HIV+], because I was seeing her living a normal life, I decided to not hide it from her..." (**Mother who had received infant HIV PCR test results, 35 years, single, 3 children**).*

Silence or not saying the word HIV suggests how HIV disease is perceived in the rural communities. There is still discomfort in saying it. This demonstrates cultural and linguistic barriers when dealing with diseases such as HIV. The use of pronouns and euphemisms by the HIV positive women reflects the difficulties that participants had in directly saying the

word ‘HIV’. Similarly, other studies have found that communication about HIV is not always easy and, therefore, could lead to the use of euphemisms (Watermeyer & Penn, 2008; Ware et al., 2009).

Women’s lived experiences further reveal that fear of HIV is reflected by child-birth experiences in the context of being HIV positive. Giving birth in this study, was characterised by fear “*…I was scared, I had told myself that for sure HIV people are not the type of people who would give birth naturally …”* The description of fear in this excerpt does not seem similar to the anxiety that women in general experience when giving birth. Similar fear was expressed by a 23 year old mother who said “*I got scared when I saw blood, babies crying, I got scared. When they checked my blood pressure, it was very high because of that fear…”* The fear described by these participants appeared to be fear of the unknown especially, for the unborn child, because of the mothers’ HIV positive status. The fear expressed by the participants seemed to be caused by the lack of knowledge of the PMTCT processes to come, especially those related to giving birth.

Analysis further shows that the fear of HIV also triggered thoughts of abortion to a few women in the study. It is important to note that most HIV positive women participating in this study perceived abortion as an act that is generally not acceptable because of the value of life. Even though this was reported as the case, data revealed that a few participants attempted and contemplated an abortion but failed because of gestational age and the non-effectiveness of the chemicals/ products used to abort their babies illegally. An example of a non-successful abortion attempts is presented below.

> *I tried to drink many things saying I want to take it out [abort the baby]. I drank stameta [medication for cleansing blood], it did not do anything. I just had diarrhoea. I remember that I had not told anyone that I am pregnant. I asked one of my friends that there is somebody who is pregnant and she does not want the child. By that time I was two months pregnant. She told me to use prevention [family planning] tablets. There is another red one, it makes blood to come out [menstruation]. The other one is white; it stops blood [menstruation]. I drank all the red ones [in a packet] they did not do anything.” (**Mother who had just given birth, 24years, single, 1 child**).*

A 30 year old pregnant woman on AZT treatment also shared the failure to do abortion due to gestational age "*When they checked me, they said I am 3months pregnant, I will not be able to do it [abortion]…I had stress but there is no way, we just have to keep the child because abortion issues has failed…"* The behaviour of these participants seems to indicate the lack of information on avoiding abortion by giving the baby up for adoption, if the baby is not wanted. However, the challenge that remains is that some women start antenatal care late, which hampers them from getting crucial information that would inform them should they not wish to keep the baby once they discover that they are pregnant and are also HIV positive. The attempts to perform abortion after being diagnosed with HIV seemed to indicate fear of HIV and the non-acceptance of a positive HIV status (Chi, Hanh, Rasch & Gammeltoft, 2010).

5.2.2.4 Fear of HIV disease among male sexual partners

"… he just said if I have it [HIV], it means he also has it…"

Besides the 'fear' of HIV disease by the women in the study, the fourth sub-theme under HIV testing perceptions reveal the 'fear' of HIV by the male sexual partners of the HIV positive women. The participants shared their lived experiences on the dynamics they were encountering or had encountered in their relationships, regarding adherence to the PMTCT cascade processes. Chapter Five reveal partner dynamics relating to male partner HIV testing. A few of the HIV positive women in this study indicated that their partners expressed a willingness to test for HIV, while most of the participants raised convincing their male partner to test for HIV as a challenge. Even though male partners knew about their female partner's HIV status, they still found excuses not to test. One 27 year old pregnant woman shared her frustration of having to convince her partner to test for HIV *"…he knows that I have tested. He tells me the same thing that he tests at work, you know male people are always in denial…"* This seems to indicate a lack of interest in HIV testing by some male partners as shared by the participants. Their non-willingness to test suggests a possible lack of knowledge about the benefits of HIV testing in relation to the PMTCT programme or they have fear for doing it.

Similarly, Homsy et al. (2006) found low rates of male involvement in antenatal care programmes. The issue of partner testing remains a challenge, as it has been highlighted in

numerous previous studies (Manzi et al., 2005; Medley, Garcia-Moreno, McGill, & Maman, 2004; Bwirire et al., 2008). A study conducted in South Africa showed that men are hardly involved in reproductive issues, including family planning and antenatal care (Mullick, Kunene & Wanjiru, 2005). Studies have shown that, usually, when a male partner does not support the female partner in testing for HIV, he would not test and that his partner would also refuse HIV testing (Sarker, Sanou, Snow, Ganame & Gondos, 2007; Dahl, Mellhammar, Bajunirwe & Björkman, 2008). Numerous studies have emphasised male involvement during antenatal care services as a strategy for preventing vertical HIV transmission (Kasenga et al., 2010; Nkuoh et al., 2010).

The lived experiences of HIV positive women in this study further showed that some male partners had a prevailing perception that they do not have HIV as a result of religious beliefs. A 43 year old mother shared one reason that is given by her partner for not testing.

> "*I told him [about] my status but he is refusing to go and test…he knows where he stands, he is hiding it from me, but I am free, I told him…[he always responds by saying] I do not have that thing, I drink my tea, I am an [X Church member], I do not have that thing [HIV]" (**Mother who had received infant HIV PCR test results received, 43years, single, 5 children**).*

The current study provides additional factors for male non-involvement on PMTCT processes such as HIV testing. This complements an existing literature which reveals men's constructions on the reasons why antenatal programmes were not tailored to them. For instance, they reported that the HCPs' attitudes were not appealing (Homsy et al., 2006; Mbonye et al., 2010); cultural role of male is violated (Mbonye et al., 2010; Tonwe-Gold et al., 2009) and antenatal care is known to be societal ridicule of man (Theuring et al., 2009). Most of the HIV positive women in this study expressed that their partners believed that the woman's HIV status mirrored their own. One pregnant woman aged 22 years said "*…He is not angry, he just said if I have it [HIV], it means he also has it…"*

Similarly, Rujumba (2012a), Homsy et al. (2006) and Msellati (2009) found misconceptions, where male partners inferred their own HIV status based on the female partner's status. Although women in a study conducted by Peltzer, Skinner, Mfecane, Shisana, Ngeketo, & Mosala et al. (2005) indicated the importance of male involvement in PMTCT for its

effectiveness, the HIV positive women lived experiences in the current study showed reluctance towards men going to the healthcare facility. Studies conducted in Cameron have shown that although men (79%) generally report that they accompany their female partner to the healthcare facility for antenatal care, only a few men actually practice this behaviour (Nkuoh et al, 2010). The full participation of men is prohibited by socio-cultural barriers and traditional gender roles that emphasise that a man is supposed to provide financial support to the family. In the above study, it was found that 30.6% of men indicated that it was not good to accompany their partner to antenatal care services, although they had knowledge that ARVs reduce the risk of infecting the unborn child with HIV. Tshibumbu (2006) highlighted a differing view, that culturally a man is regarded as bewitched if he accompanies the wife to the clinic. In other studies it has been suggested that a man who accompanies his wife to the clinic is a jealous man who does not want other men to speak to his wife. Male involvement has shown improved retention of PMTCT services (Betancourt et al., 2010), however, for the current study, that has not been realized.

The avoidance of HIV testing through self-inference of HIV infection and using religion as a scapegoat for non-testing, seems to suggest fear HIV testing by the men. One woman shared an observation about male practices when it comes to utilisation of healthcare facilities.

> "*…to tell you the truth, that side where I stay, the issue of testing…I am telling the truth I have never seen a person from that side coming to the clinic, I come to the clinic often but I have never [seen them]" (**Pregnant woman on AZT, 30years, single, 1 child**).*

Similarly, other studies have found that the reason for the lack of male participation in PMTCT processes seemed predominantly due to a fear of HIV testing (Bwirire et al., 2008; Magagula and Mkhatshwa, 2004). Other studies argue that stigma and non-acceptance of HIV disease as a reflection of denialism (Heywood, 2004). Some HIV positive women also shared some of the misconceptions about and the lack of trust/ belief in the HIV test by their male partners and other men in their communities.

> *"Most of the boys are saying the tests [HIV] are lying they are not telling the truth. They say when you test [HIV] this month it will say negative and when you test again next month it will say positive. They say one will only test when*

*he is seeing that he is dying…" (**Mother waiting for infant HIV PCR test results, 30years, single, 2 children**).*

The above excerpt suggests that HIV testing for men happens when they are in the last stage of the disease. The lower risk perception of a disease causes health seeking behaviours to be poor (Wringe et al., 2008). Acceptance of susceptibility has been shown to influence action taking (Rosenstock, 2005). The participants further reported men's beliefs on how HIV is acquired. For example, some men in the community believe that the act of HIV testing implies that they infect them with AIDS because the HIV test results are always positive. A 21 year old mother who had just given birth said "*…others say it is the same, you go to the clinic because you are sick, they test you to check if you have AIDS or cancer or TB or Asthma. When you go to the clinic because you are sick [let's say] you have flue, they will start by checking HIV and other diseases like TB…"* The above excerpt shows the lack of knowledge about the benefits HIV testing by the male partners of the participants. It also reflects the misconceptions and fear of HIV testing which have the potential to debilitate PMTCT effectiveness. The next section discusses HIV treatment lived experiences which also forms a very important part of the PMTCT cascade processes.

5.2.3 Theme 3: Fear and HIV treatment perceptions

Theme three gives an account of the HIV treatment lived experiences which is also a critical step for the PMTCT cascade process. It provides the narratives of HIV treatment perceptions for preventing the baby from being infected with HIV. The narratives of the HIV treatment are discussed by focusing on the four sub-themes falling directly under this theme namely: HIV treatment understanding, adherence and impact, treatment buddy views, infant negative HIV PCR test results and treatment challenges.

5.2.3.1 HIV treatment understanding, adherence, and impact

"Treatment helps quite a lot lot lot lot!...It's like when you have a headache…to be fine, you need a headache tablet."

The first sub-theme focused on participants' HIV treatment understanding, adherence and impact. Chapter Five reveals that all women in the study knew that Nevirapine tablet should be taken just before giving birth in order to prevent the child from contracting HIV. Such understanding is reflected by one woman who had just given birth who indicated that she knows that "*there is a tablet that she needs to take when she is having labour pains…they call it Nevirapine."* Another 26 year old mother of three also shared how easy it was to take Nevirapine table "*I tested and they gave me [Nevirapine tablet] and I took it on time and I never had complications…"* As discussed under theme two of this Chapter, this understanding could be attributed to the good service provided by the healthcare workers especially the peer counsellors during health education.

However, the excerpt below suggests that some participants in this study lacked knowledge about the actual treatment names. Such lack of knowledge is shown by a 21 year old mother who had just given birth to her first child who said "*it is just tablets, I have not read it."* Another mother was also not knowledgeable about the names of the treatment she was giving to her child.

> "*…At first, after birth they gave her [child] the medication, what do they call that medication? They gave her [child] the medication that she was supposed to take for 14 days" (**Mother who received infant HIV PCR test results, 35years, single, 3 children**).*

Although it was difficult to actually remember treatment names and other HIV terminology, an attempt was made by two women to use some terminology related to treatment. A 25 year old mother of two described her treatment packaging and also mentioned the first part of the name "*They gave me tablets, they gave me tablets in a pink box and they said they are called zido what what , the name is too long. The name starts with zido what what…."* Some participants actually spoke about having high CD4 count. One mother narrated what she was told at the healthcare facility "*They explained to me that because my CD4 count is still high, I will not receive [treatment]…"*

Common knowledge amongst all of the participants was the benefits of adhering to HIV treatment. Unlike the current study which found low knowledge levels of HIV and PMTCT terminology, Gilbert and Walker (2009) found that participants were very familiar with HIV terminology, such as CD4, viral loads etc., even though they did not understand what these

terms meant. Most of the participants in the current study indicated that they were not initiated on ARV treatment due to a high CD4 count at the time of study. This is in opposition to other recent studies which highlight the positive effects of the early initiation ART with a high CD4 count (Braithwaite et al., 2008).

Studies show that ART adherence in South Africa is influenced by the social, historical, cultural and geographical context of HIV (Gilbert & Walker, 2009). For some HIV positive women in this study, treatment adherence was influenced by social factors. For example, a few participants' treatment adherence was mainly ensured to avoid physical symptoms that could be easily seen by people. This is reflected by a 32 year pregnant mother on AZT who said "*I am able to live [a healthy life] and if people see me, I do not show the [signs] of whether I am sick or not."* This finding is in line with that of Castro and Farmer (2005) who argued that ARV minimises the visible signs of HIV. Not wanting the symptoms to show is due to the anticipated societal stigma of HIV. A few women in the current study spoke about normalising HIV treatment as a facilitator for adherence "*Treatment helps quite a lot lot lot lot!...It's like when you have a headache…to be fine, you need a headache tablet*." Gilbert and Walker (2009) explored the social complexity of ART in South Africa and found that the fear of stigma was dominating patients' experiences of HIV, even though they believed that ARVs were normalising their lives (Pierret, 2007). Participants also reflected knowledge of the importance of proper timing of antenatal care. For example, they associated early attendance of antenatal care services with early access to treatment for preventing the child from contracting HIV. The women in the current study adhered to the Nevirapine for the sake of their children's health (Gilbert & Walker, 2009).

5.2.3.2 Treatment buddy experiences

The second sub-theme under fear and HIV treatment perceptions is that of treatment buddy experiences. The data showed that only two participants expressed that they had treatment buddies, or people who were also HIV positive were supporting them for treatment adherence purposes. This suggests that the concept of the treatment buddies is not yet fully integrated in the PMTCT services in Mpumalanga. In this Province, there are individuals referred to as family treatment supporters, who are normally requested when the HIV positive patient initiates treatment. Family treatment supporters' credentials are not normally verified to

check that they are indeed family, a friend, an acquaintance or even a stranger. Having family treatment supporters forces one to disclose their HIV positive status regardless of their state of readiness. A mother of five children shared how treatment buddies facilitate adherence to treatment.

> "*My friends are also on treatment, we always remind each other. I always say, friend, you know what, the time for you to go for treatment has come. Go to get treatment…do not wait to be bedridden, if you can be bedridden, know that that is the end with you. Go to the clinic and do not be afraid of people. If you are scared of people, [it means] you are always scared for your body… listen to what the nurses are saying, take your treatment."*

Chapter Five shows that treatment buddies were also suggested to assist in dealing with issues of perceived or self-stigma (Stinson & Myer, 2012; Kasenga et al., 2010) and fear. Other studies also points reciprocated support as one of the benefits for having treatment buddies (Abrahams & Jewkes, 2012). However, one pregnant woman in the current study was totally against treatment buddies because she felt that she will be reminded of her HIV status "*Because we will always talk about that thing [HIV], so it will always be in our thoughts, that will disturb me… [for instance] while we are seated we start talking about the same topic [HIV], after few instances we start again, you see…I am not happy with having a buddy*." This shows how this woman yearns for HIV disease to be normalised and not be a central topic of discussion. However, it also reflects her fear of stigma even by people in a similar situation. Thus the involvement of treatment buddies would encourage people to avoid thinking about what other people would say but at the same time, this study suggests that it makes one to always remember that they are HIV positive.

5.2.3.3 Infant negative HIV PCR test results

The third sub-theme under fear and HIV treatment perceptions is that of infant negative HIV PCR test results. Although other studies have found low rates of infant HIV testing (Doherty et al., 2003a; Sherman, Jones, Coovadia, Urban & Bolton, 2004), the HIV positive mothers in the current study took their babies for HIV PCR testing, and those whose children had just been born or those still pregnant all expressed the intention to take their babies for HIV PCR

testing. Most mothers in this study reported that their infants were HIV tested and that the results were negative for HIV. Below excerpt shows the expression of two mothers who received negative infant HIV PCR test result.

> *"When I received the results for the baby [!], I was happy because you know he was negative [HIV] and that made me realise that at least I was able to follow the rules [PMTCT rules], so it was better…" (**Mother who received infant infant HIV PCR test results, 26years, single, 2 children; Mother waiting for infant HIV PCR test results, 24years, single, 1 child**).*

According to most participants in this study, the negative infant HIV PCR test suggests the effectiveness of the PMTCT programme and the excellent work that the healthcare workers did in terms of the educational messages they gave to patients. In a study conducted by O'Gorman et al. (2010), grandmothers and male partners were found to be influential in motivating women to bring their babies to receive Nevirapine syrup at the healthcare facility. This study showed that the involvement of other family members in the PMTCT programme significantly improved PMTCT uptake, adherence to treatment and provision of emotional support (Magagula & Mkhatswa, 2004; Peltzer, Mosala, Shisana, Nqueko & Mngqundaniso, 2007).

The data from this study further showed that the waiting period for the infant HIV PCR test results for most women was characterised by a lot of anxiety and fear about the outcome of the test "*I waited for the baby results for 3 weeks. I was [stammering], I was scared that maybe he will come being HIV positive, I was very scared*." The HIV positive women appeared to have a desire for their children to have healthy lives. According to these women, the anxiety was caused by the fear of stigma that would occur if the child tests positive and the lack of trust in the PMTCT programme. One woman said *"It's like I have this thing of not trusting that he/she can be negative."*

Similarly, other studies have found that HIV positive mothers doubted the efficacy of the ARVs for MTCT (Duff, Rubaale & Kipp, 2012; Levy, 2009), while other studies have suggested that the ARV prophylaxis could harm the unborn child (Towle & Lande (2008). There are no studies that address the interventions that are needed for the HIV positive mother during the waiting period for infant HIV PCR test results. Having such interventions

within the PMTCT programme might have the potential to facilitate adherence to PMTCT cascade services postnatally.

5.2.3.4 HIV treatment challenges

> ***"And my friends kept on asking why do l always go to the clinic, is it not because you are taking ARVs?"***

The fourth and last sub-theme under fear and HIV treatment perceptions is that of HIV treatment challenges. It reveals numerous HIV treatment challenges that have the potential to hamper the effectiveness of the PMTCT programme. The first challenge concerns the lack of a centralised system with regard to ARV administration in the healthcare facilities of the Dr JS Moroka sub-district. For instance, one participant raised a challenge of not being able to access treatment in different healthcare settings. This 26 year old mother shared her frustrations in trying to access treatment at different sites *"I have a problem, they never help me [give me treatment] because I take my treatment at [name of healthcare facility]. They said I must bring a letter, they never wanted to hear my story…it's like when you go there, you need to take a referral letter from where you come from, so they do not welcome everybody."*

The above scenario reveals a need to adhere to PMTCT processes (such as taking treatment) by some HIV positive women, however, they are prevented from doing so by the structure of the existing healthcare system. As a result, if this health system barrier is not addressed, it could lead to continuous non-utilisation of PMTCT services. The other challenges experienced by the HIV positive women when it comes to adhering to treatment were related to fear of HIV status disclosure. Some participants did not feel free to adhere to treatment because of the non-disclosure of their HIV status to their social networks. An example below reflects other similar situations that affect HIV positive women which ultimately lead to poor adherence to HIV treatment.

> *"…it was tough, sometimes I would be with a friend and having it [treatment] but [you will find that] I am scared of taking it. Then I asked myself where will I end with this thing of being scared of taking treatment in front of my friends? And my friends kept on asking why do l always go to the clinic, [they asked me]*

is it not because you are taking ARVs? They said to me, every time you are at the clinic, a week does not go by without you going to the clinic, why? You are always not well, is it not because you go there to get ARVs? You are HIV positive and you are scared of disclosing to us? I said to them, when I am HIV positive, I will tell you…" ***(Mother waiting for infant HIV PCR test results, 26years, single, 1 child)****.*

The lived experiences of some of the HIV positive women in this study show that fear of HIV status disclosure leads to treatment non-adherence. Even though the participants expressed a desire to adhere to treatment, they were faced with social network barriers which mostly involved anticipated stigma. This point is highlighted by other studies which show that women may not follow specific PMTCT programme recommendations because of stigma (Thorsen et al., 2008; Kebaabetswe, 2007; O'Gorman et al, 2010). Another participant mentioned that she found herself being 'scared' of taking treatment in front of her friends because of HIV non-disclosure. According to Gilbert and Walker (2009) the fear of taking HIV treatment is mostly due to non-disclosure of HIV status and fear of being stigmatised and discriminated against because of HIV. Similarly, other studies have also found that HIV non-disclosure could lead to poor treatment adherence (Mepham et al., 2011; Kasenga, Hurtig & Emmelin, 2010; Laher et al., 2012). Hence, these results are not surprising as they suggest that treatment challenges could affect the effectiveness of the PMTCT programme. Other treatment challenges related to ARVs being a lifelong treatment. One participant said "*…You are not supposed to take it because a lot of times when you start taking treatment and leave it, you will get sick…"* This suggests that having the knowledge that ARVs are a lifelong treatment leads to late treatment initiation because of the fear of being sick (in a case where there is non-adherence). This suggests that PMTCT messages need to be delivered in a way that would not discourage people from initiating treatment early. The next section discusses HIV disclosure and non-disclosure lived experiences which also forms a vital role in the PMTCT programme.

5.2.4 Theme 4: Fear causing a dilemma between silence and telling

The next narrative account provided by the HIV positive women is on HIV disclosure at different levels. Non-HIV disclosure reasons were also provided. The narratives about HIV

disclosure and non-disclosure are presented on Figure 5.3 and they reflect the three sub-themes falling directly under this theme: Family HIV disclosure, partner HIV disclosure and HIV non-disclosure reasons.

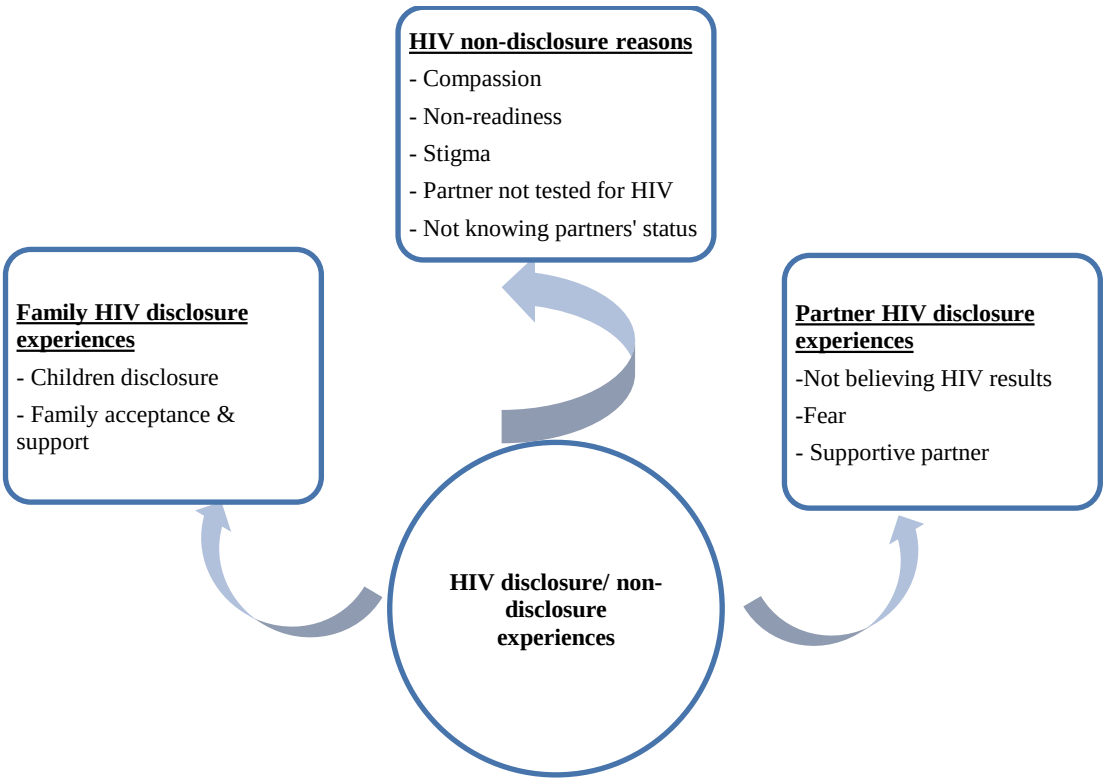


Figure 5.2 Lived experiences of HIV disclosure and non-HIV disclosure

5.2.4.1 Family HIV status disclosure

"*At home they told me that because I am pregnant, I need to stop stressing*".

The first sub-theme under the main theme of lived experiences of HIV disclosure and non-disclosure is family HIV disclosure. The participants lived experiences show many levels of HIV disclosure within the family such as disclosure to the mother alone, mother and father, aunt, own children, grandmother alone, sister alone and the whole family. Although there were many levels of HIV disclosure, the lived experiences of the HIV positive women showed that HIV disclosure within the family had positive spinoffs. After disclosing their HIV status to family, participants expressed that they always received support, in the form of advice on healthy eating and how to live as a pregnant woman,

especially one who is HIV positive. One participant shared the reaction from her family after disclosure and how the mother continues to advise her healthy eating *"She [my mum] knew what positive people were supposed to eat. So even when I was pregnant, they used to buy me veggies [vegetables] and fruits. They [my family] never shouted at me saying I was not looking at myself doing whatever, whatever…they shouted at me the first day and then after that they never did it again."* Another mother who had just given birth reiterated that her family supports her and that she never hid her HIV positive status *"At home they support me, I told them the truth at home. I told her [grandmother] straight that I am [HIV] positive. My grandmother understands, I told her first and then when my mum came back I told her, they both understand."* One woman also said "*My family is supporting me, they are supportive, they give me love"*

According to the HIV positive women in this study, family support post HIV disclosure is critical for the success of the PMTCT programme. For instance, participants indicated that support leads to adherence to PMTCT processes, such as attendance of antenatal care, postnatal care, treatment adherence etc. Chapter Five shows loving family relationships post HIV disclosure (Abrahams & Jewkes, 2012). Unlike the findings of a South African study, which found that pregnant women could only disclose their pregnancy to their in-laws when they started to show (Skinner, Mfecane, Henda, Dorkenoo, Davida, & Shisana, 2003), the women in the current study were mostly single and only struggled to disclose their HIV status to the family or partner. This was because of self-disappointment and not wanting to burden their family with their HIV positive status. This feeling was intertwined with the fear of disclosure, due to fear of community stigma which was anticipated by most of the women in the study and not knowing how the family will react.

One participant shared that HIV disclosure from parent to children and vice versa was well accepted, without any form of discrimination. She reported that she had received an overwhelming support from her children, without being judged. Her narration on how she disclosed to her children follows *"I told my children and they do not have a problem, they said I am their parent who gave birth to them, so they will not forsake me. [They said] we will live with you the way we used to live, again we love you for taking us to school even though you are suffering…"* In this case, children were found to be the source of encouragement for the participant to fully accept her positive HIV status. The current study also found that when children disclose their HIV status to parents, they equally received support from

them. As a result of this support, children are encouraged to accept their positive HIV status.

> *"At home they told me that I need to accept [my HIV status], but in the beginning, my heart was painful. I used to be stressed a lot…Then I stopped and I started living the way I used to live before…" (**Mother waiting for infant HIV PCR test results, 24years, single, 1 child**).*

The lived experiences of HIV disclosure clearly suggest that the family unit is a very important component of the PMTCT programme. Given family support, post HIV disclosure, PMTCT processes would be adhered to properly. Studies have shown that HIV disclosure is central to the PMTCT programme, because it facilitates adherence to the PMTCT cascade and is crucial to ending HIV related stigma (Obermeyer et al., 2011).

The analysis of data suggests that participants mostly disclosed HIV status to their mothers first. Similarly, a study conducted in Botswana found that mothers and sisters were the first people with whom the HIV positive status was shared (Eide et al., 2006). Kasenga (2010) also found that the first point of HIV disclosure was mothers, followed by other close family members and friends. Disclosure to mothers seems to assist in HIV status acceptance and in providing general emotional support. As found in the current study, review studies showed that HIV disclosure is linked to support expectation (Obermeyer et al., 2011; Kasenga et al., 2010). These studies have also shown that HIV disclosure is higher in cases where the person feels that he or she will get help, and alternatively very low in cases where he or she does not believe that support will be given. Makin, Forsyth, Visser, Sikkemma Neufeld and Jeffery (2008) showed that women are likely to disclose their HIV status when they feel supported. Research has generally demonstrated that even though HIV disclosure is shocking at first, family and significant others are supportive (Lee et al., 2010; Makin et al., 2008; Visser, Neufeld, De Villiers, Makin, & Forsyth, 2008; Falnes et al., 2011). Studies have suggested various positive spinoffs that HIV disclosure may harvest, such as family support, improved access to care and low vertical HIV transmission rates. On the contrary, there are also negative spinoffs, such as stigma, discrimination and relationship catastrophes (Makin et al., 2008; Rodkjaer, Sodemann, Ostergarrd, & Lomborg, 2011; Visser et al., 2008).

HIV disclosure is not always an easy process. Brou et al. (2007) noted that disclosure can take place at four levels or points in time: onset of pregnancy, during antenatal care, during infant feeding choice or when resuming sexual activities. In the current study, women's HIV disclosure appeared to depend on the readiness of the individual at each of the stages mentioned. A study conducted with HIV positive mothers in Bangkok found that 70% of the mothers disclosed by 1 month and 24.7% by 4 months (Skunodom et al., 2006). In the current study, some women's HIV disclosure only took place after the death of the child as shared by this 25 year old mother "*Its long that I have told them after I buried my second child, I told mum because dad is not there. I came with a death certificate and said the child died of AIDS sickness."*

This suggests that the reasons for HIV disclosure continue to vary, as they are influenced by many factors, such as a stressful situation. Alternatively, Ross, Stidham and Drew (2012) argued that the predictors of HIV disclosure were specifically older age, employment and a strong support system. For the current study, HIV disclosure to family was done to receive support. The next section deals with another component of disclosure, related particularly to sexual partners.

5.2.4.2 Partner disclosure and support and dynamics

"Even though I kept on saying go and test, I did not know that I am HIV positive…"

The second sub-theme under the lived experiences of HIV disclosure and non-disclosure is partner HIV disclosure and support. HIV disclosure has been known to dissolve or build relationships. The HIV positive women in the current study raised varying views about HIV disclosure to partners. Almost half of the participants disclosed their HIV positive status to their male partners. Although some partners were in shock, they showed them love and compassion by providing positive comforting words. An excerpt below by one of the participants reflects the sexual partner reaction towards HIV disclosure.

> "*When I left this place [clinic], I went to the public phones, I bought airtime and called my man [partner] and I told him [that I am HIV positive]. He kept on saying he does not believe it, even now he does not believe it…When I told him that I am like this [HIV positive], he [now] loves me more. He does not believe*

*that this thing [HIV] is there (**Mother who had just given birth, 36years, married, 1 child**).*

The lived experiences of some of the HIV positive women in this study suggest the stereotypical behaviour that is normally observed in men regarding their perceptions of the HIV disease. Such stereotypical behaviour includes not believing that HIV disease exists. Interesting about the above excerpt is that even though the partner does not believe that the participant is HIV positive, she sees him as more loving after HIV status disclosure. In a study conducted by Hardon et al. (2012), it was found that partner disclosure took place in only one-third of HIV positive women. In concurrence with the current study, Hardon et al. (2012) also found that one participant mentioned that their male partner did not believe their HIV test results when they came back positive. Furthermore, some HIV positive women in this study feared disclosing their HIV positive status to their partners until there were symptoms of a disease. One participant shared her fear of HIV disclosure to the partner as shown on below excerpt.

"*… But I stayed without telling my partner, I was afraid of telling him straight, busy winding and winding, but its long since I have been telling him to go and test [for HIV]… I went to him and told him that you must know that I am pregnant, but I did not tell him that I am positive. I was afraid of telling him until he had chicken pox and went to the clinic, they said to him let's test you first. Then he called me saying they are saying I am positive [HIV]…it was then that I told him that even me they say I am positive (**Mother who received infant HIV PCR test results, 25years, single, 2 children**).*

The HIV positive women's lived experiences revealed that HIV disclosure is not an easy process for some HIV positive women. Some women in the current study found ways of encouraging their male partners to test for HIV, without necessarily disclosing their own status. Another participant shared a similar experience of a partner who took it in a calm way after she disclosed her HIV status " *…I got scared but when I arrived at home, I send a please call to the father of my children and then I told him. He took it very simple and nice and he said sister don't complain, you are not the first person and you will not be the last."* Although the partner in this excerpt is saying the words in a consoling manner, he seems to reflect how men perceive HIV diagnosis "*you are not the first person and you will not be the last*." Such calmness shows an

understanding by some men that HIV will eventually affect all. Therefore, this is disturbing as it suggests that risky behaviours might continue due to such perception. Furthermore, the fear of HIV disclosure to partners could be as a result of threats to end the relationship or due to the fear that the partner would kill them (Gilbert & Walker 2009). According to the HIV positive women's lived experiences of HIV disclosure, even if the male partners tested late for HIV, they often disclosed their HIV status to their female partners immediately (King et al., 2008). A few similar cases were also mentioned by the participants in the current study. Two other participants expressed that they were in sero-discordant relationships and their partners had accepted them as they are.

> *"[laughing]…my partner does not have a problem, he has accepted me and I have also accepted him…he has tested [for HIV], he is not like that [HIV positive]* **(*Mother who had just given birth, 41years, divorced, 5 children; Mother who received infant HIV PCR test results, 28years, married, 3 children*)**.

The lived experiences of the HIV positive women in this study showed that the women wait for the right moment for their partner (in terms of how he would react to the news) to disclose their positive status. This implies that they used an "approach goal" (discussed in Chapter Two), which indicates that disclosure happens when the person disclosing is hoping for a positive reaction from the confidant (Chandoir & Fisher (2010). Some HIV positive women in this study had to wait for the right time in terms of when they thought disclosure would be beneficial for them. Other participants were in sero-concordant relationships and they continued to stay together even after HIV disclosure. The use of an "approach goal" when disclosing HIV status prompted some male partners to want to know their own HIV status. One woman said:

> "*He was scared, I am not sure how he is dealing with it….He also tested after I tested and he found that he was also like that [HIV positive]. We are still together (**Mother who had just received infant HIV PCR test results, 23years, single, 1 child**).*

One participant also showed how she never struggled to disclose her HIV status to the partner *"…I told my boyfriend only about my [HIV] status. You know I just told him that I am from the clinic, so you also have to go and test, I have AIDS. He never refused but he asked me questions. Where did*

you get it or where did I get it? Perhaps I came with it…" According to the HIV positive women, male partners react differently to the HIV positive diagnosis. Some are receptive, others do not believe that it exists and others hide behind their religious beliefs.

Chapter Five further reveal the relationship catastrophes which were presented in terms of arguments about who had brought HIV to the relationship, and other outside affairs. A 25 year old mother waiting for infant HIV PCR test results shared what her partner said about her HIV infection "*He said it came with you, I said we do not know who is having affairs [outside our relationship]… it just comes, it's a disease…"* The above excerpt illustrates possible communication challenges between sexual partners upon the discovery of each other's HIV status. It also illustrates differing gender perspectives about the source of HIV. Because HIV is a gendered pandemic which seems to affect mostly women (Squire, 2007), even within dating relationships, women seems to be regarded as the ones bringing HIV. The current study supports the findings of other studies, which indicate that women are vulnerable to HIV infection because of their inability to negotiate safe sex as a result social and economic imbalances (UNAIDS, 2012; Kako et al., 2012). The male partner in the above excerpt was reported to express that HIV came with the woman, suggesting that the woman had extra-marital affairs and thus got infected. This goes against the norm or popular belief that men bring HIV to the relationship. Studies have found that there are factors that could facilitate male involvement in PMTCT by focusing on relationship dynamics, such as partner communication about PMTCT (Katz et al., 2009) and sero-concordance HIV status (Desgrees-du-Lou, 2005). Improving communication between men and women has been identified as one of the predictors of male participation in the PMTCT programme (Ditekemena et al., 2012). Participants also reported unfaithfulness of partners as a factor leading to relationship catastrophe. The excerpt below reflects the lived experience of one of the participants who is subjected to living with a partner who is unfaithful.

> "E*x-girlfriend's child needs ancestral ceremony. But all along [he had said]he does no longer want this lady, but since there was ancestral ceremony for the child, he has two families, it is me and that lady according to him. Like when I leave my house, like now I came home, it may happen that that lady is there right now… (**Mother who had received infant HIV PCR test results, 26years, single, 3 children**).*

A relationship catastrophe such as the one expressed above also shows gender and cultural stereotypes which seem to support that a man could have multiple partners (Leclerc-Madlala, 2000; Wechberg et al., 2008). This study also shows poor communication between partners as a factor which places women at risk of contracting HIV. As indicated above, communication improvement between partners leads to adherence to programmes such as PMTCT (Ditekemena et al., 2012).

5.2.4.3 Reasons for HIV non-disclosure

"I have not told mum, my other heart feeling says I must tell her, but when I look at her, I think it will disturb her emotionally".

The third sub-theme under the lived experiences of HIV disclosure and non-disclosure focuses on reasons for non-disclosure of HIV status. Participants suggested various reasons for not disclosing their positive HIV status. One reason was out of compassion for parents.

> "*No to tell the truth I have not told mum. My other heart feeling says I must tell her, but when I look at her, I think it will disturb her emotionally. I have not told her, I only told the person [partner] who did this thing" (**Pregnant woman on AZT, 32years, single, 1 child***).

Similarly, Medley et al. (2004) found that women did not disclose their HIV positive status because of fear of disrupting their family and not wanting to burden parents (Abrahams & Jewkes, 2012). The other reasons for non-disclosure related to non-readiness and effects of HIV disclosure. A 28 year old mother who had received infant HIV PCR test results advocated for the delay in HIV disclosure and she said "*If I can just stay a little while longer I do not know, I am not ready as yet but I want to. At home I know that if I can tell them, they will give me support but you will find that it is difficult, [they will be saying] she is sick whatever whatever…"* Similarly, Visser et al. (2008) found that some pregnant HIV positive women felt they were not emotionally ready to disclose their HIV status.

The data further showed that other participants feared being gossiped about:

> *"There are those others that you cannot tell that you are sick, because you will find that he goes around saying he is sick what what, that thing it will be stress.*

*Or maybe that person is drinking, have you seen what happen at the beer place, eh my child is sick what, things like that" (**Pregnant woman on AZT, 30years, single, 1 child**).*

Along the same view, another 23 year old mother said "*I am not comfortable to disclose my status, isn't people judge, so I just keep quiet*." The analysis suggest that in cases where the HIV positive women thought they might receive a negative reaction, they used the "avoidance goal" (Chandoir, 2009; Chandoir & Fisher, 2010). As previously discussed, the avoidance goal implies that the discloser studies the situation before saying anything to the confidant. If they believe that they would receive a negative reaction, they avoid disclosure. The avoidance goal is mainly used because of the fear of rejection and anticipated stigma (Chandoir, 2009). Moral judgment also was found to affect HIV disclosure in the current study (Abrahams & Jewkes, 2012). As already discussed in previous sections of this Chapter, the study also showed that the reasons given for non-HIV disclosure were related to anticipated HIV stigma and how the community and family perceive a person living with HIV. In a study conducted in Burkina Faso, Kenya, Malawi and Uganda it was found that 79% of women decided to withhold their positive HIV status because of stigma and fear (Hardon et al., 2012). Women feared being stigmatised by the community.

Some of the reasons for HIV non-disclosure were similar to those in a study conducted in Bangkok, where it was found that HIV non-disclosure was a result of not having a partner who had tested for HIV, not knowing the partner's HIV status, learning of HIV status during delivery or after delivery and having two lifetime partners. A study conducted in South Africa found that even though 81% of the women had disclosed their HIV status to at least one person, early HIV disclosure to their partners depended on the state of their relationship (Makin et al., 2008). In this study it was also suggested that HIV disclosure was related to economic factors. The next theme discusses HIV positive women's lived experiences of infant feeding in the context of PMTCT.

5.2.5 Theme 5: Fear of HIV stigma influences infant feeding practices

Theme five gives an account of infant feeding lived experiences as one of the important components of the PMTCT programme. It provides narratives of infant feeding options

chosen by the mothers post child-delivery. As shown on Figure 5.4 below, infant feeding lived experiences are discussed by focusing on the three sub-themes falling directly under this theme namely: breastfeeding experiences, formula feeding experiences and mixed feeding traditions in the study context. This theme is central to the PMTCT cascade processes which encourage the correct infant feeding habits.

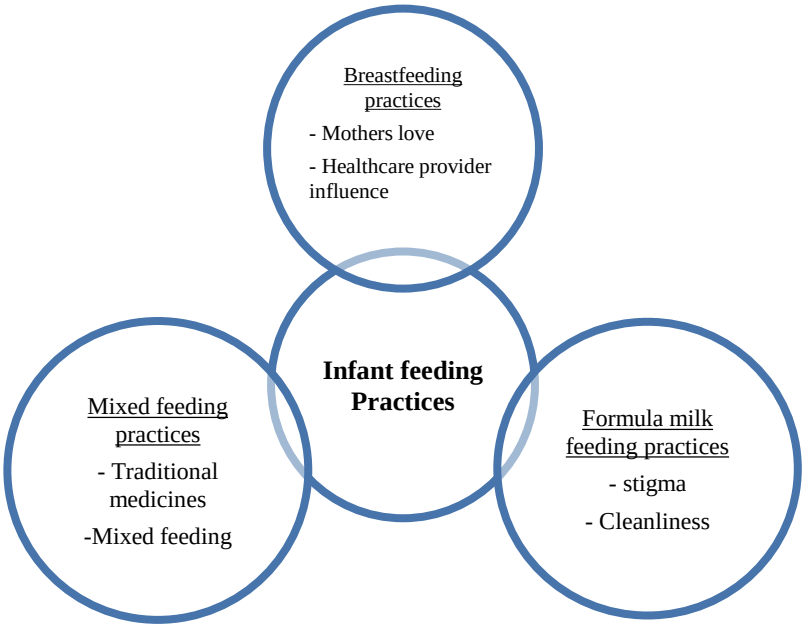


Figure 5.3 Infant feeding lived experiences

5.2.5.1 Breastfeeding practices

The first sub-theme under infant feeding lived experiences is that of breastfeeding practices. Participants in the current study reflected on the infant feeding method of their choice by sharing their views and experiences of infant feeding in the context of PMTCT. Breastfeeding practices were supported by some participants in the current study. For instance, some participants chose the breastfeeding method because of the benefits that go with it. The common reason mentioned was that breastfeeding is associated with mothers' love "*I like breastfeeding because it provides the child with the mother's love. You can give your child the bottle and I breastfeed, you will see the difference in children…*" According to some HIV positive women, the choice of breastfeeding was mainly for benefiting the child, who would receive the mothers' love from the breast. Besides the mothers' love, another woman

added that her family also supports breastfeeding because "*... the breast is healthy for the child, it will not make him/her sick."* A similar view was shared by another woman who said *"...they [HCP] were telling us that the breast is healthy for the children, like the child stays alright."*

Because of the preference for breastfeeding, formula milk feeding in this study was portrayed by some participants as a reflection of a lack of love for the child. The participants' views on infant feeding showed that even HIV positive people stigmatise each other. This was shown by their negative labelling of any infant feeding method other than breastfeeding. Another view on breastfeeding practices is related to the healthcare provider preferences of infant feeding methods. According to some participants, the HCPs push for total adherence to the breastfeeding method. As a result, some of the HIV positive mothers in this study felt coerced into choosing the breastfeeding method. The excerpt below reflects some views from a few other participants about coercion into infant feeding choices.

> "*...at the clinic there is a poster that shows that the best thing for the child is the breast, it is the mothers' milk. Even at the clinic they do not want to see the bottle, they say if you are bottle-feeding, do it outside the clinic..."(**Mothers waiting for infant HIV PCR test results, 24years, single, 1 child**).*

Although it is clear that formula feeding is not acceptable to the HCP, another woman said the HCPs are treating her differently "*They do not want to see the bottle inside the clinic. I explained to them my situation, they understand, and then I am able to give bottle in the clinic."* This seems to indicate differences in patient treatment even though they all have HIV disease. This Chapter further shows that HCPs' attitudes towards formula milk feeding made some of the participants resort to breastfeeding. A few HIV positive women in the current study also breastfeeding felt that formula milk feeding was not pleasurable because of issues related to cleanliness.

> *"Sometimes the bottles are not washed clean or maybe sometimes you are not there and you left the child with somebody. The person does not wash it clean, now you will find that it has germs and the child will start being sick" (**Pregnant woman on AZT, 30years, single, 1 child**).*

The push for exclusive breastfeeding could be a result of the infant feeding guidelines provided by WHO (2010) which clearly stipulate "exclusive breastfeeding for six months for all new mothers" regardless of their HIV status. All the nine South African provinces adopted the "exclusive breastfeeding for all" guideline in August 2011 and this has subsequently, led to the regrettable discontinuation of the supply of free formula milk (Ijumba et al., 2013). Although there is a push for policy adherence, this seems to reflect the limited power by the HIV positive in making decisions about infant feeding. In this context, the HCPs appear to have the power to choose the infant feeding method. Chapter Five further reveals that predictors for selecting the breastfeeding method for some of the HIV positive women were cleanliness, giving mothers' love and HCP advise on the type of infant feeding method and avoiding stigma. None of the narrative accounts provided by the participants made a mention of some of the common knowledge about breastfeeding benefits in this rural context. Some breastfeeding benefits that could have been mentioned by the HIV positive women include: weight reduction, body recovers fast from pregnancy and the womb returns to its normal size post-delivery.

5.2.5.2 Formula milk feeding practices and associated challenges

The second sub-theme under infant feeding lived experiences is that of formula milk infant feeding practices and its associated challenges. According to the HIV positive women in this study, there was stigma that related to formula milk feeding, which was caused by the association of formula milk with HIV. In the community, there is a misconception that if you formula feed, it means you are HIV positive.

> "*Most of the time they talk about HIV if a person does not breastfeed the child. They start asking, why are you not breastfeeding the child and giving him/her the bottle? You then just see that a person can see that you\ are sick, because most of them they think that when a person does not breastfeed the child [then] she is HIV positive"(**Mother who received infant HIV PCR test results received, 26years, single, 2 children**).*

The above excerpt provides further support for the earlier discussion which implies that there is discrimination when it comes to the choice of infant feeding method. The discrimination

seems to be across all levels, that is, at societal level, at the healthcare facility and amongst the HIV positive women individually. The statement that "*a person can just see that you are sick*" reflect perceived stigma (Turan & Nyblade, 2013). Similar to the current study, Chinkonde, Sundby and Martinson (2009) conducted a study in Malawi and found that formula feeding women were classified as being HIV positive by members of the community. One participant also indicated that formula milk feeding could be due common practices in the community and good socio economic status. This woman portrays formula milk feeding as a civilized way of infant feeding:

> "*There is no person who takes the breast out to breastfeed. People in this community they give their children bottles. Isn't you know how the ladies are. I do not want my child to take the breast, I want my child to drink from the bottle, her father is working I want her to drink the milk from the bottle" (**Pregnant woman on AZT, 30 years, 2 children**).*

Although formula milk feeding is regarded as a civilized way of infant feeding, in the context of this study whereby almost all the participants were unemployed, the ongoing purchasing of formula milk could actually bring some financial burden. The financial instability for participants is also reflected by the source of income for most of the participants which is government social grants. Although literature has shown that women lack power to make decisions on infant feeding method and taking charge of resources (UNICEF, 2011), this participant seemed to have made a decision of providing formula milk to the child. Therefore, one could also argue that it is the individual prerogative which allows them to have power to make certain decisions even in this rural context. Another varying view about the selection of formula milk feeding is due to fear of infecting the child and that it is a common practice by the youth in this study setting. This view is supported by a narrative from one participant who said:

> *"I was afraid that I will infect her. Isn't it I had not started the treatment, so I thought I should give him the bottle. Even at home they suggested that I give him the bottle. They do not have a problem with that, it is something we are used to. Giving the child a bottle is something we are used to, they will not ask what are you doing, what are you not doing in another way. It is more common among the youth **(Mother who had just given birth, 21 years old, 1 child).***

A similar experience is shared by another woman who opted to formula milk feed because of the lack of trust or belief that a baby born by an HIV positive mother may turn out to be HIV negative. This woman said:

> "*...It's like I have this thing of not trusting that he/she can be negative [if I am HIV positive]. Maybe he/she is weak, like his immune system is weak; he/she can be infected easily. I think bottle feeding is the best!" (**Mother who received infant HIV PCR test results, 26years, single, 3 children**).*

Although the South African PMTCT guidelines state that every antenatal care programme should provide infant counselling, the lack of trust by the participants in this study seems to undermine the effectiveness of the infant feeding counselling. Studies have argued that poor HIV counselling could lead to lack of trust in the PMTCT programme (Sibeko et al., 2009; Buskens & Jaffe, 2008). The results in this Chapter do not concur with these studies, as the participants in this study preferred to participate in interactions with the peer counsellors as opposed to the nurses. They reported feeling free to talk to peer counsellors because they are able to convey some of the messages more clearly than the nurses, and that they trust peer counsellors because they are also HIV positive. The fear of infecting the child through breastfeeding seems to suggest poor knowledge about PMTCT in relation to infant feeding. It also shows denialism of HIV which is presented by the stigmatising behaviours on the choice of infant feeding (Heywood, 2004). The common practices referred to on the above excerpt reflect the power of societal constructions on infant feeding in this study setting. Chapter Five therefore reveals that predictors for selecting formula milk method for some of the HIV positive women were good socio economic status, societal/ peer influence and fear of HIV transmission to the child.

5.2.5.3 Mixed feeding practices

The third sub-theme for infant feeding lived experiences is the mixed feeding practices. The data in this Chapter reveals that appropriate infant feeding is disturbed by certain cultural practices that participants found themselves having to adhere to. For instance, a 25 year old mother waiting for infant HIV PCR test results indicated that her child is given medicine by

the traditional healer to drink in order to "cure" his or her 'fontanel' and to stop the child from crying "*I give her the breast milk only. I have not started to give her the water. Another thing that I give her is the medicine for the 'fontanel'. When she is suffering from the 'fontanel', I take her to that person [traditional healer]… When she drinks it, she becomes fine, she does not become irritable…* This excerpt shows that some HIV positive women lacked knowledge about how mixed feeding occurs. For instance, they did not know that even if the mother had chosen to breastfeed only, the provision of water from the traditional healers still implies mixed-feeding. Similarly, Varga and Brookes (2008b) highlight that mixed feeding is a very common practice that is culturally acceptable among South African women. A number of studies also show that exclusive breastfeeding is still a challenge in SSA (Ladzani et al., 2011; Sera, Cicciò, OceroMusana, & Makumbi, 2010; Kinuthia, Kiarie, Kibera, Farquhar, & John-Stewart, 2010; Morgan, Masaba, Nyikuri, & Thomas, 2010) and therefore mixed-feeding behaviours continue. Coovadia et al. (2007) suggested that breastfeeding for 3-6 months is hard to maintain due to customary practices. A study conducted in South Africa on beliefs, attitudes and practices of breastfeeding mothers from a peri-urban community found that none of the women were exclusively breastfeeding (Sibeko et al., 2009). The study found that women were engaging in mixed feeding by the first month of life. Solid foods were given because the mothers expressed that they did not have enough breast milk. Similar to findings of the current study, infants were given traditional herbal medication, 'muti', as part of the ritual for young children (Sibeko et al., 2009). In Vietnam it was also found that although breastfeeding was desirable to many people, exclusive breastfeeding was limited (Vietnam Ministry of Health, 2005). A study conducted by Petrovic, Maimbolwa and Johansson (2009) found that women had very little knowledge about exclusive breastfeeding. As a result, most of them planned starting solid foods (like porridge) as soon as the baby turned three months.

Data further showed that participants in the current study believed that if a child cries, it means he or she is in need of food. Women in this study also mentioned a habit that is believed to be practiced by all the mothers who come to the clinic for postnatal care services. One participant described this habit: when women are at the clinic, they listen to what the HCPs say, and when they get home, they practice mixed-feeding. They give the child 'ntsu', the Setswana word for lukewarm water mixed with sugar. It is believed that this kind of water has a positive effect on the infant. It makes the child stop crying. The excerpt below

demonstrates this exact behaviour by women both in their homes and at the healthcare facility.

> "*They teach us about infant feeding, but when we get home we do it ourselves because the child will be crying. Everyone who is here, there is no one who can tell me that her child is not eating food. Because I am here I will say I have never given my baby any food but when you get home you give him/ her. You see right now when we were coming to the clinic, I gave him a little bit, he is not going to cry totally. After feeding him, I bath him and give him "ntsu" and put him there. I am able to work with him seated there, and leave him with mum the whole day, he will never cry..." (**Mother waiting for infant HIV PCR test results, 25years, single, 1 child**).*

The above excerpt provides a crux of what happens in real life situations, as far as infant feeding habits are concerned. The behaviour of the HIV positive women is not only contradictory, but also seems confusing. Such behaviour could be fueled by grandmothers as mentioned by one of the participants that "*the grannies would say give him low water. They say you are supposed to make him drink low water."* In earlier sections of this Chapter, the women suggested the desire to have healthy children, and yet they practice mixed feeding. Although this suggests poor comprehension of PMTCT interventions, it also shows the lack of power to make decisions on infant feeding by the women at household level. Grandmothers seem to have the power to make infant feeding decisions and that role seems difficult to be challenged by the mothers. Bezner-Kerr et al., (2008) shows better adherence to paternal grandmothers' advise on infant feeding instead of following healthcare provider advise. A study conducted in the Vhembe district of Limpopo Province in South Africa found that of 76% of HIV positive women who practiced exclusive breastfeeding, 43% introduced solid food when the baby was 3 months and 15% introduced it at 2 months (Mushaphi et al., 2008). Another study conducted in Mpumalanga Province found that 23% of HIV positive women in the sample practiced mixed feeding (Ukpe et al., 2009).

HIV stigma in relation to infant feeding was found to be a challenge in numerous studies, where HIV positive women were forced to conform to some of the traditional norms regarding infant feeding (Shapiro, Lockman, Thior, Stocking, Kebaabetswe, & Wester, 2003; Eide et al., 2006). In the current study, the participants had the belief that infants do not get

full from breast milk alone and, therefore, they are mixed-fed. Similar results were found in a study by Kakute et al. (2005) and Varga and Brookes (2008b). Alternatively, Kasenga et al. (2010) found that because of the suspicion that people were gossiping about them, women stopped breastfeeding early. In the same study, participants reported a lack of clear information about the importance of exclusive breastfeeding. Contrary to some of the HIV positive women's lived experiences in this study, Goga, Doherty, Jackson, Sanders, Colvin and Kuhn (2012) found safer infant feeding practices amongst HIV positive women compared to HIV negative women. The participant lived experiences of infant feeding reveal that the predictors of mixed feeding practices in this study were the use of traditional medicines, belief that the child is not full, grandmothers' influence and double standard feeding in order to satisfy the HCPs.

5.2.6 Theme 6: PMTCT Programme obstructions within and beyond the healthcare system

Having shared their lived experiences on decisions for utilising PMTCT services, HIV testing, HIV disclosure and infant feeding, participants in this study mentioned a number of additional obstructions that might affect the effectiveness of the PMTCT programme. These challenges indicate individual factors, community factors and health systems factors.

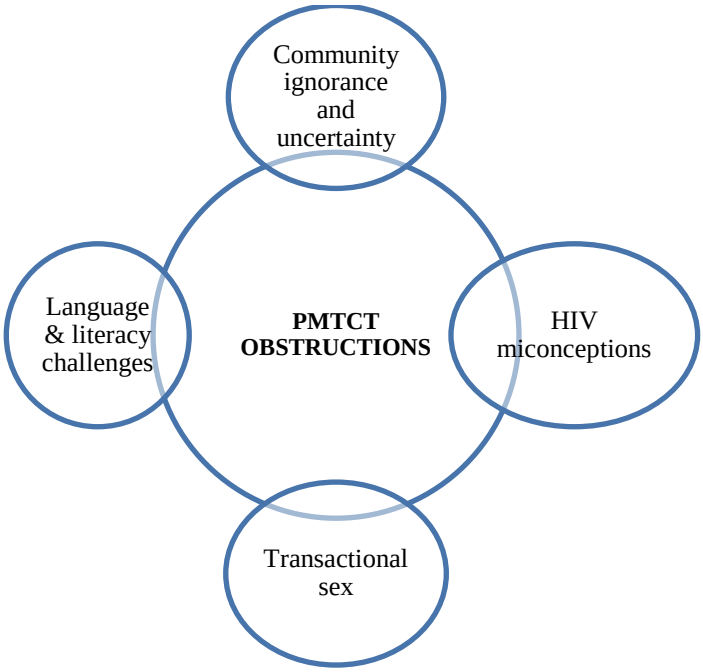


Figure 5.4 PMTCT obstructions in a rural context

5.2.6.1 Community ignorance and uncertainty about PMTCT messages

The first sub-theme related to PMTCT obstructions within and beyond healthcare system is community ignorance and uncertainty. The data showed that the HIV positive women regarded community ignorance on healthcare utilisation and uncertainty as a problem that is affecting the effectiveness of the PMTCT programme. This view is shared by a 23 year old mother who said "*The community is very stubborn, I am not sure how to think of them, things have changed."* This indicates that the community is still stuck on the old habits of health services utilisation before HIV disease emerged. This participant feels that, because of the HIV disease, the community has to change their reluctance towards health issues. However, one participant further indicated that such community ignorance on health matters could be due to lack of belief in PMTCT messages by the community.

> "*…When I tell many people, they do not believe that if you do not seek help, it [HIV] will kill you, they do not believe that. …They do not believe that HIV kills. They say that this disease goes in stages, it escalate…as time goes on, you have full –blown AIDS and then you start getting mixed up, the mouth becomes pink and the feet get swollen…"* (***Mother waiting for infant HIV PCR test results, 30years, single, 2 children***).

According to some HIV positive women in this study, the community perceptions of HIV do not seem to reflect an understanding of MTCT. The community's perceptions revolve around the physical symptoms of HIV and they are reported to show a general lack of knowledge of the PMTCT programme. This is thought to be hazardous, because if the general HIV knowledge of the community is low, then PMTCT uptake is likely to also be affected (Kagee, 2008; Mugore, Engelsmann, Ndoro, Dabis & Perez, 2008). One participant also indicated community ignorance of campaigns about HIV "*They [community] do not even attend awareness campaigns [for HIV] in the community. They are ignorant, they do not know many things [about health]."* Such ignorance may be due to societal and cultural norms. As already mentioned previously, Thompson et al. (2012) argued that societal and cultural norms influence health seeking behaviour. On the other hand, Cameron (2005) argues that such ignorance could be due to AIDS denialism. According to HIV positive women, if the community ignores or undermines health matters, their health seeking behaviours might be affected. Another

participant added that community has an understanding of PMTCT but such knowledge is defeated by ignorance.

> *The community has an understanding of PMTCT, they are just ignorant. They fear this thing that when you come here [health facility], people will know you are HIV positive. It's not like they do not know,they know" (**Mother who had just received infant HIV PCR test results, 26 years, 3 children).***

This seems to suggest that ignorance with regard to PMTCT services utilisation is also caused by fear of stigma. Another participant added that PMTCT knowledge is there especially among the younger generation "*I think those who know [about PMTCT] is the young generation that is currently giving birth because they explain to them at the clinic, but the older generation, do not…do not know."* The irony is that even the young age group of women in the current study seemed to not fully comprehend PMTCT and this is shown by the perceptions of HIV already mentioned. Another irony is that the very same grandmothers who the participants suggested lack PMTCT knowledge are the individuals caring for their grandchildren. Chapter Six of this thesis explains, in detail, the challenges of grandmothers, as caregivers. A review conducted by Frizelle et al. (2009) on behalf of UNICEF-CADRE, also documented a general lack of HIV and PMTCT knowledge in the general population. The current study findings differ from findings by Petrie, Schmidt, Koornhof & Marias (2007), which found adequate knowledge of HIV and MTCT in the Western Cape Province, South Africa. Another study alternatively, found high PMTCT knowledge among the grandmothers (Falnes et al., 2011).

5.2.6.2 HIV misconceptions

The second sub-theme relating to PMTCT obstructions beyond the healthcare system is HIV misconceptions. The HIV positive women in this study saw community HIV misconceptions as a further PMTCT hindrance. For instance, one woman shared that some community members believe that HIV affects certain people "*They [community people] still believe that it is the disease that affects certain people, they do not think that they can also have it…*" According to most participants, because of the community's belief that only certain people (such as those having multiple partnerships) acquire HIV, the individual risk perception is low and thus

makes it difficult for them to participate in any health programmes. As already discussed in Chapter Two, the health-seeking behaviour is mostly influenced by the belief of benefiting from such action (Rosenstock, 2005). The current study showed that although people seem to have a general idea about what HIV is, there is a general lack of knowledge of what MTCT or PMTCT is (Eyakuze, Jones, Starrs & Sorkin, 2008; Mushi, Mpembeni & Jahn, 2007). Another participant mentioned some of the misconceptions that the community has about HIV. For instance, they believe that they are bewitched when they show symptoms of HIV. The excerpt below shows a narrative provided by one of the participants about an encounter of community misconceptions.

> "*A certain grandmother who stays in our area, once called me...she said "I heard that you are sick and you are suffering from a disease such as these and these. I agreed… she is sick but she does not know what she is suffering from... she told herself that she is bewitched, she is dark, she has pimples…Many [people] are saying they have been bewitched…when it is this very same disease [HIV]…"* (***Mother waiting for infant HIV PCR test results, 30years, single, 2 children***).

Similar results were found in other studies, where witchcraft was cited as the cause for diseases (Yamba, 1997). The HIV positive women in the current study have provided possible explanations for the late utilisation of PMTCT services and have identified misconceptions such as witchcraft beliefs as a contributing factor to this.

5.2.6.3 Transactional sexual relationships

The third sub theme relating to PMTCT obstructions beyond the healthcare system is sexual behaviour. Transactional sexual relationships, that is having sex in exchange for material goods and money (Norris et al., 2009; Stoebenau et al., 2011) were also mentioned as a hindrance to the PMTCT programme by two HIV positive women. This finding suggests a major obstacle to the effort that is being made to prevent the spread of HIV, which ultimately affects the child negatively. According to these women, the young girls in their communities are reported to be engaging in transactional sexual relationships. As shown by the excerpt below, this seems to be as a result of wanting to improve their economic well-being.

> *"That child…used to say her mother buys poor quality clothes…those are the things that made her to stay [have relationships] with older people who will buy expensive clothes for her and then she also contracted the disease…"* ***(Pregnant woman on AZT, 30years, single, 1 child)***.

Being involved in transactional sexual relationship may be considered a sign of a structural violence faced by poor women in rural communities (Farmer et al., 1996; Jewkes, Dunkle, Nduna & Shai, 2012). This suggests that because of poor socio-economic conditions, these poor women are utilising survival strategies which put them at risk of contracting HIV, in an attempt to flee from these conditions (Farmer et al., 1996). Hence, as shown in the above excerpt, having the need for good quality clothing puts young women at risk of being infected with HIV. But in this case it could also be due to wanting to build ones self-esteem in order to fit well amongst the peers (Jewkes, Dunkle, Nduna & Shai, 2012). Another participant also said "*there is a child who fell pregnant at 13 years of age who lives next door. She was impregnated by a big man [sugar daddy] not a young boy*." This indicates some of the obstructions towards an effective PMTCT programme and therefore, requires further interventions that will address teenage pregnancy and male control of sexual matters in the context of PMTCT. This seems to indicate that young women are overpowered by older men who in turn place them at risk of contracting HIV. It also shows the impact of poor socio-economic status as a big obstacle towards reducing the spread of HIV.

5.2.6.4 Language and literacy challenges

The fourth sub-theme related to PMTCT obstructions within the healthcare system is that of language and literacy challenges. Even though PMTCT language was previously suggested to be understandable, some participants said that it is not that easy to understand HIV terminology, especially for the older generation. One participant said "*it is understandable but I think the older generation are the people who do not understand [and they are] those who cannot read."* Some HIV positive women in this study see themselves as being knowledgeable and understanding PMTCT language more than the grandmothers who happen to be caregivers for their children. This belief is based on the poor educational qualification of the grandmothers, as they could hardly read any PMTCT messages. Chapter Six deals with grandmothers' views of PMTCT and will thus address the HIV positive women's concerns

on language and literacy challenges. Although the HIV positive women expressed the grandmothers' PMTCT language and literacy challenges, other studies have suggested that grandmothers are known for having plenty of indigenous knowledge and cultural values which are always transferred to younger generations (USAID, 2011). Grandmothers are also involved in child-caring activities (Bezner-Kerr et al., 2008; Barrett, 2008; Barratt & Penn, 2009).

Some HIV positive women in this study highlighted the important aspect of PMTCT language comprehension which also relates to patient behaviour during the consultations at the healthcare facility. For instance, they noted that many a times, they would not ask about the different services within the PMTCT programme, especially when they came for the routine check-ups for both themselves and their children. All that mattered was that they were told that they were both (mother and child) in good health. Participants indicated that they did not have an interest in understanding the meanings of terms like CD4 count, infant HIV PCR testing, viral load and AZT. They believed that if there was a problem, the healthcare worker would communicate it to them in language that they understand. Many HIV positive women in this study did not really have an interest in understanding how the programme was named, however, what seemed important for them was what the programme could do for their children. The concern for most of the women was not about themselves, but their children. During the routine check-ups, the only thing that they cared about was the status of their children as they knew their HIV status would not change in any way. Participants showed no interest in reading the names of the treatment they were on.

Ironically in this study, one participants claimed to not understand the language used in PMTCT, because she was still new in the programme, even though she had already given birth. This finding makes sense because it implies that those women who were not fully informed about the PMTCT processes started antenatal care late. This supports the finding of a previous study which suggested that late antenatal care initiation denies HIV positive women information on how to protect their child from getting HIV (Solarin & Black, 2013).

5.2.7 Theme 7: PMTCT services enhancement in a rural context

After sharing their lived experiences starting from deciding to utilise PMTCT services up to identifying PMTCT obstructions, Chapter Five further demonstrates that participants suggested a number of actions that need to be taken, in order for the PMTCT programme to be more effective**.** Figure 5.7 shows the three sub-themes under PMTCT services enhancement, provided by the HIV positive women.

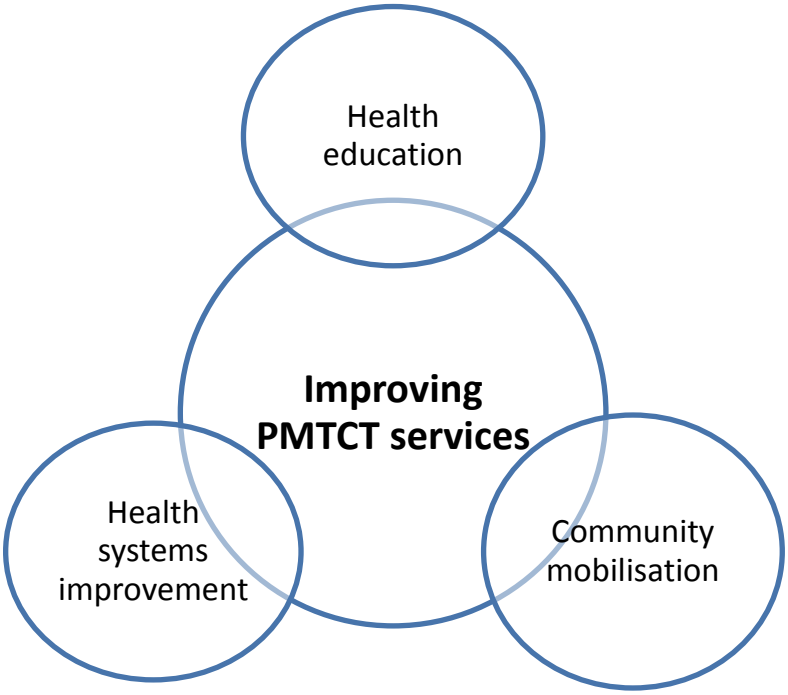


Figure 5.5 Improving PMTCT services

Based on the analysis of the data, HIV positive women appeared to suggest that PMTCT information should be taught at school. Although a few participants mentioned this, one woman said "*...if it was possible, children were supposed to be taught at school about this disease that whatever, whatever because their parents are not telling them anything…this disease is spreading...*" They also recommended that there should be door-to-door campaigns to teach people who do not believe that HIV exists *"If there can be campaigns in the community to teach people about AIDS, other people still don't believe, like grandmothers. They still refuse that they cannot be positive [HIV] because they no longer indulge on sexual activities."* Another participant suggested community involvement as key "*Maybe if you can organize an event and involve them [community] to come and learn about HIV…maybe that is when they can understand…*" Some

participants suggested the use of peer counsellors for running such campaigns and also conduct home HIV testing.

> "*I think people like peer counsellors if they can go house to house and explain about their [HIV] status… They tell you that if you have it there is a treatment and they test you there and there. If you are very sick, they transport you to a hospital and there you will be properly checked for your CD4 count …" (**Mother waiting for infant HIV PCR test results, 30years, single, 2 children**).*

Other suggestions included the use of "loud speakers" to call people to the clinic, having a person doing "home education" on health issues; providing "daily lessons" at the clinic etc. Finally, they recommended the improvement of the healthcare system, especially related to treatment administration for HIV positive people *"you need to take a referral letter from where you come from, so they do not welcome everybody."* In other studies, community mobilisation, using community workers or home-based workers led to an increase in retention of care (Busza et al., 2012). Community mobilisation was also recommended in Uganda for ending the vertical transmission of HIV (Mburu et al., 2012). All the suggested interventions by the HIV positive women in this study, shows practical and less expensive way of approaching HIV education at a rural community level. Such intervention strategies need to be explored in order to assess their impact on the PMTCT programme.

5.3 Conclusion

Chapter Five revealed that there are seven key themes that have been identified from the data provided by the HIV positive women following PMTCT cascade steps. The thematic analysis findings revealed that decision-making for utilising PMTCT services is characterised by fear which is brought about by HIV testing at the healthcare facility. Non-participation in the PMTCT services is mainly due to fear of HIV and fear of stigma by social networks. Non-preference of healthcare systems seemed to be due to the negative attitudes of healthcare workers. Although the benefits of PMTCT services are known, fear and the lack of trust in the PMTCT programme prevails. The fear in this group of participants appeared to be also caused by self-stigma and anticipated stigmatisation by others. Therefore, the motivating factor for non-utilisation of healthcare services was a need for self-protection. The lack of trust was also a result of doubt of the PMTCT programme effectiveness.

The lived experiences of the HIV positive women also showed that partner dynamics related to PMTCT still persist. In addition, this Chapter showed that mixed feeding of infants is the biggest challenge in a rural context which is aggravated by the lack of power to make decisions. The poor infant feeding habits were mostly influenced by cultural and traditional norms. Formula infant feeding method and breastfeeding method were also stigmatized in this study. Furthermore, this Chapter showed the positive spinoffs of HIV disclosure, with HIV non-disclosure mostly being attributed to self and anticipated stigma (including the avoidance of stress to family). This Chapter further outlined the PMTCT programme obstructions that are within and beyond the healthcare system. The PMTCT challenges within the healthcare system included a lack of understanding for the PMTCT programme, as well as language and literacy issues. The PMTCT obstructions beyond the healthcare system showed societal/ community barriers which affect proper adherence to the PMTCT cascade processes. Finally, this Chapter suggested ways of improving the PMTCT programme which included education and community mobilisation as key to the success of the PMTCT programme. Improvement of the healthcare system was also found to be necessary for the improvement of the PMTCT programme.

CHAPTER 6
GRANDMOTHERS' VIEWS OF THE PMTCT PROGRAMME: FEAR OF HIV BURDEN AND HIV INFECTION

6.1 Introduction

This Chapter is the second of the three Chapters dealing with the results of this study. It provides a detailed description of the results which arose from thematic analysis of the focus group discussions (FDGs) that were conducted with the grandmothers receiving health services at the three healthcare facilities in the Dr JS Moroka sub-district of Mpumalanga Province. A conclusion is provided at the end of this Chapter, teasing out critical issues that are raised. Additional results obtained from thematic analysis of data provided by the HCPs will be presented in Chapter Seven.

6.2 Thematic analysis, narrative descriptions and discussion

The results on this Chapter focus on grandmothers' perceptions of the PMTCT programme and their lived experiences of child-caring. Because grandmothers in this study were not directly involved on the PMTCT programme and were not even related to the HIV positive women in Chapter Five, the overall story for this Chapter is structured according to their general perceptions and observations on the healthcare utilisation by child-bearing women (especially in relation to PMTCT) in the community. Therefore the narrative thematic sequence of the grandmothers' lived experiences is presented according to the sequence of the PMTCT cascade stages discussed in Chapter Two of this thesis. The presentation of the main narrative for this Chapter following PMTCT cascade steps allows for identification of challenges at each subsequent step. Figure 6.1 provides a narrative sequence of the seven main themes that will be followed in presenting the results: 1) health seeking behaviour, 2) Perceptions of antenatal HIV testing, 3) HIV treatment perceptions, 4) A dilemma between silence and telling, 5) infant feeding perspectives, 6) PMTCT obstructions and 7) PMTCT programme enhancement.

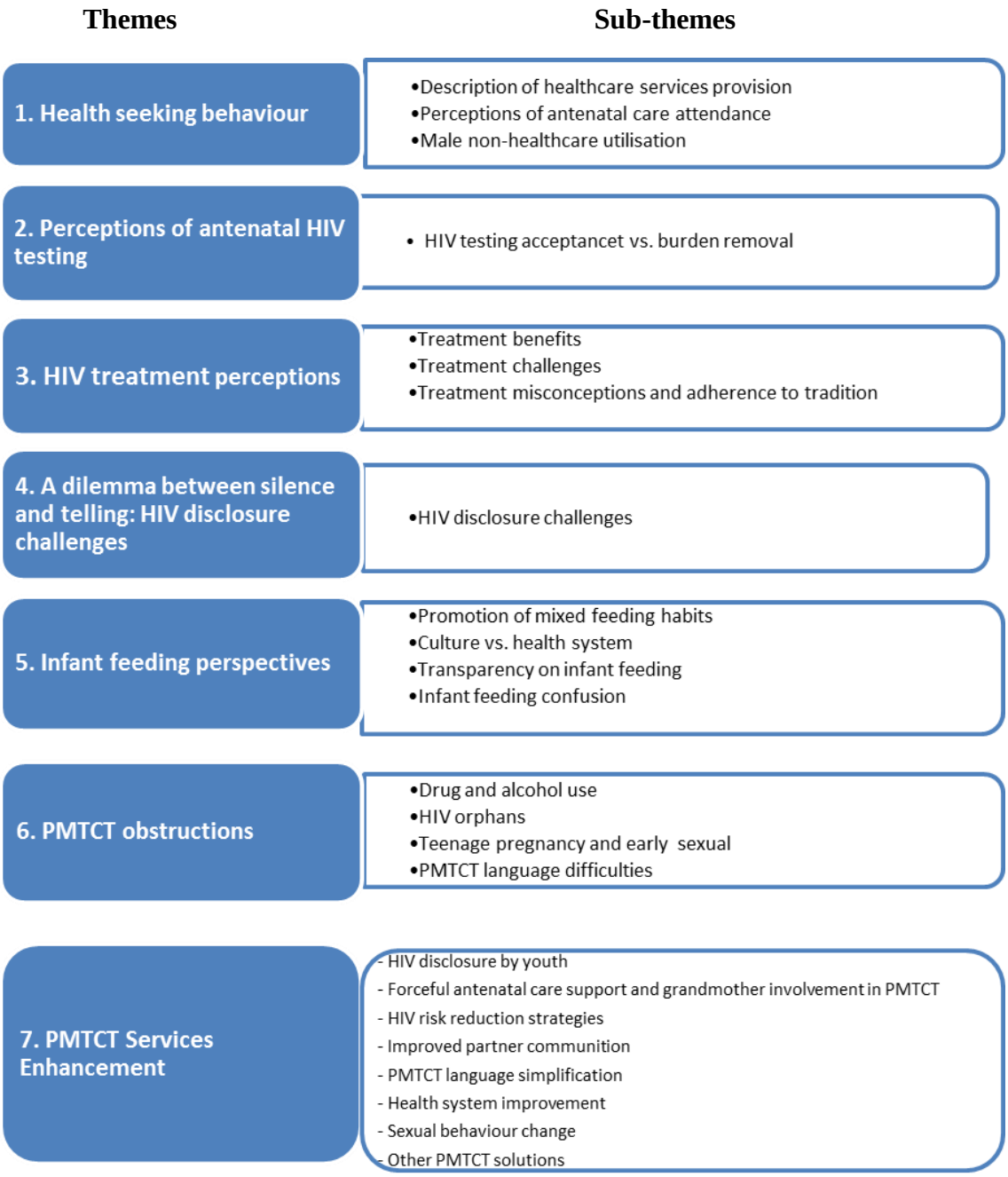


Figure 6.1 Seven themes providing an account of PMTCT programme perception by the grandmothers

Although there are seven themes which are following PMTCT cascade steps, there are two key aspects which dominate this Chapter: fear of the burden because of the grandchildren who are infected with HIV, and the fear of being infected with HIV because of non-HIV disclosure. The results for this Chapter are presented according to each theme and sub-theme, providing

illustrative excerpts from participants. The illustrative excerpts from FGDs were selected based on their in-depth, detailed descriptions provided by the participants. The results are further described and discussed.

6.2.1 Theme 1: Healthcare seeking behaviour in the context of PMTCT

Theme one begins by providing the narrative account of how health seeking behaviour is perceived by grandmothers in the context of PMTCT. Utilising healthcare services is the beginning point of the PMTCT cascade process. This was explored by obtaining narratives from the grandmothers about their general perceptions of healthcare services utilisation in the study setting. In order to provide an account of health seeking behaviour in the study context, grandmothers' narratives focused on the following three aspects presented as sub-themes: description of healthcare services provision, antenatal care attendance perceptions and male non-healthcare service utilisation.

6.2.1.1 Description of healthcare services provision

The first sub-theme under healthcare seeking behaviour focused on describing general services provided at healthcare level. This kind of narrative by grandmothers is important because it provides an understanding of how health services including PMTCT are provided to patients in this context. The healthcare service descriptions were in terms of the attitude of the HCPs, staffing and infrastructure issues. In terms of the health service provision attitude by the HCPs, grandmothers showed general satisfaction with regard to how services are rendered. This point is made clear by one grandmother from FGD1, aged 64 who said "*they [HCPs] are treating us well…we are satisfied with the clinic services*." A few other grandmothers also indicated that there are health talks that are provided by the HCPs on a daily basis to the patients. Such health talks are perceived to be helpful and seem to be encouraging their healing as said by a 74 year old grandmother from FGD1:

> *"Every morning there is a church meeting after church meeting [health education] whereby we are told about the rules of health. And we have to listen*

to everything that they are teaching us. Everything that is been said really gets to our minds, can you see we will be healed."

Although the grandmothers seemed happy with the healthcare facility services, they strongly believed that the current healthcare services could be improved by increasing staff and having a better infrastructure. One grandmother gave a staffing scenario which shows the current service provision by HCPs in the study setting:

> *"…with other clinics, when one group of nurses go for breakfast, others continue working and when they return, others who were working are relieved. So with ours [clinic], there are only three nurses, when they go for breakfast, lunch, or workshops [patients are left unattended]. I also wish that they can send us doctors because the nurses can only check us high blood pressure and what not, because they are not doctors. There must be doctors to examine us; I wish that our clinic can be renewed" (**FGD 4, grandmother 3, 71 years old**).*

Another grandmother aged 81 years from the same group added that "... *the nurses are working under pressure, you find that one nurse attends to 40 patients a day, so, it is easy for her to make mistakes."* Other grandmothers wished that their clinic infrastructure could be expanded to allow for more staff provision "*Yes even this clinic, I wish they could expand it and when they have done so, bring more nurses. It will be easy to do the work."* Although some grandmothers highlighted staffing challenges which subjected them to longer waiting periods before receiving services, they were not discouraged from utilising healthcare services. In fact, due to a positive attitude displayed by the healthcare providers, they were encouraged to continue utilising healthcare services. Such staffing and infrastructure challenges have also been noted in other studies (Delvaux, Konan, Aké-Tano, Gohou-Kouassi, & Bosso, 2008; Sprague, Chersich & Black, 2011). Healthcare provider negative attitudes were also found to discourage people from utilising the healthcare services (Kebaabetswe, 2007). The provision of health talks in a healthcare facility has also been indicated as one aspect that grandmothers like and actually, this is in line with other studies that also emphasised the importance of health talks for the PMTCT programme (Levy, 2009). The healthcare services description by the grandmothers provides a context in which utilisation of health services occur. It gives a clear picture of the conditions under which healthcare services are provided. The next section discusses grandmothers' perceptions of health seeking behaviour relating to antenatal care.

6.2.1.2 Perceptions of antenatal care attendance

"They are lazy."

- **Laziness delays antenatal care utilisation**

The second sub-theme under the healthcare seeking behaviour relates to perceptions of antenatal care attendance. This is the first step on the PMTCT cascade which encourages utilisation of antenatal care services in order to receive the necessary care for preventing MTCT of HIV. Most grandmothers' narratives point to the poor utilisation of the antenatal care services by the women in the study area. They identified factors such as laziness, concealing pregnancy, health messages ignorance and family advice ignorance as contributing towards poor utilisation of PMTCT services. In terms of laziness, a grandmother aged 56 years from FGD3 shared a view which seems to capture how most grandmothers feel about antenatal care attendance in this setting "*...It is laziness, it is laziness to expect [a child] and not seek help…"*Another grandmother added to the above point that "*many people [women] are lazy…[to go to the clinic*]." In addition to this, another grandmother indicated a danger of staying at home while pregnant. This is what she said:

> *"… Sometimes you stay there [at home] and you find that the child is in breech position. When the child is in breech position, it is very painful because it is like the child has entered the chest sitting in a breech position. When the child has breeched inside the tummy and the mother is waiting at home hoping to come at seven months, they [HCPs] will not manage [to deal with that]" (**FGD2, grandmother 3, 57 years).***

According to most grandmothers in the current study, laziness is the one factor that leads to non-utilisation of antenatal care which provides PMTCT services. Most grandmothers emphasised that because of laziness, their daughters and grandchildren would not timeously know if they have diseases. The non-utilisation of the antenatal care services suggest that the first step of the PMTCT cascade does not take place and when it does, it is sometimes at a later stage. Unlike other studies, which have identified community level barriers, such as societal and cultural norms as factors that could influence PMTCT programme usage (Busza et al., 2012; Bajunirwe & Muzoora, 2005; Thompson et al., 2012) the data in this Chapter suggests that women's laziness is also a contributing factor. If laziness is the norm, grandmothers

clearly do not support it and the younger generation of women seems to have obviously not learned this behaviour from them. Because of laziness, antenatal care utilisation seems to happen late in this setting. Most of the grandmothers indicated that late antenatal care utilisation could be avoided by making sure that "*when you miss the first month of menstruation, you go to the clinic to be tested [for HIV] (all grandmothers said yes).* Another grandmother said "*even if she does not tell me, if she is not feeling well, she needs to go to the clinic to check her condition*." This gives an indication of how some grandmothers are determined for their children to attend antenatal care services.

In the results, certain pregnancy misconceptions amongst grandmothers were also noted. For instance, one grandmother expressed that women would not be able to notice the disease, if they were pregnant "*[if] you have the disease, you will not be able to see it [if you leave it for too long] while the child is inside you…"* On the contrary, HIV testing is done during antenatal care in order to check if there are any diseases and to ensure that the child is protected from contracting HIV, should the mother be HIV positive (Adedimeji et al., 2012; Boyd et al., 1999; Rothpletz-Puglia, Storm, Burr, & Samuels, 2012). Some grandmothers further indicated that their children's laziness is also seen in home delivery occurrences. To emphasise the point about laziness, one grandmother indicated that their daughters are even lazy to talk.

> "*…they are lazy to talk just to say mommy today I don't feel well. If she had told me that she was not feeling well, I would not have gone far, I would have been around to see what was happening..."[but the tendency is] on the last minute she can't now even walk a distance and you as a parent you should run and go look for transport to take her to the clinic and before she gets there, she has already delivered [the baby]. That is a problem that we have, our children don't talk in time…**" (FGD2, grandmother 3, 57years)**.*

This indicates the burden of non- communication that is experienced by the grandmothers, as caregivers. Even though grandmothers are regarded as gatekeepers to knowledge of illnesses (Forrest et al., 2003), the non-communication regarding child-bearing issues indicate communication barriers to health matters. The data suggests that grandmothers perceive their grandchildren to be lazy because in the grandmothers' youth, they felt they were raised differently. And because of that kind of upbringing, grandmothers possess various qualities including being "industrious" (Penn et al., 2010).

- **Concealing pregnancy delays early antenatal care**

Some grandmothers further indicated that the silence about pregnancy and concealing it delays early antenatal care attendance. One grandmother narrated the scenario about her daughter who hid her pregnancy.

> *We discovered that my child was five months pregnant. We started realising that she is no longer that active and that her waist is starting to surprise us. We took her to the doctor and then they said she is five months pregnant, I am sure that her gestational age was more than that because we were then called urgently that she has already given birth… These children hide their pregnancy for parents so that they can avoid going to the clinic" (**FGD2, grandmother 3, 50years).***

In support of the above statement, another grandmother said "*They do not come to the clinic, the nurses are really struggling [with these women]. The women stay [at home while pregnant], others stay hiding at home so that people do not see that she is pregnant…"* Another participant in the same group provided a reason for concealing pregnancy is that "*others fear that they have made a mistake and therefore she does not know how to start explaining such a mistake at home.."* Another participant indicated that in order to conceal the pregnancy, "*... she keeps on tying her waist too much to hide the tummy from showing…it can even hit 9months without going to the clinic…*" A variant view by one grandmother was that pregnancy is hidden because of "*wanting to respect the parent*."

Analysis has revealed that another delaying factor for late antenatal care utilisation is due to concealing pregnancy. Fear of disclosing pregnancy to the family and respect for parents was noted as other reasons for concealing pregnancy. The results actually show that concealing pregnancy is triggered by the fear to utilise antenatal care services once pregnancy has been discovered. The fear to utilise antenatal services could be due to avoidance of HIV testing as mentioned by one participant. Grandmother 2 from FGD1 narrates the misconception about late antenatal care attendance: "*Others fear coming to get the treatment early. You will find that a woman went to the healthcare facility during her last month of pregnancy as a way avoiding to be tested [for HIV], nevertheless, even during late utilisation of antenatal care services, they still take blood [test for HIV]. They will never help you without taking blood…"* Such fear is mostly related to the stigma of HIV testing at the healthcare facility (Nguyen et al., 2008; Pai et al., 2008; Sinha et al., 2008; Mitra et al., 2006). This point will be discussed further under theme 2 of this

chapter. This results supports the findings of another South African study which found a lower percentage (<40%) of women who attended antenatal care services before 20weeks gestation (Barron et al., 2013). Additionally, one grandmother indicated that non-utilisation of antenatal care services due to fear of HIV testing, is because of the misconceptions that people have about the practices of the HCPs, when it comes to treating patients.

> "*...you find a person saying I won't go to a clinic because they use the same needle that they used [to prick] someone else and only to find that it is not true because he/she [just] heard that from someone...*"" (***FGD 3, grandmother 3,* 50years**).

The above excerpt suggests that the non-utilisation of the healthcare services also results from misconceptions about what happens during HIV testing. According to the grandmothers, some community members have a belief that HIV is also transmitted by the HCPs, who use the same needle for pricking during the HIV testing process. However, the above excerpt also shows that the grandmothers disaffirm such a belief. A study conducted by Musheke et al. (2013) also found that people undermined the quality of HIV testing, and therefore, lacked trust in the healthcare system. One grandmother further indicated that their grandchildren/ or young women in the community are secretive and that they would not even talk about abortion to them. As such, their children would rather die than disclose their pregnancy.

> "*There are other children, when they are pregnant they take some medication to do abortion without you knowing anything. When she starts feeling sick, and you take her there [hospital], sometimes she even dies on the way. When you arrive at the hospital, they would tell you that she has drunk poison, while you have been with her in the same house" (**FGD2, grandmother 3, 57years**).*

The above excerpt suggests that this grandmother felt that she was kept in darkness about some reproductive matters, including abortion. That being the case, the secrecy of not communicating pregnancy termination plans to the grandmothers shows that the younger generation of women actually possessed some of the grandmothers' qualities, such as keeping secrets about reproductive matters. In line with this, Penn et al. (2010) found that grandmothers are known for the role of monitoring family reproductive matters such as keeping infidelity secrets in cases where a secret lover was organised for a woman so that she could bare her husband a male child to keep the family name.

- **Health messages and family advise ignorance**

Another contributory factor towards poor utilisation of the antenatal care services is the ignorance of health messages and family advices. Grandmothers emphasised the need for their daughters and grandchildren to take the messages of the HCPs seriously. One grandmother aged 55 years, from FGD1said "*Let them listen to what the nurses are saying."* According to most grandmothers, there is a tendency to not practice the advice and messages of the HCPs, especially amongst the women in this rural setting. As a result, this burdens the grandmothers and, at the same time, hampers the effectiveness of the PMTCT programme. The excerpt below further shows that some grandmothers compared their own health-seeking behaviour to that of their grandchildren's.

> "*…Why is it that even us as grandmothers we have been through a series of testing like pap smear and all the other [tests]. We did not refuse anything because we wanted to know if we have this virus or not and [we also wanted to know if we have] the cancer, we did it [tested] here…"* **(*FGD1, grandmother3, 55years*).**

This example indicates the differences in health-seeking behaviour between the younger and the older generation. It also suggests that in general, young people seem to not adhere to the requirements of healthcare services, while the grandmothers imposingly do. This further implies that the older generation considers health issues to be serious, and does not dismiss susceptibility as a possibility, unlike the younger generation which seemed to perceive themselves as healthy (Rosenstock, 2005). Considering that the grandmothers are from an old school of thought, which was mostly influenced by the use of traditional medicines, the data suggests that educational messages on health-seeking behaviour are well understood by the grandmothers. The grandmothers' "state of readiness" to act on health issues seemed to be influenced by their perceived benefits of early health-seeking (Rosenstock, 2005, p. 6). For some reason, similar beliefs and practices are not easily transferrable to the younger women generation, hence the challenges of early antenatal care utilisation are raised.

Grandmothers' narratives further revealed family advice ignorance on health matters as another contributing factor for non-utilisation of healthcare services. Grandmothers in the current study raised their concerns about the lack of respect shown by their grandchildren, especially

when advising them to behave appropriately as a preventative measure against HIV. The excerpt below highlights some of the frustrations experienced by grandmothers as caregivers.

> "*We don't know what to do with these children anymore, we constantly pray for them in churches but they are very dangerous and we do not know what to do anymore… They are beyond our control and there are these diseases now people [nurses] are trying to guide them by doing this and that but that is just falling on deaf ears…" (**FGD2, grandmother 2, 70years**).*

The grandmothers revealed that the biggest PMTCT utilisation barrier is the lack of respect for elderly guidance given in relation to health issues. Regardless of how the grandmothers reprimand grandchildren, they are reported not to listen. This behaviour of refuting elderly guidance is not limited to parents, but also to HCPs who seem to also be ignored by young women. Most grandmothers in this study perceived prayer to be the only means that could assist them in changing their children's behaviour. This implies that they believed that praying for their children would change their behaviour of ignoring advice given by both by them and HCPs. As illustrated in excerpt below, some grandmothers in the current study were highly disturbed by grandchildren's behaviour, which places them at risk of contracting HIV.

> *"I can see but what can we say because these children are stressing us and we teach them but still they do things that they themselves do not understand… You would tell her that my child, there is a disease called AIDS and it comes within these love relationships, so be careful and when you go and get that disease you bring us problems because it is me and your grandfather who should stand up [when you are sick]…" (**FGD4, grandmother 1, 81years**).*

These words "*you bring us problems because it is me and your grandfather who should stand up [when you are sick]"* were agreed to by almost all the grandmothers in the study. This indicates that the grandmothers' advice about health is done to reduce the burden of having sick children and grandchildren. The analysis suggests that the fear of being burdened by children when they are sick is the one pushing grandmothers to force antenatal care attendance. Grandmothers as caregivers try through all means to guide their grandchildren to avoid risky behaviour that could place them at risk of contracting HIV. However, their efforts seem worthless as the risky behaviours seem to continue. Although grandmothers' roles have been

highlighted in numerous studies (Penn et al., 2010; Boon et al. 2009; Chazan, 2008; Marais, 2005), the challenge of grandchildren who are unruly towards grandmothers has been underreported. The above excerpt further suggests that grandmothers in the area of study are religious women, who resort to prayer when everything fails. The belief about the power of prayer for unruly children is an interesting one. Other studies have shown that understanding religious beliefs is important for HIV prevention (Busza et al., 2012). Hence the data presented in this Chapter shows that prayer is seen as another way of combating unruly behaviour, which might reduce HIV contraction.

Grandmothers further highlighted some traditional communication changes that they have to face, as a result of trying to provide guidance to their children and grandchildren. For instance, they expressed that 'sex' was never something that was discussed in the olden days, but they have now had to talk about it in a way that discourages their children from practising it. A 61 year old grandmother from FGD2 put it this way "*In the olden days, sex was a secret. [To] us who were raised [in the olden days we knew that] sex was a secret."* This seems to suggest that grandmothers are trying to open up about sex issues to their grandchildren, in order to reduce the spread of HIV. However, because they were from a school of thought in which it is a taboo to talk about sex, they might need to be better equipped to handle this psychosocial challenge. Furthermore, according to the grandmothers, besides the ignorance of health messages from both them and HCPs, their children and grandchildren seem to also be ignorant towards media and school health messages. They do not seem to learn from what the media and school teaches them about the dangers of HIV. One grandmother said:

> "*Our children don't listen because they talk about it on TV's and Radios and in schools…and the nurses and doctors talk about it but still, they do not listen"* ***(FGD3, grandmother 9, 55years).***

The above excerpt suggest that grandmothers may be struggling to understand why their children and grandchildren behave in risky ways, considering that people communicate freely about sex these days, compared to the olden days. A 56 year grandmother from FGD3 said "*Sex was taboo in our days but they have all this information at their disposal but they cannot say no [to sex] and they do not use condoms.***"** As highlighted earlier in this Chapter, the ignorance of guidance by HCPs and grandmothers could be due to the fact that help is sought from other sources such as churches and traditional healers. UNAIDS (2005) have also shown that despite the

availability of HIV campaigns through the media and non-media methods, the reproductive behaviour and choice of the youth remain the same. The non-usage of PMTCT services could also be due to stigma (Turan & Nyblade, 2013; Steward et al., 2008; Earnshaw & Chaudoir, 2009; Holzemer et al., 2009; Brickley et al., 2009; Turan et al., 2011; Brown et al., 2010). As highlighted in Chapter Five of this thesis, other studies have shown that women may not seek access to PMTCT, because of the fear of stigma of HIV (Skinner et al., 2003). This is because participating in PMTCT means one would be exposed to the public (Thorsen et al., 2008; Kebaabetswe, 2007).

- **Other community dynamics**

Another contributory factor towards poor utilisation of the antenatal care services is community dynamics. Other community dynamics mentioned by the grandmothers included that families usually hide sick family members from home-based caregivers (HBCs) who assist in looking after bedridden patients. According to the grandmothers, the community is promoting a lack of health-seeking behaviour among the youth by behaving in such way. Grandmothers' experiences suggest that community non-involvement in health issues would cause the PMTCT programme to function in a less than optimal manner. This is important to note, as studies have shown that community involvement seems adequate in ensuring that PMTCT cascade activities are adhered to (O'Gorman et al., 2010). The next section shows that women are not the only ones not utilising healthcare services, but men also do.

6.2.1.3 Male non-healthcare services utilisation

"Most men say a clinic is for women."

The third sub-theme under the main theme healthcare seeking behaviour in the context of PMTCT is male non-healthcare services utilisation. Although the grandmothers did not indicate male non-involvement as another factor for women's poor utilisation of healthcare services, they indicated the reluctance of male partners to participate in antenatal care services, or any healthcare services for that matter. A 64 year old grandmother from FGD1 said "*men do not usually come to the clinic. You will find the women going alone [for the antenatal care]."* An important issue further raised by the grandmothers was that men do not always adhere to

healthcare rules as compared to women. According to the grandmothers, the reason why men do not see being a part of antenatal care and PMTCT services as necessary could be due to the fact that they are patriarchs of families, and therefore, see the healthcare facilities as places for women. This point is clearly shown in below excerpt, provided by one of the grandmothers.

> *"Most of the men say a clinic is for women. They had told themselves that, isn't that when a woman is pregnant and when she gives birth, she loses lot of things [blood]… That is why they are scared of coming to the clinic. As I have mentioned that I gave birth to my five children with my husband besides me but if I tell him that he is sick and he should go to a clinic, he would refuse" (**FGD3, grandmother 2, 48years**).*

The grandmothers' lived experiences revealed that male partners lack interest in attending the clinic services because of their stereo typical view of antenatal care services being associated with women. An illustration of this is shown by one of the grandmother who described her husband dislike of the clinic "*It will not happen, my husband will not come to the clinic. They tested him for high blood pressure last year. He came here and asked a nurse when is this high blood disease going to heal and she said it will heal when he gets pension..." he then decided not to come anymore."* This is an indication of how some men view the utilisation of healthcare services, it seems onerous. Most grandmothers emphasised that if male partners can attend the antenatal services, they should also be tested for HIV, in order for them to receive treatment. One grandmother said:

> "*Yes they also have to be tested [for HIV], when the woman comes, she must come with her friend [partner], so that he can also be checked…in order for both of them to get treatment because men normally do not follow the orders, we are the only one who follow orders [from the healthcare professionals]" (**FGD1, grandmother 5, 64years).***

The above excerpts seem to confirm a possible entrenched patriarchal stereotype that male partners have towards healthcare utilisation. The fear of blood by the men was another interesting point mentioned by the grandmothers. The blood indicated here refers to that which a woman normally loses during the process of giving birth. Male involvement is essential in the PMTCT programme, because high HIV infection rates have been observed during pregnancy in

South Africa (Moodley et al., 2009). Studies have shown that men reject the utilisation of female-oriented health services, due to cultural and structural barriers (Theuring, Nchimbi, Jordan-Harder & Harms, 2010; Msellati, 2009; Reece, Hollub, Nangani & Lane, 2010). Similar to findings of the current study, Orne-Gliemann et al. (2010) found that grandmothers saw the non-utilisation of healthcare services by men as a result of the fact that men regarded a clinic as a place for women. In another study, which looked at male perspectives of being incorporated into antenatal care, men reported they would prefer being tested at an HIV testing site separate from the antenatal care site (Katz et al., 2009). Another reason for the lack of interest in PMTCT by men could be due to their self-perception of good health (Kizito et al., 2008). This means that men have a tendency of perceiving themselves as being healthy and therefore do not need to visit healthcare facilities (Kizito et al., 2008).

Positive spinoffs of male involvement in PMTCT have also been observed in Tanzania. For instance, an increased NVP uptake among pregnant women was found (Becker, Mlay, Schwandt & Lyamuya, 2009). In Cote d'Ivoire PMTCT was found to facilitate improved couple communication about sexual risks (Desgrees-du-Lou, Brou, Traore, Djohan, Becquet, & Leroy 2009). Male involvement has been encouraged as it is also seen as a gateway to ARV prophylaxis adherence for both mother and child (Peltzer, Mlambo, Phaswana-Mafuya & Ladzani, 2010). There are studies that have shown that simultaneous HIV testing between sexual partners during antenatal care has led to female HIV acceptance (Sherr, 2010). However, data in this Chapter illustrate that, although male involvement in PMTCT is deemed important, it is a difficult process to facilitate across all the age groups of men. The next theme discusses HIV testing as another important aspect of the PMTCT cascade step.

6.2.2 Theme 2: Perceptions of Antenatal HIV testing

6.2.2.1 HIV testing acceptance vs. burden removal

Following the discussion about poor utilisation of antenatal care services, the next step on the PMTCT cascade is to go through HIV counselling and testing. Theme two gives an account of grandmothers' perceptions of antenatal HIV testing in the context of PMTCT. The grandmothers appeared to support fully that their children get tested for HIV while pregnant. Most

grandmothers also expressed that HIV testing will assist in reducing the burden of caring for sick children, as indicated by this 55 year old grandmother who said "*…I am saying our children should be tested when they are pregnant, they should not lay their burdens on us [when they are sick].*" This is a statement that most of the grandmothers agreed to. Another grandmother supported HIV testing when one is pregnant in order to receive proper support during delivery time. This is what she said:

> "*I think it's a good idea that they test pregnant women because if you refuse to be tested while pregnant, when it is time to deliver, whether you go to the clinic or hospital, they will not be able to help you, they want to see the outcome of an [HIV] test…*" ***FGD1, grandmother 1, 52 years.***

In support of the above statement, another grandmother agreed that HIV testing is indeed very helpful to the nation because it allows one to receive treatment. The excerpt below shows her exact narration:

> "*Eer… I see the importance of testing [for HIV] because it is helpful to the nation. If you come to the clinic sick, you need to be tested first. This is very helpful to people because if you have tested and find that you have been infected with that disease, you will receive treatment…*" (***FGD4, grandmother 3, 71 years.***

Grandmother no 5 in the same group, indicated that HIV testing is important to protect the child from being infected with HIV "*They have to check [test] her first, after being checked, she will know her status so that they can protect the child who is still coming*. In addition to that, a 59 year old grandmother from the same group indicated a varying view that HIV testing is a fearful act: "*To test [for HIV] is not easy, it is a scary act because can you imagine after being tested and they tell you that you are [HIV] positive, you start having sad spirit*." Grandmothers' views illustrate that HIV testing is supported for varying reasons. Firstly, all grandmothers in this study support that HIV testing be done by the younger generation because it would relieve them of the burden of caring for their sick children and grandchildren. The antenatal HIV non-testing behaviour of the young women is considered a source of burden to the grandmothers. The data suggest the significant role played by the grandmothers in terms of caring for their grandchildren, especially when they are sick. This important role played by grandmothers has

also been identified in studies conducted in different contexts (Chen, Liu & Mair, 2011; Penn, et al., 2010; Barratt & Penn, 2009; Mudavanhu, 2008; Boon et al., 2009; Orb & Davey, 2005). Although grandmothers are known for the child-caring role, according to the grandmothers in the current study, caring due to sickness is, in fact, burdensome for them.

Although HIV testing was encouraged by the grandmothers for their own benefit, they also indicated other reasons which promote the well-being of the mother and child such as receiving proper care during delivery time, treatment support and protection of child from being infected with HIV. The protection of mother and child's health through treatment provision supports global targets of keeping the mother healthy as well (UNAIDS, 2011; UNAIDS, 2012) instead of the mother being viewed as a conduit for growing a healthy baby (Attawell, 2008). Grandmothers' views reflect that HIV testing is an important part of the PMTCT programme (Nguyen et al. 2008) which allows for the protection of the child from being infected with HIV (Kasenga et al., 2010; Levy 2009). Both the mother and child's health seems important for the grandmothers because of the fear of being burdened. Providing proper care during delivery seem to suggest that grandmothers encourage HIV testing for protection of healthcare providers as well.

Therefore, the analysis suggests that grandmothers perceive HIV testing as some sort of relief provider for them and HCPs in order to avoid the burden of caring for the sick mother and child. One grandmother indicated that although HIV testing is good, taking such act could be affected by fear of finding an HIV positive result. This indicates a fear of HIV stigma even amongst grandmothers. The fear of stigma has also been found to delay HIV testing in other studies (Nguyen et al., 2008; Pai et al., 2008; Sinha et al., 2008; Mitra et al., 2006). The concept of MTCT of HIV was touched minimally by at least two grandmothers, hence the discussion focused extensively on the burden that the grandmothers were feeling. Results suggest that HIV testing is an important step in the PMTCT cascade which is supported in order to relieve child and mother caring burden for the grandmothers. The next section discusses HIV treatment perceptions which also form part of the PMTCT cascade process.

6.2.3 Theme 3: HIV treatment perceptions

"A pill is a pill, they give you a pill after they have checked you for whatever you are suffering from."

The analysis reveals three sub-themes which fall directly under HIV treatment perceptions. The three sub-themes are treatment benefits, treatment challenges and treatment misconceptions and adherence to tradition.

6.2.3.1 Treatment benefits

Theme three gives an account of the HIV treatment perceptions among grandmothers in the context of PMTCT. The first sub-theme shows that the grandmothers in the current study emphasised the importance of treatment adherence which is especially done to "*prevent the child from having the same disease."* Some grandmothers were found to have knowledge about the treatment that is given to the mother to prevent HIV transmission. A 53 year old grandmother from FGD 4 said "*It is possible to prevent the child from having the mothers' disease [HIV]…the things they give to the mother [treatment] is for protecting the child from being infected."* Another grandmother aged 48 added that "*If your child has [HIV] disease, there is a tablet that they give to pregnant women to prevent the child from getting this disease.*" Another one said "*the nurses will give the mother prevention [treatment] so that the child can be born without the [HIV] disease."*

The analysis suggests that grandmothers were generally knowledgeable about the 'tablet' that is given to an HIV positive pregnant mother for preventing HIV transmission to the baby. Such knowledge could have been obtained through the health talks that they normally attend as indicated under theme one of this Chapter. Another source of information could be the media as indicated by one of the grandmothers from FGD4 that "*We get information about health from TV and also when we come to the clinic, there are pamphlets that explain about different diseases. We take those pamphlets and read…*" This indicates that some grandmothers are eager to learn and know more about HIV, however, such cannot be said about the children and grandchildren as already mentioned under theme one of this Chapter.

6.2.3.2 Treatment challenges

The second sub-theme under HIV treatment perception is that of treatment challenges. Grandmothers explained why HIV treatment is not adhered to. For instance, they expressed that people react differently to a treatment.

> "*There are problems, people are not the same. Some are happy with the treatment and some say when they take it, they become sick [and get worse]. Some have even stopped taking it and that is where the disease [worsen]"* ***(FGD3, grandmother 1, 45years)****.*

Most grandmothers indicated that according to their observations, treatment side effects lead to non-adherence. This seems to suggest that grandmothers had knowledge of the consequences of non-treatment adherence. Similarly, Ammassari et al. (2002) found that drug side effects are associated with treatment non-adherence. Differing from the factors expressed by the grandmothers in the current study, Ammassari et al. (2002) also found that psychological distress, lack of family support, increased antiretroviral regimen, low self-efficacy and inconvenience of treatment also led to non-adherence.

6.2.3.2 Treatment misconceptions and adherence to tradition

The third sub-theme under treatment perceptions is that of treatment misconceptions and adherence to tradition. One of the grandmothers admitted that there are some misconceptions about how some of the Western medication is made, which could explain the reluctance towards taking Western medication including ARVs.

> *"The treatment is fine even though other people reject it. Let me say we black people have a problem, we love our tradition and we don't take that pill. I remember one grandmother telling me that a Panado is made out of human brain …a pill is a pill, they give you a pill after they have checked you for whatever you are suffering from. It might be sugar diabetes, high blood pressure etc…"* ***(FGD3, grandmother 4, 47years)****.*

This grandmother expressed an important point that the Black Africans do not usually adhere to Western treatment because of their tradition. This suggests that Black Africans, especially those residing in rural communities, prefer traditional medicines to Western medication. Numerous studies have also found a preference of traditional medicines over Western medication, such as ARVs (Mephem et al., 2011; Stinson & Myer, 2012; Theilgaard et al., 2011). As already highlighted in Chapter Five, this is in line with Gilbert and Walker (2009), who found that cultural, historical, social and geographical factors had an influence on ART

treatment adherence. The grandmothers further suggested that the current traditional and religious practices have serious implications for the PMTCT programme. This point is explained by a 56 year old grandmother in FGD3.

> "*You find at home we have been given these things [treatment from clinic], but people stop using them and go to the traditional healers [dingaka] and also use church treatments [ditaelo]. These diseases [HIV] they cannot be treated like that. You will find that the patient starts being very sick and then they start hiding him saying he/she is not here we have taken him/her to such and such a place [traditional healer's place]".*

The above excerpt suggests that religion and tradition have the potential to hamper the effectiveness of the PMTCT programme. Grandmothers emphasised that there is treatment non-adherence to Western medication, because of the high belief in traditional and religious leaders' interventions. Unlike the findings of the current study, which show that treatment non-adherence could be due to treatment side-effects and a strong belief in traditional and religious treatments, Gilbert and Walker (2009) found that HIV participants in their study were motivated to adhere to treatment, regardless of the side-effects. Participants in a study by Watermeyer (2008) also linked treatment adherence to gaining life. Gourlay et al. (2013) also found that the use of traditional healers and birth attendants affected treatment adherence. The next section discusses grandmothers' views about HIV disclosure.

6.2.4 Theme 4: A dilemma between silence and telling

"…our children hide themselves [their status] from us … especially grandmothers ..."

6.2.4.1 HIV disclosure challenges

Although HIV disclosure does not really form part of the PMTCT cascade processes, it is an important factor as it facilitates adherence to the PMTCT cascade steps. Theme four shows the next narrative account provided by the grandmothers on HIV non-disclosure issues. The grandmothers in the current study shared their experiences of some of their children/ grandchildren's behaviour regarding HIV disclosure. For instance, their children/

grandchildren were reported to not disclose their HIV status to them after they had been tested for HIV. One grandmother said:

> *"…when our children are told that they suffer from this [HIV], they should also tell as the parents because many a times when they go for counselling, they call the parent as well so that she can protect herself [from being infected]" (**FGD2, grandmother 3, 57years**).*

In support of the above statement, another grandmother from FGD1 said "*they must tell us what they are saying at the clinic when they arrive at home*." As put by another grandmother, HIV disclosure is important so that "*when I touch her, I can know how to handle her …*"" According to most grandmothers' narratives, it is important that children disclose their HIV status to them so that they (grandmothers) can protect themselves. This implies that the lack of HIV disclosure by their children and grandchildren, places the grandmothers at risk of contracting HIV. Results discussed in Chapter Five showed that even though HIV disclosure facilitates adherence to PMTCT cascade processes (Obermeyer, et al., 2011), it is not always an easy process especially for younger women. Most grandmothers felt that they were victims most of the time since they are the ones caring for the grandchildren. One grandmother pointed a view shared by most grandmothers, she said:

> "*If you can look at it, our children hide themselves [their status] from us… especially grandmothers …" they do not disclose their [HIV] status to the grandmothers, they would just say its 'sejeso' [food poisoning through witchcraft" (**FGD2, grandmother 3, 57years).***

The above excerpt suggests that grandmothers felt that they were kept in the dark about what their children and grandchildren were suffering from. Their children encourage them to believe that they are suffering from diseases such as '*sejeso*' (associated with food poisoning through the use of traditional herb called *muti*), which in their belief does not need medical attention, but rather traditional intervention. As a result, grandmothers assist their children without protecting themselves, and thus become exposed to or vulnerable to HIV. The above excerpt suggests that traditional diseases such as '*sejeso*' *[food poisoning through witchcraft]* do not require extra precaution when handling the patient, even in the era of HIV. Furthermore, the excerpt below suggests that the grandmothers' role in child caring places

them at risk of HIV contraction. One grandmother gave a scenario of how they engage with a sick child:

> "*I would feel pity for her and start bathing her and [meanwhile] she knows [her HIV status]. Maybe [in the end] God remembers her [pass away] or not, then I start getting sick. When I start getting sick, when I go to the hospital or clinic and they test me and tell me that grandmother, you also have that thing [HIV positive]. It is the problem that I am seeing from our children, especially grandchildren …" (**FGD2, grandmother 5, 73years**).*

The above excerpt suggests that lack of knowledge about the HIV disease and PMTCT places the grandmothers at risk of contracting it. It also revealed that grandmothers seem to perceive being infected with HIV in a negative way, especially because they are part of the older generation. Furthermore, the data indicated that grandmothers seem to link certain diseases to traditional causes first, before they associate them with HIV. This is a cause for concern, because grandmothers' health seems to be compromised in the process of caring for their grandchildren. Similarly, Busza et al. (2012) argued that religious beliefs and cultural norms affect health seeking behaviour.

As discussed in Chapter Five of this thesis, studies have shown that HIV disclosure facilitates family support (Lee et al., 2010; Makin et al., 2008; Visser et al., 2008; Falnes et al., 2011). However, data analysed suggests that grandmothers are always supportive, irrespective of whether disclosure is practiced or not. The grandmothers in the current study were assisting their daughters and grandchildren without stating HIV disclosure as a condition for offering their assistance. This may explain why they were worried about being infected with HIV. This finding is confusing and perhaps contradictory to certain literature, considering that the HIV process disclosure model of Chaudoir and Fisher (2010) indicates that disclosure avoidance behaviour occurs when the person does not feel that he or she will get support or love from family. In the current study, avoidance of disclosure seems to pose a significant risk of contracting HIV to the grandmothers Chapter. The non-HIV disclosure affects the utilisation of PMTCT cascade steps as shown by the grandmothers views presented in theme one to four of this Chapter. The data presented under this sub-theme appears to disagree with the findings of a study conducted by Dwadwa-Henda, Mfecane, Phalan, Kelly, Myers and Hajiyiannis (2010), which found that elderly women were willing to assist their children (daughters,

daughters-in-law and grandchildren) but were mostly inhibited by their children's lack of HIV disclosure to them. Therefore, theme four reflects HIV disclosure challenges of confusing HIV disease with other traditional diseases such as 'sejeso'. PMTCT interventions at a rural context need to address this challenge.

6.2.5 Theme 5: Infant feeding perspectives

Another important step on the PMTCT cascade process is ensuring safe infant feeding practices. Theme five gives an account of infant feeding practices of grandmothers in the context of PMTCT. Grandmothers gave their lived experiences of how they handle infant feeding issues in their context. As shown on Figure 6.2 below, infant feeding lived experiences are discussed by focusing on the four sub-themes falling directly under this theme namely: 1) promotion of mixed feeding; 2) culture vs. health system; 3) transparency and 4) confusion about infant feeding.

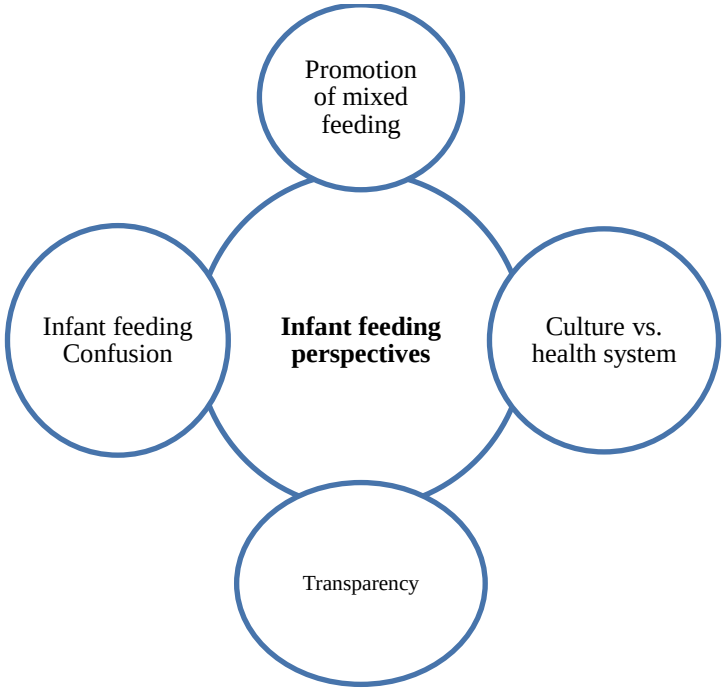


Figure 6. 2 Grandmother infant feeding perspectives

6.2.5.1 Promotion of mixed feeding habits

"When the child is 3 weeks old he or she must start eating porridge."

The first sub-theme for infant feeding perspectives relates to the promotion of mixed feeding habits by grandmothers. Most of the grandmothers in the current study expressed their dissatisfaction with the recommendations related to infant feeding time periods suggested by the healthcare system, as it is against traditional mixed feeding practices. As reflected in excerpt below, the grandmothers firmly believe that a child needs to be fed solid food from three weeks of age, in order to stop him or her from crying unnecessarily. Although this is an excerpt from one grandmother, it captures a view shared by all the grandmothers in this Chapter.

> "*We do not like the issue that the child is supposed to eat [solids] when he/she is 6 months [old]. [This is] because the child will keep on crying due to not being full. When the child is 3 weeks old he/she must start eating porridge so that it can stay for longer in the stomach. Because [if solids are not introduced] then you will find the child is crying sucking fingers and crying continuously, without us knowing how to console him/her only to find that the child is hungry" (**FGD1, grandmother 2, 40years**).*

The above excerpt suggests that the grandmothers as caregivers of children do not want to look after children who are always crying. This is because of their belief that if a child cries, it means that he or she is hungry. According to the grandmothers, solids stay in the stomach longer, compared to baby milk. Hence, for this reason, mixed feeding is practiced to stop the child from crying due to hunger. According to the grandmothers, introducing solids immediately after birth also assists with the strengthening of the umbilicus and reduces pains. One grandmother said: "*...the **navel [umbilicus]** for the child is strengthened by eating. The child should eat, if he/ she does not eat, they will have cramps on the navel and he/she will cry."*

Unlike studies which have suggested that mixed feeding results from the low supply of FFM (Doherty et al., 2003a), the data presented in this Chapter suggests that mixed feeding is practised to stop the child from crying and to strengthen the infant's navel. The issue of navel strengthening by solid food appears to contradict the PMTCT messages on infant feeding, which state that exclusive breastfeeding for the first six months of life may protect an infant from HIV transmission (WHO, 2010). The analysis also highlight the challenges of mixed feeding which have been confirmed in many studies (Ladzani et al., 2011; Sera et al., 2010;

Kinuthia et al., 2010; Morgan et al., 2010). In concurrence with other studies, mixed feeding was found to be mostly influenced by the belief that the baby does not get full from the mother's milk (Kakute et al, 2005; Varga & Brookes, 2008b). Chapter Six reveals that none of the grandmothers' narratives provided other accounts that could have led to mixed feeding such as the lack of milk from the mothers' breast (Bezner-Kerr et al., 2008). If the mother does not have enough milk, there is a high likelihood that her breast milk will be topped up with additional food. Furthermore, grandmothers' narratives did not indicate some misconceptions in a rural setting including beliefs that a fat baby is generally regarded as healthy compared to an underweight baby. Regardless of the new WHO guidelines which states that exclusive breastfeeding is recommended for all women irrespective of their HIV status, not having enough milk could lead to other ways of infant feeding such as giving breast milk and top up with infant formula milk. This is something that can happen to women regardless of a specific culture.

6.2.5.2 Culture vs. health system

"…But when we get home, we do what we [normally] do at home because these kids are born with hunger."

The second sub-theme that falls under infant feeding perspectives relates to cultural beliefs vs. the healthcare system. The issue of mixed feeding is deeply rooted in culture, as alluded to by the participants (both HIV positive women and grandmothers) in this study. The data in this Chapter shows that it is a tradition of the grandmothers to mixed-feed, and as a result, they are used to practising multiple infant feeding methods when they are at home and the healthcare facility. One grandmother said *"It is our culture, if at the clinic they tell us this, when we come to the clinic we do what they want at the clinic [do not mixed feed] but when we get home, we do what we [normally] do [mixed feed] because these kids are born with hunger… "*

The above excerpt reflects the dominant cultural practices related to infant feeding issues. Regardless of the high HIV prevalence in Mpumalanga Province (National Department of Health, South Africa, 2011a), grandmothers are adamant to continue their own infant feeding practices. The emphasis on the continuation of mixed feeding habits reflect the decision making powers that grandmothers have on infant feeding and this is because they have been playing this role for decades and therefore it is almost impossible to let go (Aubel, 2012).

Varga and Brookes (2008b) also highlighted the same findings related to mixed-feeding practices. The data in this Chapter further suggests that infant feeding choice is a family matter which involves grandmothers playing a key role in making decisions about it. Similarly, Doherty et al. (2006), found that family plays a significant in the choice of infant feeding method, and that mixed feeding habits start as early as one month of age (Sibeko et al., 2009). Of importance to note is that grandmothers in the current study did not highlight that mixed feeding occurs because culturally they are the ones caring for the children even when the mothers of the children are not necessarily working. In this study context, it is an acceptable tradition for grandmothers to participate on infant feeding issues as such mothers might find it difficult to not adhere to their advices. The mothers' adherence to grandmother' infant feeding requests could be due to wanting their ongoing support. And therefore, not following the grandmothers' advice on infant feeding could be regarded as showing disrespect for the elderly. This is the same disrespect that one of the grandmothers alluded to in theme one of this Chapter that these women think they are respecting the elderly by 'hiding' and 'concealing' their pregnancies. Again, it could be that because of the 'laziness' which has already been discussed in theme one of this Chapter, the mothers do not really concern themselves about infant feeding matters. Their laziness also prevents them from voicing important messages about infant feeding. Lastly, non-HIV disclosure could also make it difficult for the women to tell grandmothers how to feed their children as they will need an explanation for that. One grandmother rightfully puts it that grandmothers should always enquire from their grandchildren as to why they have opted for a particular infant feeding method especially since there is HIV.

6.2.5.3 Transparency on infant feeding

> ***"…we are not supposed to hide how we deal with children at home because they are also supposed to accept how we treat the children."***

The third sub-theme of infant feeding perspectives relates to the transparency of infant feeding. The grandmothers in this study reported that infant feeding practices, traditions and guidelines should be harmonised between the healthcare facility and themselves. They appeared to believe that this kind of harmony will stop them from hiding their behaviours related to infant feeding. One grandmother said:

*"In other words, we are not supposed to hide how we deal with children at home because they are also supposed to accept how we treat the children in order to be able to work together. All I am asking the clinic [staff] is that what we are discussing as grandmothers, we need to work together [with the clinic staff]. What we are doing at home with the children at home, they should not blame us when we come here [clinic]" (**FGD1, grandmother3, 55years**).*

What this grandmother is saying about infant feeding shows the traditional role that grandmothers play when it comes to infant feeding. As much as they do not like their grandchildren to hide their pregnancies and their HIV statuses, they also do not want to hide how they feed the children. The confidence on infant feeding is brought by the years of experience on the matter. Grandmothers further requested that the HCPs not blame them, because they adhere to other clinic activities, such as bringing children to the facility for immunisation as requested by the HCPs. One grandmother said *"because we live with these children, we stay with them. We do bring them [children] at the stipulated times [for immunization] that we are given. They should not blame us. Let us work together."* The request of the grandmothers implies that the healthcare system should accommodate mixed feeding on an on-going basis. This clearly indicates the lack of understanding about infant feeding importance in relation to PMTCT programme. Similarly, other studies have reported the same issue of mixed-feeding habits (Ladzani et al., 2011; Sera et al., 2010; Varga and Brookes, 2008b). The request for transparency on infant feeding issues shows that traditionally, grandmothers seems confident about feeding children. Therefore, interventions for infant feeding need to address the cultural roles of the grandmothers in the context of PMTCT. However, the 'working together' could also mean that grandmothers are involved on changing infant feeding habits which do not support safe infant feeding as indicated on the PMTCT cascade steps.

6.2.5.4 Infant feeding confusion

"Others say you can breastfeed [the child] for a month and then when it finish, wean the [child]…"

The fourth and final sub-theme under infant feeding perspectives relates to the confusion regarding how a child should be fed. The grandmothers suggested that breastfeeding in the olden days was a symbol of respect shown by women. Hence, this seems to suggest that any other form of infant feeding demonstrates a lack of respect by the mothers. Moreover, the data

seems to suggest that in this era, there is confusion regarding the length of time that women are supposed to breastfeed. This excerpt below also illustrates a lack of communication between grandmothers and mothers about why women are not breastfeeding.

> "*The ladies in the olden days used to respect, they were breastfeeding. Nowadays when they deliver at the hospital, they say do not breastfeed this child, we do not know what they see at the hospital. Others say you can breastfeed [the child] for a month and then when it finish, wean the [child] from drinking… we do not know why the doctors are doing that" (**FGD2, grandmother 3, 57years**).*

As shown above, the PMTCT infant feeding messages are still not clear to grandmothers as the caregivers of the grandchildren. This lack of clarity seems to have culminated into them practising mixed feeding habits immediately after the child has been born. The confusion of infant feeding is shown by a 74 year grandmother who said "*I thought when they said the child must eat at 6 months, was because the food disturbs the navel…"* A further confusion is shown by other grandmothers who have the right information about the infant breastfeeding period, but are not sure why they should adhere to it. As a result, they appear to resort to any alternative explanation which they see as feasible. It is also worth mentioning that the grandmothers in the current study did not talk about exclusive infant feeding at all. Although they mentioned the importance of breastfeeding, it was to be done in conjunction with solid foods. This could be because traditionally, mixed feeding is an acceptable way of feeding infants. Alternatively, one grandmother seemed knowledgeable about infant feeding, as they applied the recommended principles of feeding to their children *"… I have three children, I was following the clinic rules. I was breastfeeding them for the whole 6months and then after that I wean them and then I give them porridge…).*

The lived experiences of infant feeding practices by grandmothers suggest that the grandmothers have different levels of understanding, and this may be due to the age factor. The young grandmothers seem to understand the concept of infant feeding better than the older ones. In concurrence with other studies, the grandmothers' lived experiences suggest that the infant feeding confusion seems to be mostly due to the lack of knowledge. For some grandmothers, there seems to be no knowledge of the recommended feeding options (National Department of Health South Africa, 2008). Therefore, when grandmothers say 'do not blame us' this is an indication of the lack of knowledge and how they are expected to act culturally.

According to culture, they have all the power to dictate how the infants are supposed to be fed. As such, the ongoing changes on infant feeding guidelines bring confusion of their roles and the manner of feeding in a rural context. PMTCT interventions are therefore required to deal with the lack of a system for addressing the power bargaining of grandmothers on infant feeding issues.

6.2.6 Theme 6: PMTCT obstructions in a rural context

Having shared grandmothers' perceptions based on the sequence of PMTCT cascade steps such as utilising PMTCT services, HIV testing, HIV treatment perceptions, HIV disclosure and infant feeding practices, participants in this study further mentioned a number of additional obstructions that might affect the effectiveness of the PMTCT programme. It is important to understand these obstructions as they seem to be affecting the utilisation of PMTCT services in this study setting. These challenges indicate individual factors, community factors and health systems factors. Figure 6.3 reflects the four sub-themes falling directly under the main theme on PMTCT obstructions in a rural context.

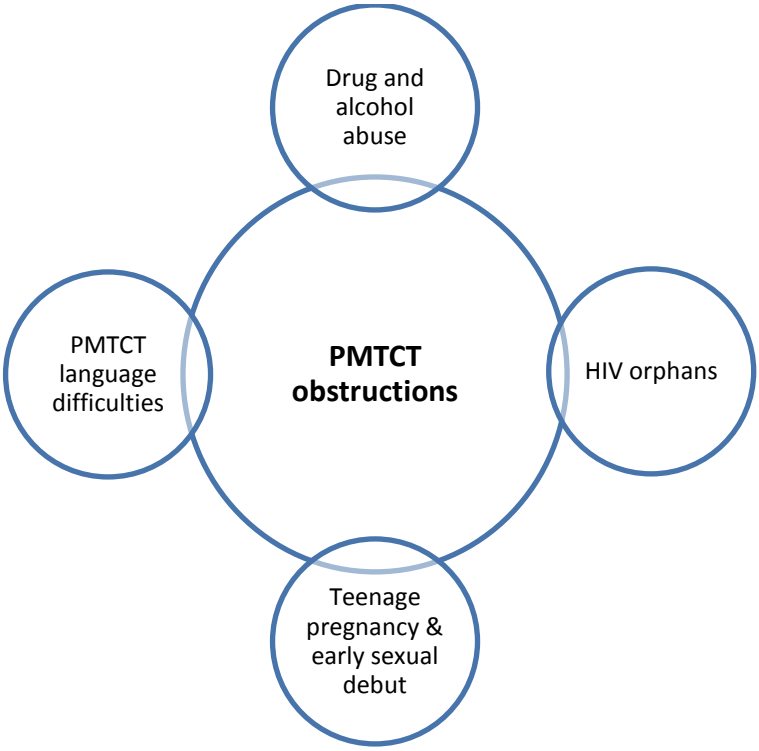


Figure 6.3 PMTCT obstructions

6.2.6.1 Impact of drug and alcohol use

"… they do not enforce the law that say children under the age of 20 must not be allowed, our children are filling up those taverns."

The first sub-theme falling directly under the main theme on PMTCT obstructions is that of drug and alcohol use in a rural context. The data collected shows that the grandmothers in the current study were faced with multiple challenges related to being caregivers. For instance, children and youth engaged in unruly behaviour, involving the use of drugs and alcohol which are illegally supplied by people older than them.

> *"…the state of health here at [name of area] is critical especially because the youth, they are on drugs and they take alcohol too much. There are grown up people who also take these young people to taverns and they give them drugs as well…Some [children] are in their primary school but are already in those taverns and even at home they don't see them and they go on with those things..."* ***(FGD3, grandmother 1, 45years)****.*

The above excerpt is an example that suggests the amount of stress that grandmothers feel, is caused by substance abuse by the youth. An earlier section in this Chapter highlighted that the youth ignore elderly guidance, including that provided by HCPs and by media which teaches them about the risky behaviours that might lead to HIV infection. The fact that the youth and even younger children (who are in primary schools) use drugs and alcohol seems to explain why they ignore advises coming from various sources. This also seems to suggest that substance abuse leads to risky behaviour, which could thwart PMTCT programme endeavours. Unlike other studies which found that societal, cultural and individual factors (Peltzer et al., 2007; Petrie et al., 2007) are the ones contributing to the non-utilisation of PMTCT, the above excerpt provides evidence that substance abuse may also form a contributing factor. An expansion on this is provided in Chapter Eight of this thesis, where substance abuse in a rural context is discussed.

6.2.6.2 HIV orphans

"Those children are orphans, all of them are orphans and they wear tattered clothes to school."

The second sub-theme falling directly under the main theme on PMTCT obstructions relates to the impact of HIV which leads to a high prevalence of orphans in the rural context. The grandmothers indicated that the entire burden that they are experiencing is as a result of grandchildren being orphaned. The data revealed in this Chapter that there are high numbers of orphans in the area of study due to the HIV/AIDS disease. A 57 year old grandmother gave an exact scenario of the current situation in the study setting, as reflected by below excerpt.

> "*When you see a grandmother passing with a child, you must know that it does not have the mother. All these grandmothers who are here at the clinic have stress from all these orphans. It is these diseases that are taking our children, this disease is cruel, it is incurable…It is not HIV? They say it is HIV and AIDS…"*

Another grandmother added to the above point that "*… You will feel a lot of shame for them, orphans in this area appears to be more than everywhere else."* According to the grandmothers' caring lived experiences, the high prevalence of orphans in resource- poor settings, such as Nkangala district, is mainly due to the HIV disease. The grandmothers are faced with the situation of having to ensure their well-being while at the same time having to care for their grandchildren, who place them at risk of contracting HIV. This reflects the burden that grandmothers have of raising orphans who in turn suffers from HIV disease. Similarly, some studies have argued that the grandmothers' role of caregiving is not by choice, but out of force to look after their grandchildren who are AIDS orphans (Mudavanhu, 2008).

The lived experiences of the grandmothers suggest that the women who are non-adherent to PMTCT services could be AIDS orphans who experience psychosocial stress of not having parents, and thus become very unruly. Other studies have also suggested that psychological barriers are contributing factors to non-utilisation of PMTCT services (Peltzer et al., 2007; Doherty et al., 2005; Kebaabetswe, 2007; King et al., 2008).

6.2.6.3 Teenage pregnancy and early sexual debut barriers

"…the child gets pregnant when she is only 12-13 years…"

The third sub-theme falling directly under the main theme on PMTCT obstructions relates to sexual behaviour by young girls. According to the grandmothers, another observed PMTCT obstruction is teenage pregnancy, which seems to be a big challenge in the area of the current study. They further indicated challenges regarding the age at which young girls fall pregnant in the study area. A 52 year old grandmother from FGD3 said "*We have a problem of teenage pregnancy, the child gets pregnant when she is only 12-13 years, that is a problem that gives us sleepless nights in this area…"*The study reflects an early pregnancy of 12-13 years which indicates that sexual debut of young girls is around that age, or even younger. This seems to differ from the findings of other studies which found an early sexual debut of 16 years (Zuma, Setswe, Ketye, Mzolo, Rehle & Mbelle, 2010). According to the grandmothers, early pregnancy is due to the fact that children start to menstruate early, which is also facilitated by an early sexual debut and witnessing their parents having sex. This seems to suggest that early menstruation for young girls in this context is triggered by an early sexual debut. One grandmother shared a scenario that illustrates some of the risky behaviours reported to grandmothers by their own grandchildren.

> "*[the reason] for our children to start menstruating early [is because of early sexual debut] …"most of the time my child would come back crying saying he found other children aged 6, 7, 8, 9, and 10 doing each other [having sex] in the toilet. So that thing[sex] shakes the blood of the child and then the child starts getting used to the fact that she is doing it..."Boys and girls do each other [have sex], you see they are still young but they are able to do it in there because they saw mum and dad doing it…" (**FGD3, grandmother 5, 56years**).*

According to some grandmothers' perceptions of PMTCT programme obstructions, the sexual behaviour of young children leads to early menstruation and pregnancy. Furthermore, the act of having sex in school toilets exposes children to HIV at an early age, if they were not already infected by their late mothers. Grandmothers also believed that early sexual debut is caused by children witnessing sexual acts between parents. This factor needs to be explored by further research in the context of PMTCT. Some grandmothers also mentioned another factor that could be fuelling early sexual debuts and early pregnancy. They appeared to believe that

young children who are orphans have their own children early in order to boost their socio-economic situation. One grandmother said "*I think it is this [child] grants they are getting, you know they finish giving birth, then there is another child, 123 [immediately], when the child starts walking, she is pregnant with another child. But I think it is this money for [child] grants that they are getting."*

According to some grandmothers, the child support grant is detrimental to the society as it encourages risky sexual behaviour, which in the end leads to high rates of teenage pregnancy. Grandmothers further expressed that the need to improve the economic situation is shown by their grandchildren's boyfriends who accompany them to obtain grants for their children. The excerpt below illustrates the narrative given by one of the grandmothers about how young women and men behave in relation to social grants.

> **"***You should see the fathers of their children at the pensioners/grants pay point; you will find them waiting outside for their little women [girlfriends], when they get the money [for children]…" (**FGD2, grandmother 4, 61years**).*

The situation surrounding childcare grants suggests an unstable economic situation in the area of study, which might be contributing to the non-utilisation of PMTCT services. The grandmothers lived experiences point to poverty as a factor which encourages young men and women to continue putting their lives at risk, in an attempt to escape poverty (Farmer et al., 1996). Grandmothers further expressed an extreme case of teenage pregnancy which not only affects them, but teachers as well. One grandmother shared this:

> "*Since you asked her[your grandchild] that why do you seem like you are pregnant and she keeps quiet and the next thing we were called the other day by the principal telling us about the same issue of pregnancies [at school]. He told us that the teachers have problems even at their homes because we as parents send our children to school in the months when they are supposed to be giving birth. When the class is in progress, they would just see water breaking. When that happens, they would call an ambulance and it would pick up the child and send her to [name of hospital]. Because they are mostly men [at school] and they don't know anything about pregnancies they send these lady teachers and when they get there, you find that the child should be operated, and this teacher should now stay with the child because she is the one who accompanied her. When the*

*husband gets home the lady teacher is not there and she will come home midnight because of our children and we don't even know. So, he was saying all that in pain and asking that we should teach our children good norms because it seems like we don't. He said that there is lot of pregnant children in the school and we as parents, we don't know" (**FGD4, grandmother 1, 81years**).*

The above excerpt suggests that some grandparents and parents do not know their children well. Parents cannot see that their children are pregnant until their child's water breaks at school. The grandmothers suggested that school children do not utilise antenatal care services because they hide their pregnancy until they are due to deliver. This also suggests that there is poor communication between the school and the parents, or rather grandparents. As pointed out by other literature, being in a rural area may also be a cause of teenage pregnancy (Varga & Brookes, 2008b). However, according to the grandmothers, teenage pregnancy is also used as a strategy for getting grant money.

6.2.6.4 PMTCT language difficulties

"Other grandmothers have not been to school, they do not even know 'a'."

The fourth and final sub-theme falling directly under the main theme on PMTCT obstructions is that of PMTCT language challenges. According to the grandmothers, another PMTCT programme obstruction that is affecting the health system is PMTCT language comprehension difficulties. Although some grandmothers have indicated that they have heard about PMTCT, the majority expressed that the challenge they have is that they are generally not learned. This makes it even more difficult for them to understand the pictures on the posters. In support of this, a 45 year old grandmother from FGD1 said " *Other grandmothers have not been to school, they do not even know 'a', she just sees a picture that is written, but she does not know what it means, she just sees a person or two but she does not know what is happening."*

Data analysis suggests that lack of understanding of language used in PMTCT is also due to the lack of education among grandmothers. It is suggested that poor education prohibits grandmothers from fully understanding PMTCT processes, which is detrimental to the success of the programme. This finding is similar to that of a study conducted in South Africa, which found that grandmothers were not knowledgeable about PMTCT processes (Dwadwa-Henda et al., 2010). The difference between the findings of Dwadwa-Henda et al. (2010) and those of

the current study is that the former found that PMTCT awareness was promoted amongst grandmothers, whilst in the latter it was not. Penn and Watermeyer (2012) argued that proper communication is needed to understand a disease. Therefore, addressing PMTCT language challenges is vital in promoting PMTCT programme effectiveness.

6.2.7 Theme 7: PMTCT services enhancement in a rural context

The final theme in Chapter Six relates to suggestions on PMTCT services enhancement. This Chapter demonstrates that grandmothers suggested a number of actions that need to be taken, in order to improve adherence to PMCT cascade steps**.** Figure 7.1 shows the seven practical solutions suggested by the grandmothers that could enhance PMTCT services especially in a resource-poor setting such as the Dr JS Moroka sub-district.

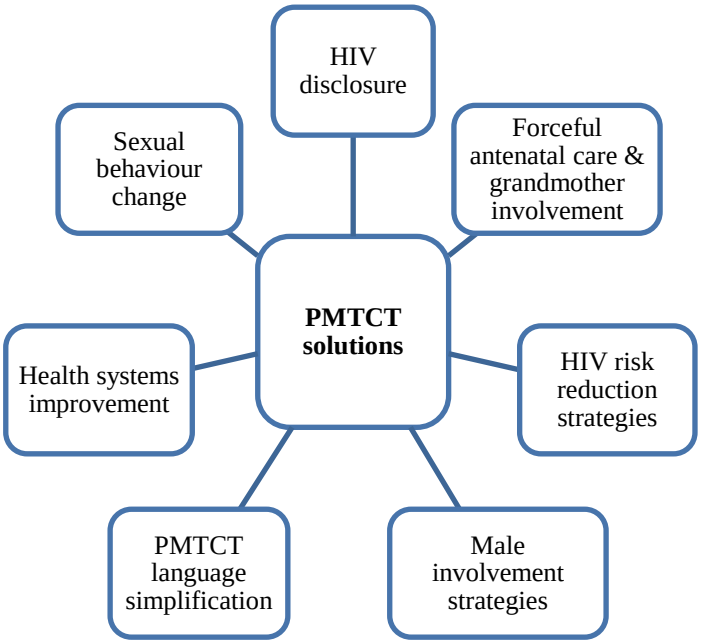


Figure 6.4 Suggested PMTCT programme solutions by grandmothers

6.2.7.1 HIV disclosure by youth

"They must tell us because we stay with them."

The first sub-theme under PMTCT services enhancement relates to HIV disclosure by youth. In order for PMTCT effectiveness to be realised, the grandmothers alluded to the importance of

HIV disclosure by the youth. They mentioned two key factors related to HIV disclosure: grandchildren should not fear them and a quest for self-protection from HIV is crucial. They indicated that HIV is no longer a scary disease, therefore, their children should feel free to disclose their status. A 74 year old grandmother from FGD 1 said "*They should not be afraid of us, this thing [HIV] is no longer scary. She must tell me that mum, I am from there [clinic] and they say I have the [HIV] virus, so that when I touch her, I can know how to handle her…"*

Although many grandmothers suggested that HIV is no longer a scary disease, data seemed to suggest that they do not wish to be infected with it, because of the lack of knowledge about what their grandchildren are suffering from. According to the grandmothers, self-protection is key, once HIV disclosure has taken place. This also implies that support for their grandchildren would not stop because of their HIV positive status. It would continue, but with a lot of caution from the grandmothers. The quest for self-protection by grandmothers is due to the fear of being stigmatised by the community. A review study showed that HIV disclosure is linked to support expectation (Obermeyer et al., 2011). The lack of HIV disclosure by the grandchildren suggests that they do not expect support from their grandmothers once they have disclosed their status. Disclosure is considered a proxy measure for stigma (Nyblade, 2006), suggesting that once the HIV status has been disclosed, one would be able to tell if people will discriminate against or support her.

6.2.7.2 Forceful antenatal care support and grandmothers' involvement in PMTCT

"She has to be forced to come to the clinic."

The second sub-theme which falls under PMTCT services enhancement is about strategies for supporting early antenatal care attendance. Grandmothers in this study highlighted some practical strategies to be employed in encouraging the utilisation of the antenatal care services. For instance, they proposed the use of forceful strategies to achieve antenatal care attendance and treatment adherence. In an account of how to go about forcing antenatal care utilisation, a 55 year old grandmother said:

> "*You have to **force** her to go to the clinic when you know that it is her time to do so. Yes because she is a child, she can tell you that I went to the clinic without really going…When you see that the child has a problem, while you still can,*

> ***accompany*** *her to the clinic and make sure that she* ***takes her treatment*** *from the clinic and when you get home,* ***force*** *her to take the medication."*

The above excerpt possibly indicates that grandmothers see themselves as being instrumental in forcing antenatal care attendance and treatment adherence. According to the grandmothers, using force might actually facilitate attendance of the antenatal care services. The force would mean accompanying mothers to the clinic and making sure they adhere to treatment given at the healthcare facility. Although they use the word 'force', they appear to suggest that the pregnant woman would be encouraged to seek medical help on an on-going basis. Hence the data presented in this section points to the three key factors that are required from the grandmothers such as on-going encouragement (reminders), accompanying the woman to the clinic and ensuring treatment adherence. The recommendations made by the grandmothers show that they are indeed "family and reproductive monitors" (Penn et al., 2010, p. 13) and that they have power to make decisions at family level. This also showed their readiness to keep families healthy by ensuring forceful health seeking behaviours. Their eagerness to participate in PMTCT activities shows their traditional role of family in supporting other family members, without any limits or reservations (Foster, 2000).

Another area where the grandmothers saw themselves as contributing positively was in postnatal care, especially related to the infant feeding aspect. One grandmother said:

> "*When a child comes back with a baby, you as a grandmother you should take a stand and make sure you know what is going on with your child and the baby. When your child tells you that the baby should be formula milk-fed, you must go and seek the truth where she comes from to show that you want the love and growth in your child. When the child says they said she should breastfeed, ask for the reason… If she does not tell you, take her papers and go ask someone to help you understand them because you might not understand them yourself" (****FGD3, grandmother 1, 45years****).*

The above excerpt suggests that postnatal care involvement of the grandmothers would be mainly to understand the infant feeding choice of the mother. It is suggested that if the grandmothers could understand the reasons for the infant feeding choice, they would be able to support the mother instead of forcing mixed feeding practises. Unlike the suggestions made by

grandmothers, which involve them supporting their children postnatally, other studies identified the important role that could be played by mentor mothers to support HIV positive mothers in adhering to PMTCT services once they have started attending antenatal and postnatal services (Scorgie & Crankshaw, 2008). In Uganda they proposed the involvement of community leaders in PMTCT (IMAU & CDC Uganda, 2003). Thorsen et al. (2008) encouraged community HIV testing to reduce stigma. This Chapter has highlighted that the biggest challenge relates to taking the initial step to seek medical help.

6.2.7.3 HIV risk reduction strategies (scare tactics)

"…they will go and stay alone in a tin house [shack]…"

The third sub-theme under PMTCT services enhancement relates to HIV risk reduction strategies. As a way of reducing the risk of HIV infection among the youth, some young grandmothers who still have young children of their own, proposed using scare tactics to make their children aware of the HIV disease. A 57 year old grandmother from FGD2 said: "*…with my children, I told them that since they know that there is a disease [HIV] and if they sleep around and become infected (isn't I should scare them),… they will go and stay alone in a tin house [shack] and I will apply pine gel on them [cleaning disinfectant] and spray them with water using a hose pipe"* The use of scare tactics seemed to work for some of the grandmothers, as this paints a horrible picture in the minds of children in terms of what would happen to them should they become infected with HIV. At the same time, this type of talk actually portrays the HIV disease as something that is highly infectious, where one has to stay in solitary confinement to receive minimal care. This further shows that some grandmothers have stigmatising attitude towards HIV positive people. This could be regarded as enacted stigma as it involves conducting acts which reflects discrimination and abuse (Bharat et al., 2001). This also shows reflect that at household level, stigma manifest itself in the form of verbal abuse and eviction of a person with HIV (Bond et al., 2002; Brickley et al., 2009). This kind of behaviour shows that a person with HIV is devalued (Weiss & Ramakrishna, 2004) by being isolated from the family. Therefore, such stigmatising behaviour as described by one grandmother on the above excerpt might lead to feelings of disempowerment especially due to being HIV positive. HIV interventions in a rural context need to address stigmatising behaviour at family level as this might be contributing to poor utilisation of PMTCT services.

6.2.7.4 Improved partner communication as a strategy for male involvement

"Beg him and he will eventually come with you."

The fourth sub-theme under PMTCT services enhancement relates to improved partner communication. The data presented in this Chapter suggested that the only practical solution suggested by the grandmothers to increase male participation in the PMTCT programme was to talk to them in a loving way, using special, endearing names when talking to them. The excerpt below provides a practical way of convincing male partners to participate in the PMTCT programme, as suggested by one of the grandmothers.

> *"..." Beg him and talk to him well and call him with those names [pet names]...but mine will refuse because he is the old generation and he has grey hair and he is over 60years old and when I say we should come, he is stubborn and he won't understand. Even if I can say we must come for HIV tests, he would say he is only with me and he is not sleeping around but the youth should talk with their partners that they should come to the clinic together or even give him an ultimatum that if you don't come, I will leave you" (**FGD3, grandmother 5, 56years**).*

Although this grandmother encouraged smooth talking to male partners, she did not view that method as one that would work on her own older husband, because he would argue that he does not sleep around. Other studies recommended similar strategies to those suggested by the grandmothers, such as improvement in partner communication about PMTCT (Katz et al., 2009). The above excerpt further illustrates that some grandmothers believe that giving ultimatums to end the relationship would encourage male partners to participate in the PMTCT programme. Contrary to the grandmothers' views, other studies have recommended different interventions, such as sending letters of invitation to men, community sensitisation activities, increasing ARV availability at the healthcare facility (Mohlala et al., 2011) and giving male partners time to consider the PMTCT programme recommendation (Mbonye et al., 2010) and previous HIV testing (Nkuoh et al., 2010).

6.2.7.5 PMTCT language simplification for grandmothers

"…how about if our government or people who make posters can simplify them …"

The fifth sub-theme under PMTCT services enhancement relates to PMTCT language simplification for the grandmothers. Understanding language used in PMTCT is critical for the grandmothers as they play a significant role, as caregivers. The grandmothers indicated a need for the simplification of the language on posters, and the provision of education that is solely for grandmothers who cannot read and write. A shared view by most grandmothers suggested that pure PMTCT language simplification is a possible way of improving their knowledge of the programme. A 45 year old grandmother from FGD 3 said:

> "*So I am saying, how about if our government or people who make posters can simplify the posters. And even in the clinic, when we arrive, take our grandmothers and grandfathers who cannot read those things [posters] that have been placed on the walls…[and let them] be taught…"*

The quest for knowledge by the grandmothers shows their willingness to be a part of PMTCT programme. The lack of understanding of the PMTCT programme has yielded some detrimental effects, especially related to infant feeding. Other studies have shown that providing PMTCT education to grandmothers promoted PMTCT knowledge (Dwadwa-Henda et al., 2010).

6.2.7.6 Healthcare system improvement

"I wish that the clinic would open even at night because we encounter problems with the pregnant women here at [name of the area]."

The sixth sub-theme under PMTCT services enhancement relates to healthcare system improvement. The grandmothers identified key health system factors that would lead to the improvement of the PMTCT programme, such as: increase of medical staff in order to reduce staff workload, longer working hours and infrastructure improvement as crucial in resolving some of the PMTCT capacity constraints. The grandmothers further expressed a need for their own transport when coming to the healthcare facility *"You find that the parent encounters problems when she has to find transport for transporting the woman to the hospital and even the money is a problem because the owner of the car will want his money same time.* Some of the recommendations

given by the grandmothers are similar to the findings of the WHO and UNICEF (2007) which indicated that poor infrastructure inhibited the delivery of good quality services within the health system.

6.2.7.7 Sexual behaviour change

"If he wants that job [to have sex] he must use a condom."

The seventh sub-theme under PMTCT services enhancement relates to sexual behaviour change. Grandmothers also emphasised the importance of change in sexual behaviour, such as abstinence. They also spoke about the importance of men using protection during sexual intercourse, if one could not abstain "*If he wants that job [sex] he must use a condom…"* This Chapter also shows a variant view by one of the grandmothers who seem to believed that HIV protection was brought about by the White Africans "*White [African] people have made condoms for us…God and white people loved us [so much], we have condoms and tablets [HIV treatment]and everything else…"* According to the grandmothers, HIV seems to be regarded as a race-specific disease, where the belief exists that it affects Black African people and not necessarily White Africans. The White Africans seems to be portrayed as life savers of the Black African generation. This kind of mentality shows a lack of knowledge about HIV origins in a rural context.

Grandmothers further shared some of the practices they used to adhere to when they were having children. For instance, they would abstain from all sexual activity for a maximum of two years even though they were married "*Even if you are married, according to olden day's rules, they [parents] were staying with us and we were married and they would say the child is still growing. Nowadays children already sleep with a man when the child is only one month old. We used to spend two years, being married [without sex], that was parent's rules)".*

Most grandmothers in this study highlighted the fact that there has been a total change in behaviour nowadays, when it comes to the sexual issues. UNAIDS (2005) also indicated that the youth today is practising risky behaviour that is difficult to change by means of varying interventions. Other studies also found low condom use among people who have many partners (Lichtenstein, Desmond & Schwebke, 2008).

6.2.7.8 Other PMTCT solutions

The eighth and last sub-theme under PMTCT services enhancement indicate prayer as another way that can improve the PMTCT programme. The grandmothers in the current study appeared to be very religious and as a result, they saw prayer as the only weapon to overcome these burdensome health challenges. This seems to be a unique PMTCT solution, which has not been suggested in other studies to help lead to optimum function of the PMTCT. It might be necessary to conduct studies that may assist in exploring this aspect.

6.3 Conclusion

The results of this Chapter encompass PMTCT barriers that are directly linked to the healthcare system, as well as those beyond the healthcare system. This Chapter also covered the infant feeding perspectives of the grandmothers and their possible solutions to ensure an effective PMTCT programme. The dominant themes which emerged from the grandmothers' lived experiences were as follows: fear of the HIV disease burden, accentuation of the burden of HIV, infant feeding lived experiences and limited kno+wledge and understanding of PMTCT. The fear of grandmothers related to HIV is two-pronged: fear of the burden because of the grandchildren who are infected with HIV, and the fear of being infected with HIV because of non-HIV disclosure. Although the grandmothers expressed the challenge of non-utilisation of PMTCT services (HIV testing and antenatal care), their concern was related to having a healthy mother and child in order to avoid burden of HIV. This Chapter also showed the lack of PMTCT understanding, especially related to PMTCT terminology. Chapter Six further highlighted the firmness of the grandmothers when it comes to the topic of infant feeding. Their mind-set on infant feeding does not accommodate the HIV challenge, which infant feeding guidelines are trying to address. Lastly, this Chapter emphasised intervention strategies needed, particularly those that promote the involvement of the grandmothers and men.

CHAPTER 7

HEALTHCARE PROVIDERS' LIVED EXPERIENCES OF PROVIDING PMTCT PROGRAMME SERVICES IN A RURAL CONTEXT

7.1 Introduction

This Chapter provides a detailed description of the findings which arose from thematic analysis of the individual interviews that were conducted with the health workers providing PMTCT services at the three healthcare facilities in the Dr JS Moroka sub-district in Mpumalanga Province. A conclusion is provided at the end of the Chapter, connecting with findings of the previous two Chapters. The conclusion will lead to the identification of theme intersections among the three groups of participants and the small story analysis case studies in subsequent Chapters Eight and Nine.

7.2 Thematic analysis, narrative descriptions and discussion

Thematic analysis was used to analyse the data that emerged from the individual HCPs' interviews. There are five main themes that emerged from the five individual interviews that were conducted: 1) Overview of PMTCT in the healthcare facility; 2) PMTCT barriers affecting the healthcare system; 3) PMTCT barriers beyond the healthcare system; 4) PMTCT successes and 5) PMTCT programme solutions. These are presented in Figure 7.1 together with sub-themes. The HCPs' lived experiences are presented according to each theme and sub-theme indicating participants' illustrative excerpts. The illustrative excerpts from individual interviews with HCPs were selected based on their in-depth, detailed descriptions. The results are then further described and discussed.

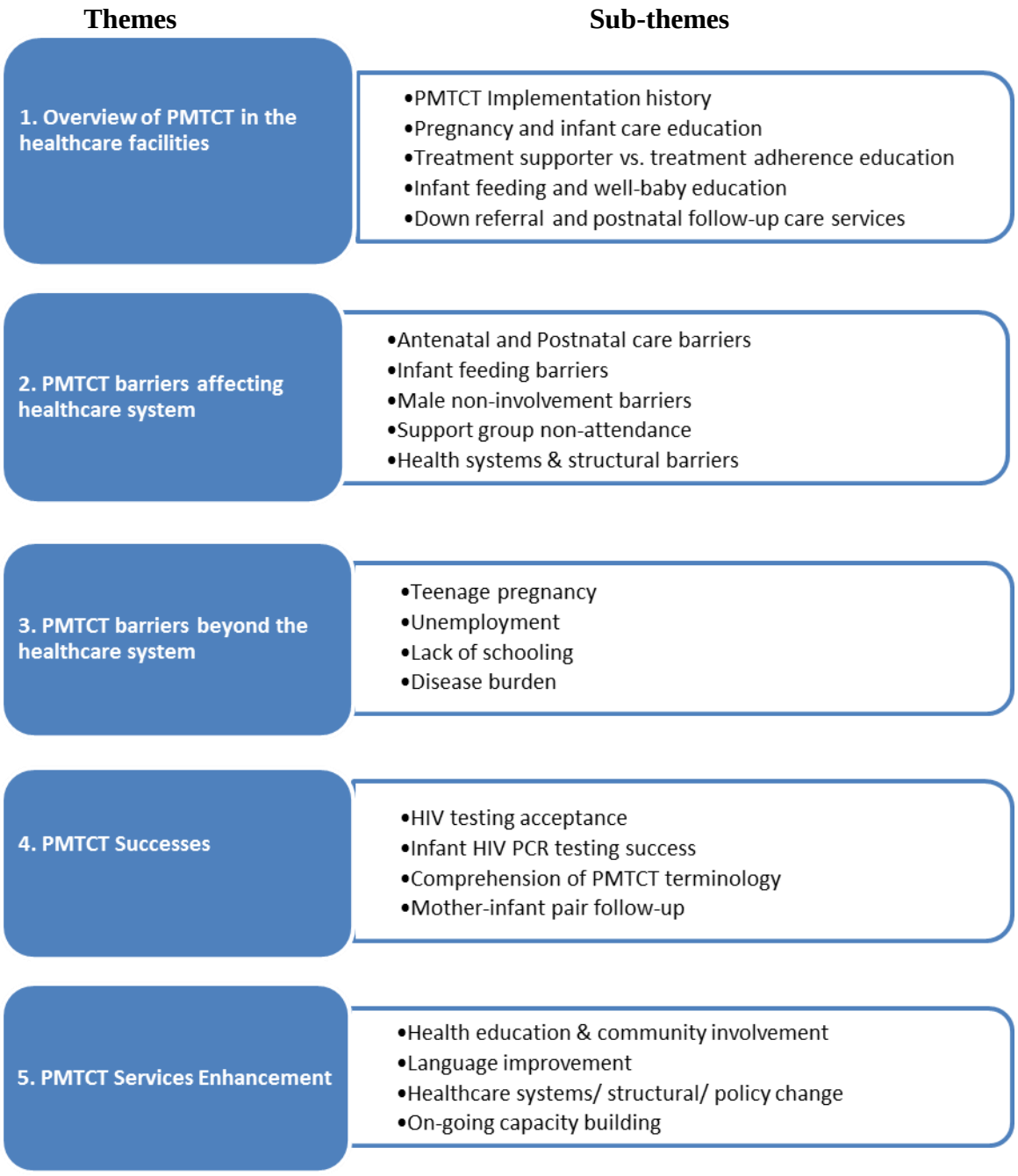


Figure 7.1 Five themes and sub-themes providing an account of PMTCT service provision by the Healthcare providers

7.2.1 Theme 1: Overview of PMTCT at the healthcare facilities

The HCPs gave an overview of the PMTCT programme services which they offer at the health facilities. Figure 7.2 shows that there are five sub-themes which fall under this theme. The sub-themes reflect intense education provided by the HCPs on the following aspects:

pregnancy and infant care, treatment supporter vs. treatment adherence, infant feeding and well-baby services and down-referral services for continual care of HIV positive patients.

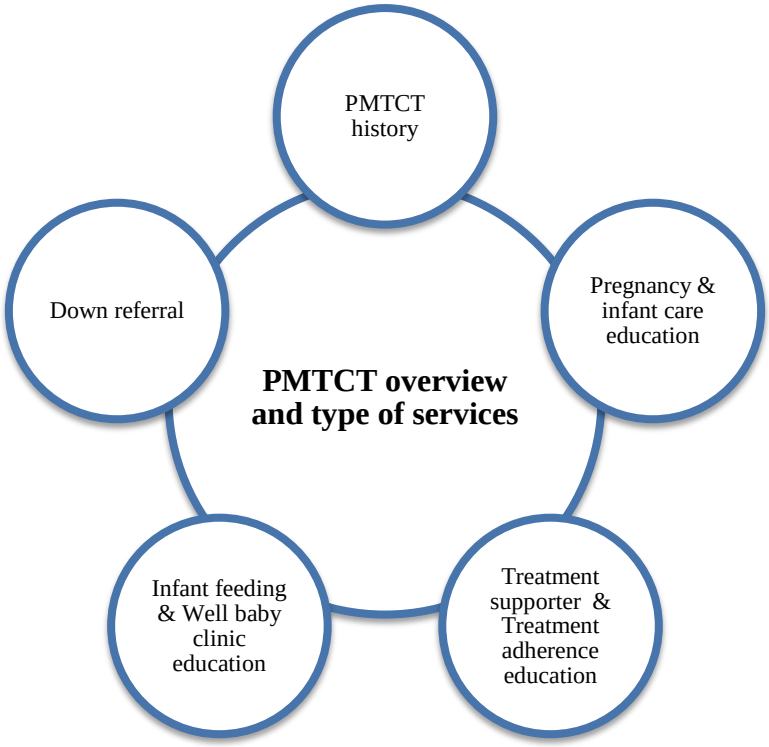


Figure 7.2 Overview of PMTCT in healthcare facilities

7.2.1.1 PMTCT history

The first sub-theme falling under PMTCT overview in healthcare facilities relates to PMTCT history in the healthcare facilities where the study was undertaken. The HCPs gave information about the PMTCT implementation history in their respective facilities, including the training undertaken by staff to implement the PMTCT programme. The excerpt below highlights some of the key activities that were undertaken in healthcare facilities since PMTCT introduction.

> *"Okay, the PMTCT here [name of facility] started in 2005. We started with trainings…we started with VCT while it was still called VCT, and now it is called HCT…from there [we were trained on] PMTCT, then couple counselling. We continued with it while also giving other colleagues in service training so that we can do [PMTCT work] together" (**female, 47 years, health facility manager**).*

The HCPs' lived experiences showed that the implementation of the PMTCT programme in Dr JS Moroka healthcare facilities started in 2005, which was four years after its initial implementation at South African healthcare facility pilot sites. Some HCPs were trained in courses related to HIV Counselling and Testing (HCT), PMTCT and couple counselling. Others received in-service training from fellow colleagues who had been previously trained on the above courses. Similarly, a study conducted by Rujumba, Tumwine, Tylleskar, Neema and Heggenhougen (2012b) found that there were healthcare workers whose only training involved in-service training as well as involvement in self-studies. Those who were not trained expressed a high need for formal training.

7.2.1.2 Pregnancy and infant care education

The second sub-theme under PMTCT overview in healthcare facilities relates to education that is provided on pregnancy and infant care. The HCPs further described the educational services they provide to patients, as part of the PMTCT programme. For instance, one of them reported that they provide general advises on the importance of early antenatal care attendance to all the women who visit the clinic.

> *"… through the health education, we tell them that when you miss your period [menstruation] please report to the clinic. Even if you can miss one [menstrual] period and you come for check-up and we find that you are four weeks pregnant, we are told that we must book patients immediately…Immediately when she comes saying I have missed my period [menstruation], we check the urine and if we find that she is pregnant, we book [antenatal care]" (**female, 47 years, health facility manager**).*

According to the lived experiences of the HCPs, early antenatal care is generally encouraged among women through health education and antenatal care booking which takes place immediately after the pregnancy test results are found to be positive. This suggests that pregnancy education is only given at the facility level, once the women have already decided to seek medical help. Women who come to the clinic for other services, other than PMTCT, also receive information about early antenatal care attendance, whilst women who do not seek medical help often only receive this information when their pregnancy is at an advanced stage and most likely when HIV infection has already occurred.

In addition to the pregnancy education, the HCPs also provide infant care education, which discourages the women from using traditional medicines on their infants' umbilical cords. However, according to the HCPs' lived experiences of PMTCT service provision, the women in this rural context have tendencies of not adhering to messages about child caring. They apply mice excretions on infants' umbilicus. The excerpt below attests to this.

> *"during antenatal care, we educate them that they should not apply anything to the baby's umbilicus/navel, [however], we educate them today [but] tomorrow when she comes for postnatal care, she comes having applied mouse faeces on the [baby's] umbilicus" (**female, 51 years, professional nurse**).*

The HCPs' lived experiences of providing PMTCT services showed that even though women are taught to avoid traditional practices that could be detrimental to the child's health, some seem to have difficulties of following HCPs advice. This seems to reflect conflicting perspectives that women have when it comes to adhering to child-caring practices suggested by HCPs. For instance, in this case, mothers are expected to adhere to the healthcare practices that have the potential to keep the infant healthy. On the other hand, there are family expectations which are mostly influenced by cultural norms on how to care for the infant. Although this finding seems to suggest that women do not trust some of the professional medical advices related to infant care, this behaviour could be due to lack of power to make decisions about infant care. As discussed in Chapter Six, it could be that grandmothers who already attested to taking care of children are the ones who have applied mice excretions on the infants' umbilicus. In concurrence with the current study, Busza et al. (2012) found that prevailing norms and traditions often influence the manner in which people engage with healthcare services. This suggests that societal norms and traditions have a great influence on how people react or respond to healthcare service requirements. Studies have also shown that traditional beliefs often affect the manner in which people comply with PMTCT services (Doherty et al., 2006). The data presented in this Chapter demonstrates that HCPs are providing education to women who utilise healthcare services to discourage traditional health-seeking behaviour, in order to facilitate the success of the PMTCT programme. However, because of lack of decision making powers by young mothers pertaining to child-caring, such effort is not realised.

7.2.1.3 Treatment supporter vs. treatment adherence education

The third sub-theme under the PMTCT overview in healthcare facilities relates to the provision of education on treatment supporters and the importance of treatment adherence. As part of education provision at the health facility level, the HCPs also appear to encourage women who are HIV positive to have treatment supporters, to assist with HIV disclosure, treatment adherence and avoidance of engaging in risky behaviour. The excerpt below explains the process that takes place prior to treatment initiation.

> *"Before we start them with the treatment, we encourage them to come with somebody who will help them, which is what will help us with HIV status disclosure. And we emphasize that if they do not have somebody who can help them with the treatment, we show [them] the importance of having such a person and what he/she will be doing, not that we are saying that person must come to know that that they are sick, but to just help her. They will help her and then support her, and then they will be able to remind her that it is time for medication..." And then also that they will be able to remind her that yes you are not supposed to do this [risky sexual behaviour] because you are sick. Even when you are out of line, they are able to put you in line…"* (***Female, 43 years, professional nurse***).

In order to ensure full commitment to the PMTCT processes, the HCPs expressed the essential role that might be played by treatment supporters, in terms of HIV disclosure and treatment adherence of HIV positive women. The HCPs did not provide details on desired characteristics of treatment supporters. Another study conducted in South Africa found that treatment supporters were usually mothers, sisters, brothers or partners of the HIV positive women and treatment supporters appeared to greatly influence patients' decisions relating to health care matters (Nachega et al., 2006). The HCPs further mentioned self-reliance as another important dimension of education provision related to treatment adherence. For example, mothers who are already on ART, are taught self-reliance at the hospital to ensure the benefit of both baby and mother. HCPs reported that the women are taught to remember treatment times for themselves and their infants while at the hospital.

> *"…when you come being on ART…and you know you have to take the medication at 3pm or what[ever] time…we leave the medication with you and then when it*

*hits 3 pm, she [patient] will call me and I will respond. Same applies for their babies, isn't they take syrup daily or as long as they are at the hospital. You know it becomes so busy so much that [you will find that] there are three (3) women in labour on the bench who have just been dropped by the ambulance. Then we educate them that, you know what, let's say she can see me that I am going to be busy, you must not miss this step. You will see her coming with this bottle [saying], sister its time [for baby syrup]…" (**female, 56 years, maternity manager**).*

According to the HCPs, it is beneficial to be self-reliant in taking medication, as self-reliance encourages women to take charge of their own health, unlike using force to facilitate treatment adherence. Being in charge of one's health means learning about what needs to be done, and doing it independently and correctly. According to the HCPs, self-reliance might even facilitate early HIV disclosure and general acceptance of the positive HIV status. Some studies alternatively found that adherence was due to the visible positive effects of HIV treatment (Miller, Ketlhapile, Rybasack-Smith & Rosen, 2010), while others have found that Nevirapine self-administration at one's own home was associated with adherence to treatment (Kuonza et al., 2010). Watermeyer and Penn (2012) however noted that treatment adherence depends on a number of factors, such as the patient-health professional relationship, contextual/ environmental and communication factors. It was found that the therapeutic relationship and communication factors (p. 603) are essential for ARV treatment adherence. In another study conducted by Watermeyer (2011), emphasis of the pharmacists on the concept of "living longer" was seen as an ARV adherence motivator for HIV positive patients. In this study, Watermeyer (2011) also emphasised the need for specialised communication skills among HCPs, in order to assist with treatment adherence. The HCPs in the current study revealed a need for a holistic treatment support system, as well as a self-reliant attitude towards ARV treatment adherence among patients.

7.2.1.4 Infant feeding and well-baby education

The fourth sub-theme under the PMTCT overview in healthcare facilities relates to the provision of education on infant feeding and well-baby information. As part of the education provision on infant feeding, the HCPs clearly indicated that they allow HIV positive mothers to decide on the infant feeding method, and thereafter advise them on exclusive infant feeding for

both breast and formula feeding. The excerpt below demonstrates how HCPs provide advice on the infant feeding option chosen by mothers.

> *"After she has chosen [infant feeding method] for herself, we then tell her that you must know that if you do formula feed, you will have to do for six months without giving other [solid] foods. When you breastfeed, you will do so for six months without any other [solid] food. And then on breastfeeding, we also indicate that [if mothers] have any problems with [baby] oral thrush or any problems with the breasts, they must immediately come to the clinic for check-up" (**female, 49 years, facility manager**).*

According to the HCPs mothers have the freedom to choose the infant feeding method which they prefer. Thereafter, they are adequately advised about exclusive infant feeding for either chosen method. The HCPs further emphasised that even though adequate education is given on infant feeding, the HIV positive women seem to display the tendency to use mixed feeding methods. Studies have shown that infant feeding in South Africa is still a dilemma. For instance, Goga, Doherty, Jackson, Sanders, Colvin and Kuhn (2012) suggested that South Africa is dominated by poor infant feeding habits. This implies that, somehow, messages related to infant feeding are not well trusted, possibly as a result of stigmatisation and stereotypes (Thairu et al., 2005) by the community. This point is further explored under infant feeding barriers in this Chapter. On the contrary, other South African studies have found that some HIV positive women are not easily coerced into mixed feeding practices (Doherty et al. (2006). Other studies conducted elsewhere also suggested family pressure (Cames et al., 2010; Doherty et al., 2006; Thairu et al., 2005), use of traditional medicines (Sibeko et al., 2009) and grandmothers' advice (Falnes et al., 2011) as aspects that contribute to mixed feeding practices. Some studies have found that HIV positive women preferred exclusive formula feeding (Ladzani et al., 2011; Leroy et al., 2007; Ukpe et al., 2009; Doherty et al., 2007). The data presented in this Chapter suggests that HCPs emphasise exclusive infant feeding, either formula feeding or breastfeeding. This illustrates that the national infant feeding strategy which states "exclusive breastfeeding for all" by WHO (2010) was not fully operational at the healthcare facilities at the time of this study.

The HCPs also reported to provide well-baby education to both antenatal and postnatal women, and that they also encourage women to come for the follow-up visits to receive further baby care services. According to the HCPs, mothers do adhere to follow-up return dates.

> *"…They [mothers also] come for the [mother-infant] three days check-up and [infant] seven days check-up…and then we explain that she must come for PCR at six weeks and they do come"* ***(female, 51 years, professional nurse) .***

The HCPs lived experiences showed that the provision of education on baby wellness is beginning to be understood by HIV positive women and that this is demonstrated by their adherence to follow-up services. If women are returning for follow-up care independently, it is implied that they are self-reliant, in terms of health care interventions. Studies have shown that adherence to follow-up services may also be due to the desire to protect the child from HIV transmission (Chetty et al.,2012), satisfaction with healthcare services (Watermeyer, 2012) and peer counselling services. It may also be a result of the fact that mothers are starting to understand PMTCT messages. A detailed discussion on peer counsellors' interventions is further discussed in another section of this chapter.

7.2.1.5 Down referral and postnatal follow-up care services

The fifth and final sub-theme under the PMTCT overview in healthcare facilities relates to down referral as part of the HCPs' postnatal follow-up system. The HCPs (especially at the hospitals) expressed that in order to increase access to care for patients, they need to take responsibility for ensuring the down-referral of patients who are on ART, so that they may continue receiving treatment at their local primary healthcare facilities. There are structured records at the hospital, which show referrals of mother-infant pairs.

> "*…we do write this side as well, it means our maternity ward keeps record. It guides us to know that after 3 days [of giving birth] that she is supposed to go to the clinic for mother and child check-up. And then we would have stated her status [in the road to health booklet (RTHBs)] and mentioned that we have given her Nevirapine here at the hospital, then they [clinic] will continue with care"* ***(female, 56 years, maternity manager****).*

According to the HCPs, there is a well- coordinated provision of services between hospitals and clinics for the mother-infant pair. This is demonstrated by the availability of patient medical history records which are completed accurately on the Road to Health Booklets (RTHBs). As such, the hospitals and clinics are able to provide well-coordinated services to PMTCT clients. This practice is in line with the PMTCT treatment guidelines, which emphasise the importance of the correct completion of RTHBs to ensure the provision of relevant services to mother-infant pair (Department of health South Africa, 2013). According to the HCPs, this precise coordination is a facilitator of an effective PMTCT programme. The dedication of the staff to service provision plays a huge role in this regard.

7.2.2 Theme 2: PMTCT barriers affecting the healthcare system

Theme Two reflects PMTCT barriers which are directly affecting the healthcare system. Figure 7.3 reflects five sub-themes, which are outlined as follows: antenatal and postnatal care, infant feeding, male non- involvement and health system and structural barriers.

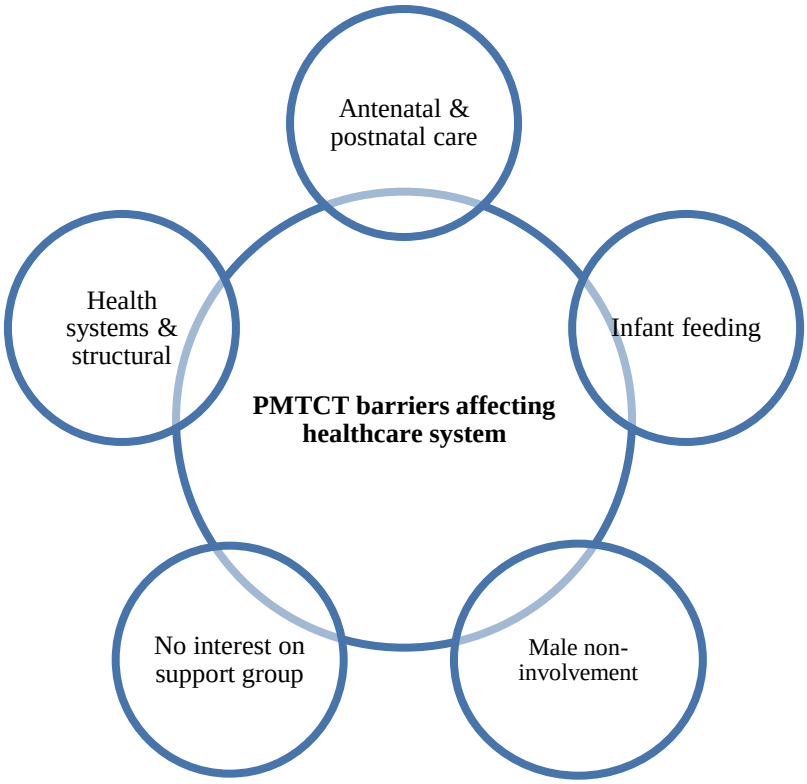


Figure 7.3 PMTCT barriers affecting the healthcare system

7.2.2.1 Antenatal and postnatal care barriers

The first sub-theme under PMTCT barriers affecting the healthcare system relates to antenatal and postnatal care. The HCPs mentioned five antenatal and postnatal care barriers: 1) PMTCT programme resistance and lack of infant follow-up 2) patient movement 3) lack of infant HIV PCR testing/ positive infant HIV PCR testing results 4) late antenatal bookings 5) HIV denial and HCP dislikes.

- **PMTCT programme resistance and lack of infant follow-up**

Healthcare providers' lived experiences of providing PMTCT services showed that there is a high resistance to the PMTCT programme from the mothers who are HIV positive. This is reflected by their non-responsive behaviour towards some of the PMTCT processes, such as early antenatal care. The excerpt below shows some of the reasons given by the women for starting antenatal care late, as reported by the HCPs.

> *"So sometimes they tell us that they start late because they do not want to be going [for antenatal care] for a very long time or I am working or I go to the private doctor" (**female, 49 years, facility manager**).*

According to the HCPs, the reasons for the late antenatal care by women include the desire to avoid long antenatal care sessions and the fact that some women are working. Other studies have found additional reasons, such as long waiting hours, a lack of information and partner dynamics as the contributing factors to PMTCT non-utilisation (Homsy et al., 2007; Thorsen et al., 2008). Another reason for late antenatal care attendance expressed by HCPs was previous experiences of child-birth.

> *"…and then but those who have that problem are the ones … let's say is those who already have other children. Those are the ones who book at 6months, 32 weeks, those are the ones…" (**female, 43 years, professional nurse**).*

According to the HCPs, experienced women already know about the various activities and elements within the healthcare setting, many of which they probably dislike (such as the HCPs' attitudes, counselling and testing processes etc.). Duff, Kipp, Wild, Rubaale and Okechojony

(2010) suggested that the lack of trust and confidence felt by patients towards HCPs caused patients to not fully utilise services. The HCPs also reported that grandmothers bear the burden of looking after sick grandchildren whose mothers are HIV positive, but have not disclosed their HIV status to them.

> "*They do not disclose their [HIV] status to the grandmothers. When the grandmothers arrive at the clinic with the child, when we check the condition of the child, we can see that there is a problem …"You find that I ask the grandmothers to tell the mother to come to the clinic… the mother does not want to come to the clinic…" (**female, 49 years, facility manager**)".*

According to the HCPs, HIV positive women are reluctant to participate in any infant post-natal care activities. As a result, the grandmothers play a critical role in looking after the children, because of the cultural responsibility they have, in terms of caring for the family (Penn et al., 2010). In this study context, grandmothers have been found to play a very significant role, especially in looking after sick children (Barratt & Penn, 2009). However, the HCPs in the current study seemed to suggest that caring for these children puts grandmothers at risk of contracting HIV, because of the lack of HIV disclosure by the mothers. The HCPs also expressed that the HIV positive women reject the infant follow-up services provided by the home-based carers (HBCs). One HCP said*…You will find that we refer these women to the home-based [carers] there is still a challenge of denial. They still do not want these people [home-based carers] to come into their homes and assist them).*

Data provided in this Chapter suggest that the PMTCT programme is resisted by many women who are HIV positive, because of the various processes that have to be adhered to, including the acceptance of HBCs into their homes. Unlike the HCPs lived experiences which showed a dislike of HBCs by HIV positive women in this rural context, Kim et al. (2012) found that the involvement of community workers as case managers for the follow-up of the mother-infant pair, led to a continuum of longitudinal care for the HIV positive women. This study further showed improved retention of the mother infant-pair.

- **Movement of pregnant women**

Another antenatal care barrier raised by HCPs relates to the movement of antenatal patients. The HCPs suggested that this is a challenge, particularly when it comes to the follow-up of

these women. Although the women attend antenatal care services in the areas where they live, when it is time to give birth, they often visit their grandmothers' homes to give birth in their grandmothers' presence. According to the HCPs, this movement makes it very difficult to follow-up the mother-infant pair in this study setting.

> *"… and the challenge that we have even now, is the movement of the pregnant women. She will leave from Gauteng Province coming here [Mpumalanga Province] with the ANC [antenatal care] card saying I will be giving birth here because my grandmother is here…. This is where we miss the PCR…No we don't have a follow-up system because for starters we do not know where they went. She just comes as a visitor [who] came to [visit] the grandmother…" (**female, 47 years, health facility manager**).*

This data seems to explain another challenge of following up the mother-infant pair within the PMTCT programme. According to the HCPs, the pregnant women's relocation close to the time of child-birth occurs because the women need support during this time. Thus they opt to go to their grandmothers, because of the traditional role that grandmothers play in looking after grandchildren (Penn et al., 2010; Barratt & Penn, 2009). This relocation during the antenatal period ends up affecting the PMTCT programme, as it creates a high rate of loss of follow-up of the HIV positive women.

- **HIV non -disclosure and hiding treatment labels**

HIV non-disclosure has been regarded as the root cause of non-adherence to the PMTCT services. One HCP narrated an incident about HIV medication which clearly demonstrated the serious repercussions of HIV non-disclosure.

> ***"…**when you arrive at the bus stop, you would often find empty containers of tablets [which belong to] people coming from the wellness [clinic] at this hospital. One day [I decided] to ask another sister [that I work with] as to why do people throw [away the medication] and she said they are exchanging their medication containers; they do not want people to know that they are taking these tablets. They put those [tablets] inside the amosbin bottle [bottle for another pain killer medication] and when she arrives at home she will be able to take her treatment free" (**female, 56 years, maternity manager**).*

According to the HCPs, HIV disclosure continues to be a challenge faced by HIV positive women. These women reportedly use various tactics to avoid disclosing their HIV positive status to their family. It is clear from the onset that women would prefer to continue presenting an unknown HIV status to their family members. Although the women take their HIV treatment, they do so in a way that is discrete and secretive (hiding treatment). Even though other studies have indicated that HIV disclosure facilitates treatment adherence (Wouters et al., 2009), the findings in the current study suggested that treatment adherence is possible even if treatment is taken in a discreet secretive way shown by a way of changing treatment labels.

7.2.2.2 Infant feeding barriers

The second sub-theme of PMTCT barriers affecting the healthcare system relates to infant feeding. The HCPs raised a number of infant feeding challenges, which were mainly related to the following factors on Figure 7.3: mixed-feeding, milk shortages and the association of formula milk with HIV.

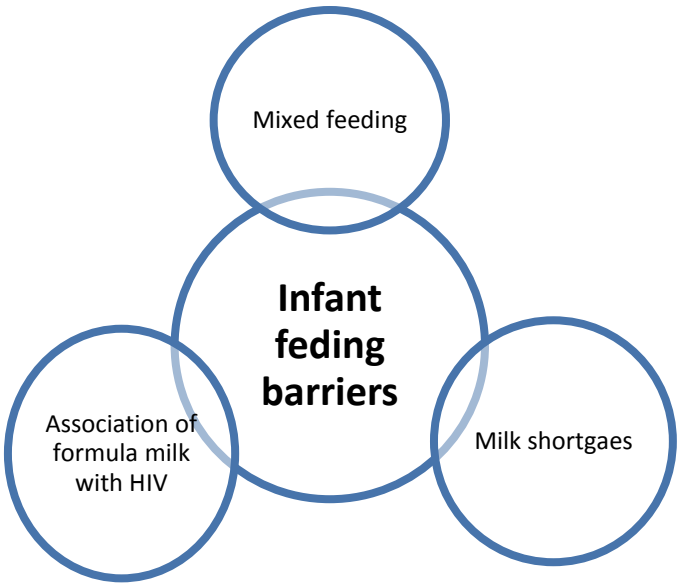


Figure 7.4 Infant feeding challenges

- **Mixed feeding**

With regard to mixed-feeding, the challenges reportedly occur in relation to family dynamics. For example, daughter in-laws are expected to mixed feed. According to the HCPs, on many occasions, married HIV positive women succumb to their in-laws' expectations out of the fear of having to disclose their HIV status. Family plays a huge role in determining HIV positive women's mixed feeding practices. As indicated by one of the HCPs, the family expectations about the infant feeding traditions seem to compel HIV positive women to mixed-feed. One of the HCPs gave a scenario of how mixed feeding occurs and how the family especially the grandmothers confuse HIV positive women who end up doing it:

> *"Mixed feeding, I do not know who will be able to deal with it, like you are interviewing me now, I can say I am exclusively breastfeeding. But when I arrive home, maybe I am a newlywed, I am the daughter in law, my mother in law is there. I will be afraid to say it [that I am HIV positive]. They will say e e e [exclaiming], here we breastfeed the child. [Then] she ends up being under pressure, she will give the child breast milk and then on the other side formula, she mixes, at the end, the child will test positive. But the grannies…they will tell you, you are grownups like this, you are now coming with these recent things of saying do this, don't do this, no. So the poor daughter in law ends up being confused" (**female, 47 years, health facility manager**).*

HCPs reported that no matter how much the woman is aware of the dangers of mixed-feeding, traditional infant feeding habits prevail. One HCP said "*All of a sudden they are happy for the newly born [and then] I do not breastfeed, when they ask what I will say?"* Similarly, Doherty et al. (2006) found that family has a great influence on the infant feeding method choice. The data presented in this Chapter suggests that the family generally disregards the possibility of HIV infection or lack the knowledge that mixed feeding is a risky practice if a child is born by an HIV positive mother. The data also suggests that women mixed feed because of the belief that *"the child does not get full. Most of them say that the child does not get full. Their problem is that [they will say] I just see that the child does not get full or at home they said I must give the child this and that*." Similarly, Bezner-Kerr et al. (2008) found that grandmothers facilitated the introduction of solid food, especially if the mother was perceived to produce little milk. Aubel (2012) also found that family members, such as grandmothers, often provide advice on the

introduction of complementary feeds. The data in this Chapter further suggest that women who mixed fed, had not disclosed their HIV status to their family. Bii et al. (2008) found that HIV disclosure facilitates adherence to the recommended infant feeding procedure. Studies have shown that mixed feeding poses a high risk to infant health (Doherty et al., 2006; Varga & Brookes, 2008b). Sibeko et al. (2005) found that 56% of infants in their study were given a first dose of '*muti*' [traditional medication] before they were 1 month old.

- **Formula milk association with HIV**

The HCPs further indicated that there is a belief that formula feeding is associated with being HI**V** positive. Due to the fear of being labelled by fellow community members and family, HIV positive women thus attempt extreme methods to hide the milk. To try and aid this situation, the HCPs expressed that they encouraged HIV positive women to come with bags that could hide the milk, or even pour it in plastic bag or another tin of milk, or send grandmothers to collect the milk, in order to avoid negative labelling and indictment. Three HCPs indicated how they used to avoid the association of formula milk with HIV. One said "*So she would pour it in there [plastic bag], it's really a shame, she would pour it [milk] in the plastic or in a tin for NAN [empty tin milk], because of being afraid of taking it home…"* The other one also said:

> *"…So others hide so that people should not see that they have come to get the milk. Because the minute you come to get the milk, it means you are positive, something is not right. Others end up sending the grandmother to come and collect the milk. They used to take it at that corner, maybe the other one would even call you to come outside so that she does not stand in the queue to go in there. We even told them to come with the bags to put the milk. So now the milk is in the counselling room" (**female, 51 years, professional nurse**).*

Another HCP also shared some stimatising behaviour from the family saying "*…You know they will also tell you that I feel like pouring that milk in the plastic because when I arrive home they will say, this is like so and so's child, it means she is sick"* According to the HCPs, the fear of HIV stigma disturbs mothers' infant feeding choice. Doherty et al. (2006) also found that infant feeding choice of formula feeding was disregarded by many. Participants in Doherty's study indicated that whenever they were seen carrying FFM, people laughed at them. As explained in Chapter Five of this study, the association of FFM with HIV, led women to formula feed at home and breastfeed in public (Omari, 2003).

- **Milk shortages**

Lastly, the HCPs expressed that milk shortages were due to the provincial discontinuation of FFM supply to HIV positive women. According to the HCPs, the healthcare facilities in Mpumalanga used to distribute FFM to HIV positive women who opted to formula milk feed, prior to the current study data collection since September 2011. The HCPs lived experiences suggested that milk shortages forced women to mixed feed (Doherty et al., 2003a). Due to the discontinuation of FFM, the HCPs in the current study reported that they had started encouraging exclusive breastfeeding to all of the women. One of the HCPs narrates the reason for encouraging women to choose exclusive breastfeeding:

> "… *But now of late, because the Province is saying they are no longer going to provide us with baby formula, we encourage these mothers to opt for exclusive breastfeeding. We are looking at this thing that if the Province is not going to provide us with any extra formula, it means she [the mother] has to pop out money from her own pocket. You will find that some of them are disadvantaged…" (**female, 56 years, maternity manager**).*

This change was made because the South African Department of Health adopted exclusive breastfeeding as the national infant feeding strategy and as a result, FFM was withdrawn from the PMTCT programme (National Department of Health South Africa, 2011a; 2011b). The exclusivity of infant feeding for all, suggest that regardless of ones' HIV status, all mothers should exclusively breastfeed for six months (National Department of Health South Africa, 2011a; 2011b). Exclusive breastfeeding is a new policy issue, hence, the HCPs in the current study appeared to not have knowledge of it. They just indicated that the Province is no longer continuing with FFM distribution. In a study conducted by Ijumba et al. (2013), varying community perceptions of FFM discontinuation were noted, due to the lack of policy change communication to ordinary community members. Dorfman, Wallack and Woodruff (2005) suggested that messages of social change should reinforce values. Individuals need to explain what is wrong, why it is wrong and what needs to be done with the current system.

7.2.2.3 Male non-involvement barrier

The third sub-theme under PMTCT barriers affecting the healthcare system relates to male non-involvement in the PMTCT programme. The HCPs indicated that men are generally not interested in participating in PMTCT services. For instance, they do not participate in the initiatives that HCPs take to involve them, even when they are invited through contact slips. According to HCPs, men continue to infect their female partners with sexually transmitted infections (STIs) and they do not participate in mother-friendly initiatives, which allow the male partners to be present during the child-birth session. HCPs further expressed that male partners believe in the use of illegal medicines that are believed to clean blood. The HCPs also highlighted some of the behaviour demonstrated by men who refuse to be treatment supporters for their female partners, whilst they are secretly on the ART treatment themselves. Lastly, the HCPs also suggested that the men have a negative attitude towards the health education provided at the clinic.

- **Non-participation in PMTCT services**

Inviting men through contact slips, given by their female partners, did not seem to work in the current setting, as mentioned by the HCPs. The non-participation of male partners in the PMTCT programme continues to put women at risk of contracting HIV (if they are not already infected). According to the HCPs, this is illustrated by a woman who had recurring STIs because her partner refused to come to the clinic to receive treatment. The HCPs also mentioned another initiative referred to as the 'mother-friendly' initiative, where male partners are encouraged to be present during childbirth. However, the men do not seem to present themselves at the time of child-birth. An example of the situation described above is shown on below excerpt:

> *"I will give you an example, practical example of most females who are consulting for sexually transmitted infections (STIs). We give them contact slip (male involvement initiative) for the partner to come [to the clinic] or to go anywhere…..Those whom their partners did not come [to the clinic] will come again [with the same condition]…" There is a mother friendly service where they encourage the [male] partners to come and be with the women during labour. They do not come. Males don't come. Yes they don't come. Companionship, the [guidelines] say we must allow them to be there when the women are in labour, so*

*that he can see the whole process that the women go through during labour, but I do not remember seeing even a single male coming to witness [the baby] delivery by a girlfriend or wife" (**female, 47 years, health facility manager**).*

HCPs seem to believe that culture plays an important role in determining men's health seeking behaviour "*…maybe the **culture** is still dominating a whole lot in such a way that they still believe that when the woman is in labour, giving birth, it's a taboo for a man to see her…"* According to the HCPs, the mother-friendly initiative does not take the role of a man into consideration. HCPs also expressed that some men believe in seeking back door help when they are not well.

"*They still believe in going for back door [things] to [get] those big bottles that are been sold, and they say it cleanses the blood" (**female, 47 years, health facility manager**).*

Studies have shown that involvement of the males leads to acceptability of PMTCT programmes, which in turn lessens the risk of MTCT of HIV (Aluisio et al., 2011; Peltzer, Mlambo & Phaweni, 2010). A review conducted by Morfaw et al. (2013) found that sending letters of invitation to men, community sensitisation activities and ARV availability in the healthcare facility (Mohlala et al., 2011) encouraged male participation in the PMTCT programme. Unlike other studies which noted improved PMTCT uptake after issuing invitation letters to male partners (Bolu, Allread, Creek, Stringer, Forna, Bulterys, & Shaffer, 2007), the HCPs in this study indicated that invitations did not work in the area of study. Similar findings to the current study were reported in a study conducted by Mohlala et al. (2011), where only 30% of pregnant women came for HIV testing with their partners.

A study conducted in Uganda also did not note any significant differences in HIV testing behaviours of male partners who were given an invitation letter as part of the intervention, as opposed to male partners who were given basic pregnancy literature (as the control group) (Byamugisha et al., 2011). Nkuoh et al. (2010) also found that attempts to involve men in the PMTCT programme did not materialise even after trying interventions such as encouraging males to accompany their spouses for antenatal care, attendance of educational PMTCT sessions, one-on-one counselling sessions, provision of tokens as incentives, free HIV testing and provision of invitation letters. In a study conducted by Mburu et al. (2012), the peer sensitisation was used as a method to encourage other men to participate in PMTCT cascade

services. This was noted to improve men's uptake of services that would reduce vertical transmission of HIV.

- **Partner HIV non-disclosure**

The HCPs also highlighted that men are also secretive about their HIV positive status. For instance, they hide their HIV positive status from their female partner. An example of this is provided by one of the HCPs:

> *"…On Friday I had one patient who is in a conflict with the partner because she wants to start the treatment but he does not want to accompany her to the clinic [as a treatment supporter]. What is sad is that the man himself is on treatment…. When we look, the partner was brought by one of his family members to the clinic. Can you see that the partner [male] has not disclosed?..."* ***(female, 43 years, professional nurse).***

This implies that men's behaviour continues to put women at risk. The data appeared to portray men as selfish towards their partners. For instance, the HCPs expressed that men refuse to be their female partner's treatment supporter, while the man himself is secretly on HIV treatment. This behaviour seems to be caused by HIV non- disclosure, which illustrates the challenges that sexual partners encounter, particularly related to HIV non-disclosure. This challenge suggests that whilst two people are together as partners, one who is aware of his or her positive status might be receiving support from his or her family, while the other is kept in the dark about the other's HIV status. There seem to be no interventions aimed at addressing this kind of behaviour. HIV testing by men is associated with communication between partners and condom use (Desgree's Du-Lou et al., 2009). The experience of the HCPs showed that even though male partners tested positive for HIV, they do not disclose their HIV status and sometimes even initiate treatment without disclosing their status to their female partner. This suggests that the male partner continues practising unsafe sex, regardless of his HIV status.

- **Men's dislike of HIV education**

The HCPs further suggested that men are generally not interested in health education. For instance, the HCPs had experienced situations, where men excused themselves from the health education session at the clinic.

> *"Even us we try to teach and men have [negative] attitude so much that when you teach, when you start talking about men, he will move from here [reception area for patients] and go and sit on the other side, you will remain teaching women as if it's [only] a women thing" (**female, 43 years, professional nurse**).*

Another HCPs indicated the ignorance on media health education "*And then you know I get surprised, even on TV, this thing is there. They advertise [about an] HIV free generation... Showing a poor man who is supportive to the pregnant woman and the children …"* This finding is similar to those of other studies, which indicated that men seem to believe that health issues are only applicable to women and as such, cannot be taught anything about health (Mbonye et al., 2010). It is, however, ironic that men are often the ones who infect women. The lack of men's interest is shown in the above excerpt. The results in this Chapter suggest that once a man has tested, he hides his status from his female partner, and may even initiate treatment secretly.

7.2.2.4 Support group attendance barrier

The fourth sub-theme for PMTCT barriers affecting the healthcare system relates to poor support group (SG) attendance by HIV positive women. The excerpt below shows the SG challenges raised by one of the HCPs.

> "[*the women say] when they arrive at home, they spread [HIV statuses of group members]. They say so and so is also like this…they are fighting among themselves this support group [members]. We tried to say people please come and they said they do not want because the community people will talk" (**female, 47 years, health facility manager).***

The above excerpt suggests that that lack of interest in support groups is due to stigma that exists against people living with HIV. The concept of 'group' seems to cause this stigma. The lived experiences of HCPs suggest that HIV positive women seem to feel more at ease with

peer counsellors. Peer counsellors have been shown to be acceptable in various settings (Baek, Mathambo, Mkhize, Friedman, Apicella, & Rutenberg, 2007). Kim et al. (2012) found high utilisation levels of antenatal and postnatal services through the involvement of peer counsellors.

7.2.2.5 Healthcare systems and structural barriers

The fifth sub-theme under PMTCT barriers affecting the healthcare system relates to health systems and structural barriers. The HCPs highlighted five key areas that affect the optimal functioning of the PMTCT programme, namely: staff shortages, infrastructure, stock supplies, incorrect statistics and healthcare facility fixed days.

The HCPs lived experiences suggested that they are burdened by staff shortages especially because those who are trained particularly on PMTCT find themselves having to assist others who are not trained. One HCP said: "*So with regard to staff, we have a physical challenge. Right now we are three nurses, so staffing shortage is a challenge…. Now it's myself and senior sisters who are on the PMTCT [programme] and these two professional nurses have not attended the PMTCT [courses]. So every time I need to help them and most of the time I'm attending workshops*. In addition to this, due to poor infrastructure at the healthcare facility, the store room is not big enough to accommodate all of the stock. Healthcare providers also expressed that they experience stock shortages "*We do not have a store room. We just put things at random, like the boxes of nutritional supplements they are just put like that. Also when we get Pelargon [milk] we do not have a specific place to put them where we would say it's under lock and key. We have a counselling room."* Another HCP indicated that "*Stock supplies are on and off. Just now we received the stock yesterday but Nevirapine syrup is not there."* The HCPs further indicated that their existing system of health facility fixed days for service provision is hampering PMTCT services. All the HCPs said other challenges include "*poor communication between private doctor and healthcare facilities, delays in treatment due to high CD4 count, staff capacity building and lack of central patient recording."*

The staff shortages, limited stock supplies and infrastructure challenges seem to work against what the PMTCT programme aims to achieve. Numerous studies conducted in South Africa have noted similar problems (Sprague, Chersich & Black, 2011) and more (late payment of lay counsellors, absenteeism and late CD4 results). The HCPs also mentioned late treatment

initiation, due to high CD4 counts and a lack of a patient centralised system as another PMTCT barrier. The lack of centralised system leads to the situation described below:

> *"Maybe the statistics can go down, for now it's extremely high. Us the working class are aware of that a person test [for HIV] here today, [and found that] he/she is positive, [then] he/she says I am no longer going to [name of clinic]. He/she [then] goes to [the name of clinic] and tests positive…"* ***(female, 47 years, health facility manager).***

The data presented in this Chapter further suggested the HCPs discontentment with the current system which imposes fixed days for providing services for different ailments. One HCP said:

> *"… We are not supposed to make patients go back. Like this thing of ours of having fixed clinic [days] of saying Monday is a day for something, Tuesday is a day for another thing. Sometimes it kills us because you find that you have tested the patient today and you tell him/her to come back next week, maybe he/she does not have money for coming back"* ***(female, 43 years, professional nurse).***

Unlike other studies which indicated that HCPs saw the provision of services to HIV positive women as a burden, because of the fear of contracting the HIV infection and high workload (Nguyen, Oosterhoff, Pham, Hardon, & Wright, 2009), the opposite was noted in this study. The HCPs expressed a strong desire to provide PMTCT services all the time, by adopting a supermarket approach. They seemed to believe that the supermarket approach, in which they could assist patients for any ailments on any given day, is preferable. The HCPs mentioned another crucial aspect for the PMTCT, which is the correct recording of data for PMTCT services "*At the end of the month we report the same person [twice]"*. Due to patient movement and relocation, the HCPs reported that patients end up being counted twice for receiving services (such as HIV testing) if they go to different facilities for the verification of their HIV status. Therefore, this is a health system issue that needs to be dealt with in order for the effectiveness of PMTCT programme to be realised.

7.2.3 Theme 3: PMTCT barriers beyond the healthcare system

The HCPs were concerned about community dynamics, which seemed to form an obstacle to the optimum function of the PMTCT programme in their area. Figure 7.5 shows four sub-themes which convey PMTCT barriers beyond the healthcare system. These are 1) teenage pregnancy; 2) unemployment; 3) lack of schooling; 4) disease burden and cultural norms.

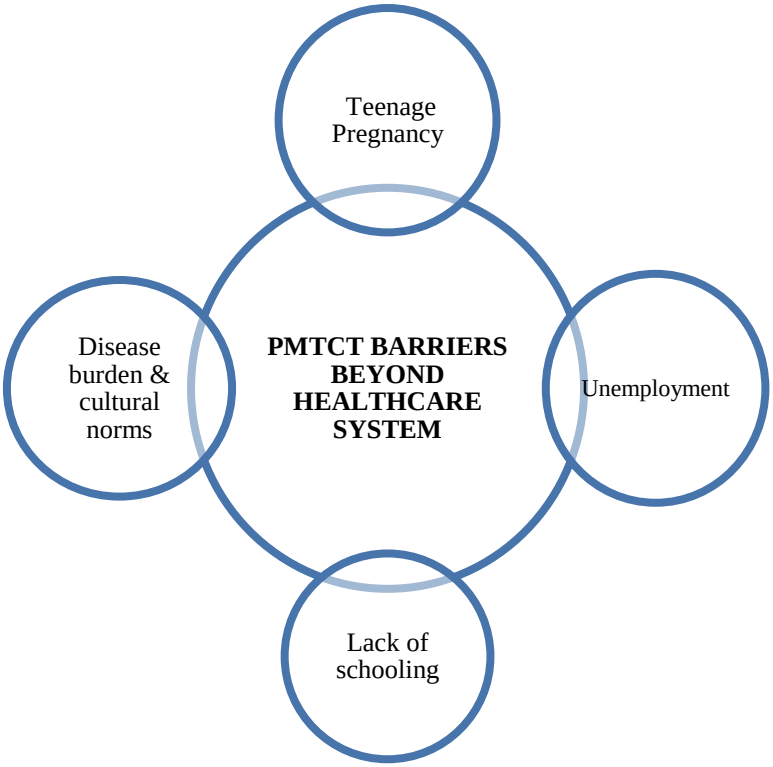


Figure 7.5 PMTCT barriers beyond healthcare system

7.2.3.1 Teenage pregnancy, lack of schooling and unemployment

"…to keep the boyfriend…I have a child with him hoping that he will marry me or support me."

Three sub-themes relating to PMTCT barriers beyond the healthcare system included teenage pregnancy, lack of schooling and unemployment. The HCPs raised concerns about teenage pregnancy as a worrying factor in the rural communities of the Dr JS Moroka sub-district. The data in this Chapter reflects the efforts made by the HCPs to understand the reasons for teenage pregnancy. They interviewed younger and older groups of women who had come to the

healthcare facility and found that socio-economic factors, such as unemployment and lack of schooling, were the main reasons for teenage pregnancy. The excerpt below highlights key factors that the younger group of women mentioned during an interview with HCPs.

> "*The first group [that we interviewed] was for the young ones [girls]. They explained that we are young, we are unemployed, we did not go to school and we are at the age of child bearing. And then I get a boyfriend, when I get him, remember I am not working and I did not go to school…to keep the boyfriend…I have a child with him hoping that he will marry me or support me. When we come [to the clinic] to check [our statuses] we find that he has HIV. And then after that, the guy is gone. You remain with HIV and the child and you are unemployed…can you see…" (****female, 47 years, health facility manager****)?."*

In the older group of women, the HCPs found that pregnancy generally occurred when they were ready for it. Unfortunately, the women reported that they meet partners who are already HIV positive. The excerpt below illustrates the outcomes of the interview with the older group of women.

> "*And then another group said…us who are the working group and have at least been to school…we want to improve the lifestyle of our families. We try not to get pregnant and go to school, work and become independent and assist [financially] at home. And then after that is then that we can start looking for a partner and have a child. For that period that you would be holding yourself saying you want 1, 2, 3 [provide assistance at home] by the time you meet a partner, you fall into HIV [positive] hands" **(female, 47 years, health facility manager).***

Unlike the study which found that teenage pregnancy is caused by FFM (Ijumba et al., 2013), the data in the current study draws a link between the lack of education and unemployment and teenage pregnancy. This link may exist because when women are not educated and unemployed, they often resort to falling pregnant with the intention that the male partner will support them. According to the HCPs, the most likely situation would involve that the woman stay in the relationship with the hope that the male partner would marry her. Regrettably, these women often end up contracting HIV, because of engaging in risky behaviour for the sake of getting married. The women's poor socio-economic status suggests that poverty is the cause of lack of unemployment, lack of education and teenage pregnancy. The HCPs portrayal of the

behaviour of young women in the area of study suggested that women's responses to poverty are influenced by institutional environments (Francis, 2006). According to Gilbert and Walker (2002), living in a rural area also contributes to the social inequalities experienced by women. The HCPs in this study further suggested that young women are at risk of contracting HIV. Similarly, other studies have indicated that young women are more susceptible to HIV infection (Pettifor et al., 2004; UNAIDS, 2010; Rehle et al., 2007; Gilbert & Walker, 2002).

7.2.3.2 Burden of the HIV disease

The fourth sub-theme under PMTCT barriers beyond the healthcare system is the burden of the HIV disease. The HCPs discussed the burden of the HIV disease carried by grandmothers, as poverty dynamic.

> "*the grandmothers said you know sister, we have a huge stress because our children get pregnant, they leave us with their children, others die, others go to [Johannesburg] to look for jobs and we remain with grandchildren. With the little pension that I am trying to survive with, we have to look after these children. At the same time, these children are HIV positive"* ***(female, 47 years, health facility manager)***.

The above excerpt illustrates that women in the area of study continue to have children because they know that they have permanent baby-carers (grandmothers) who will probably look after their children even better than them (Penn et al., 2010). According to the HCPs, the HIV status of women is burdensome to grandmothers, who are forced to share their meager pension with their infected grandchildren. In concurrence with this, other studies have also found that grandmothers play the role of financial supporter to their grandchildren (Orb & Davey, 2005; Barratt & Penn, 2009). The HCPs further suggested another reason for grandmothers caring for grandchildren as being parents' migration to towns to seek employment. This finding relates to other studies which indicated that the grandmothers' child caring role occurs due to parents' migration to cities for employment purposes (Silverstein, Cong, & Li, 2006; Barratt & Penn, 2009).

7.2.4 Theme 4: PMTCT programme successes

In opposition to the PMTCT barriers that were mentioned earlier, Figure 7.6 shows four sub-themes which reflect the positive effects of the PMTCT programme: 1) HIV testing acceptance; 2) infant HIV PCR successes; 3) comprehension of PMTCT terminology and 4) Infant follow-up.

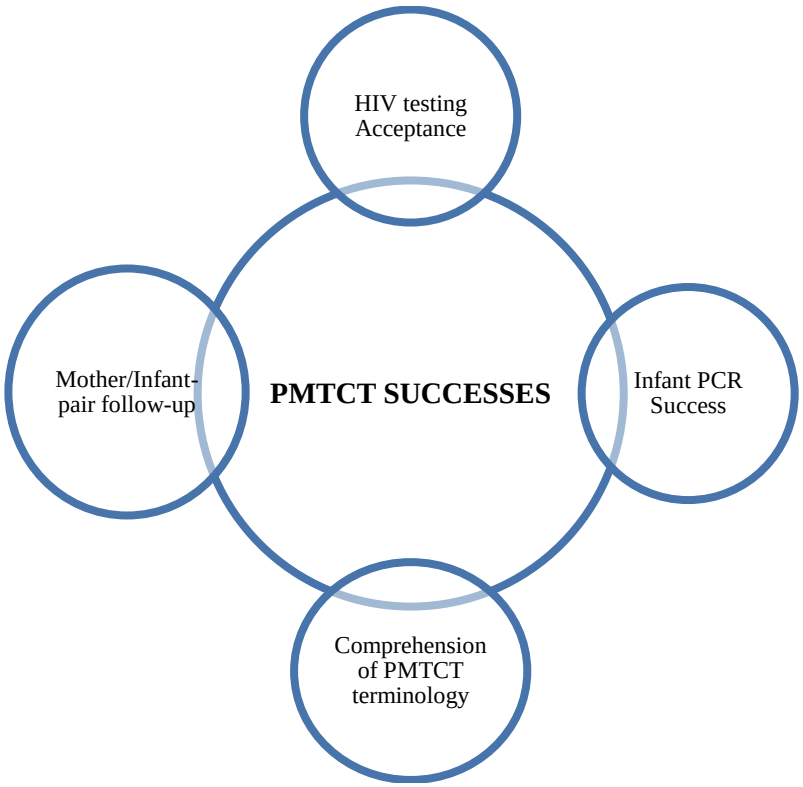


Figure 7.6 PMTCT programme successes

7.2.4.1 HIV testing Acceptance

The first sub-theme which demonstrates the success of the PMTCT programme relates to HIV testing acceptance. Although a number of challenges have been highlighted with regard to service provision of PMTCT, the HCPs admitted that there are also successes that need to be recognised. For instance, they noted that the PMTCT programme processes are now acceptable to some of the women, because of the peer HIV counselling services.

> *"Well it was difficult before because pregnant women were scared of testing because of the stigma. So, since we have this lady, its better because she tells them about her status and every pregnant woman feels that she must test because she [the peer counsellor] educates them effectively. But before she came, it was not like that and since she is also in this PMTCT programme, she is able to tell them about herself…"* ***(female, 51 years, professional nurse)*** **.**

According to the HCPs, HIV testing success in the respective study areas were due to peer counsellor health talks. The HCPs indicated that the fear of HIV testing had somewhat reduced since the peer counsellors started talking to women about their positive HIV status. Because of the positive impact of the peer counsellors, women were reported to disclose their HIV positive statuses "*They are able to talk [about their status]. They are able to disclose to us when they arrive…"* The above excerpt suggests that with good education and peer counselling, HIV acceptance is possible. The HCPs emphasised the positive impact of health education, which resulted in HIV testing by the very women. One HCP said "*So it was difficult, but because of health education, the clients are cooperating ….. When they are pregnant, they know that HIV testing is part of routine checking."*

The pregnant women's acceptance of HIV testing is key to the PMTCT programme because it is only after such acceptance that other PMTCT services may unfold (Hanh, Gammeltoft & Rasch, 2011). The HCPs further mentioned that they do not have a high number of PMTCT dropouts "*We do not have Dropouts, unless if they have moved from somewhere like I spoke about that we work with satellite clinics".* The only challenge involves patients who move from one clinic to another, in trying to verify their HIV positive status.

PMTCT programme acceptance is crucial for HIV positive women because it implies that they will continue to follow all of the required processes. In the same way, HIV testing acceptance, HIV disclosure and no dropouts suggest that the PMTCT programme is successful (Hanh, Gammeltoft & Rasch, 2011). It also suggests that these women might solicit the necessary support from family and, therefore, adhere to treatment.

7.2.4.2 Infant HIV PCR testing success

The second sub-theme which shows the success of the PMTCT programme relates to infant HIV PCR testing. The HCPs lived experiences showed that PMTCT service acceptance leads to adherent behaviour, which in the long run implies that the child will test HIV negative. The excerpt below shows that because of adherence to PMTCT services, babies are tested negative during HIV PCR testing.

> "…a*nd then the fortunate part is that the PCR for children [born by] HIV positive women, most of them tested negative. It is because of Nevirapine, it helps"* ***(female, 47 years, health facility manager)****.*

According to the HCPs, the HIV acceptance which culminated into adherence to PMTCT processes, may be the result of successful peer HIV counselling which is offered by people who are in a similar situation to the women. In Kim et al. (2012), the community health workers (CHWs) involvement in the PMTCT programme increased infant HIV PCR testing to 80.7%. They found that the overall HIV transmission rate was 4.1%. In a study conducted in KZN, South Africa, they found an infant HIV PCR testing rate of 83% and a 2.7% HIV transmission rate at 6 weeks (Chetty et al., 2012). Other studies have also acknowledged the significant role which peer counsellors play in the PMTCT programme (Rotheram-Borus et al., 2011; Besser, 2006; Futterman et al., 2010; Shetty et al., 2008).

7.2.4.3 Comprehension of PMTCT language

The third sub-theme which shows the success of the PMTCT programme was found to relate to PMTCT language comprehension. The data showed that most of the HCPs interviewed regarded terminology used in PMTCT as understandable, especially because they provide PMTCT services on a daily basis. However, the HCPs also argued that it may not be understandable for PMTCT clients *"For us the [PMTCT [terminology is fine because we deal with it [we use it often]. And then for the clients mmm [might be difficult]*."

According to the HCPs, difficulty related to understanding may arise when posters are written in the English language, which is not understood by many people living in the rural communities of the Dr JS Moroka sub-district.

> *"The posters are half user friendly because most of them are written in English language. Most of the time what they [Department of Health] send are for Zulu and Ndebele [languages]. To tell the truth, the Setswana ones are not there"* ***(female, 47 years, health facility manager).***

The above excerpt suggests some of the linguistic barriers experienced by PMTCT patients related to understanding health services. According to Penn and Watermeyer (2012), linguistic factors are critical at all levels of HIV prevention, diagnosis and treatment. Another important point mentioned by the HCPs, was that they explain some of the difficult PMTCT terminology to the PMTCT clients "*Isn't we explain what PCR does, the whole procedure that I am saying, just like pap smear, we explain that...*"" The HCPs lived experiences of the PMTCT service provision suggested that they understand the terminology used in the PMTCT programme. This shows the effectiveness of PMTCT training received by HCPs even through in-house/ internal training that is beneficial to the patients.

7.2.4.4 Mother and infant pair follow-ups

The fourth and final sub-theme which demonstrates the success of the PMTCT programme was found to be mother-infant pair follow-ups post-delivery. The HCPs shared numerous ways in which they are following up the HIV positive mother-infant pair, although they did report difficulty with this at times.

> *"...we give them the return date, we monitor their follow-up dates. Sometimes we contact them telephonically but you find that we lose contact with them, but when we see that she is due for CD4 count [check] then we follow-up. You will find that others [patients] do not know when to come to test again; we are the ones who remind them"****(female, 43 years, professional nurse****).*

The above excerpt indicates that the HCPs are doing all they can to follow-up the mother-infant pair, to ensure their continuation with the PMTCT service cascade. For instance,

patients are given return dates and they are followed up telephonically, when possible. This finding is different to that of Horwood et al. (2010) who found poor follow-up of mother and infant pair in KZN, South Africa. It is important to note that high workload may cause the absence of follow-up. According to the HCPs lived experiences, PMTCT clients do not always know about their follow-up return dates and what these dates mean. Hence, the HCPs report that it is important to emphasise the patient return dates in order for the PMTCT programme to be effective.

7.2.5 Theme 5: PMTCT Programme Ehancement

Healthcare workers indicated a need to improve the PMTCT services, and ultimately the quality of services that they provide. Figure 7.7 presents four sub-themes which serve as PMTCT programme enhancement. The sub-themes are as follows: 1) health education and community involvement; 2) language improvement; 3) health systems and structural change and 4) ongoing capacity building.

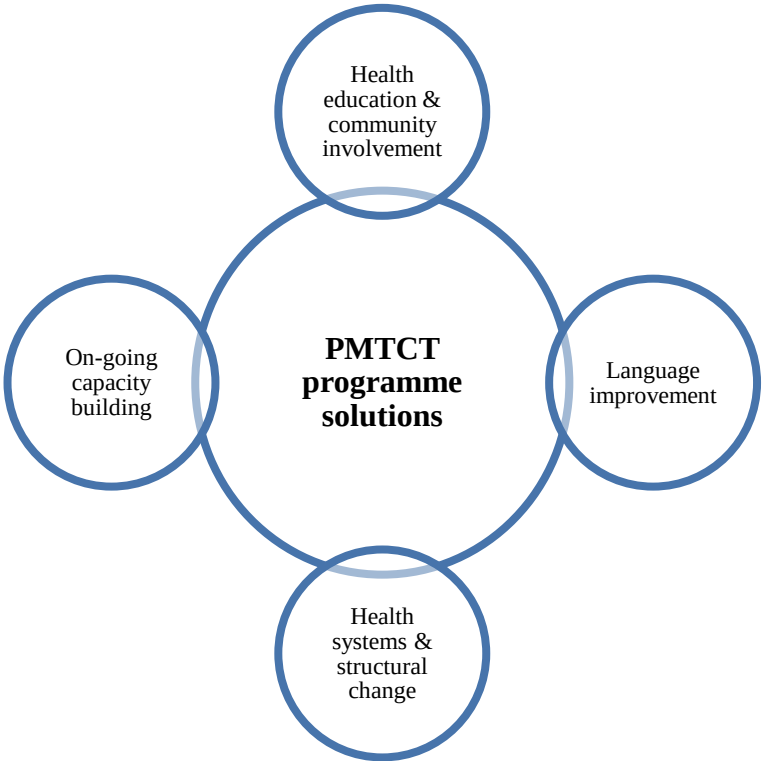


Figure 7.7 PMTCT programme solutions by healthcare providers

7.2.5.1 Health education and community involvement

"There should be awareness, awareness, awareness"

The first sub-theme which was expressed as a possible PMTCT programme solution by HCPs was health education and community involvement. The HCPs expressed that for the PMTCT programme to improve, there needs to be on-going education about the PMTCT programme at different points within the community. The excerpt below attests to this.

> *"…to improve things, it is education, education, education, these people must be educated in this regard…Awareness at home, in the community, whenever there are gatherings, we can do it at churches, at chiefs' [place] and other places where people meet like old age places. There should be awareness, awareness, awareness" (**female, 56 years, maternity ward manager**).*

This suggests that education is a key strategy for improving PMTCT service utilisation. The HCPs also indicated that "t*he* involvement is necessary. Education is vital because although people have a general knowledge of HIV/AIDS, they tend to have minimal knowledge related to MTCT and PMTCT (Eyakuze et al., 2008; Mushi et al., 2007). The HCPs suggested places where such awareness and education could take place, for example, homes, community gatherings, churches, chief meetings, and pensioners' pay points. Similar recommendations to use cultural and community events for education provision have been previously made (IMAU & CDC Uganda, 2003). Studies have shown that community involvement in the PMTCT programme could facilitate adherence to PMTCT cascade activities (O'Gorman et al., 2010). Other studies elsewhere have shown the importance of traditional leaders' involvement (Torpey et al., 2010). Community based strategies have been shown to improve utilisation of the PMTCT services (Teasdale & Besser, 2008; Futterman et al., 2010; Torpey et al., 2010; Myer et al., 2005).

The HCPs in the current study were not specific about the agents of education provision. However, they have expressed the positive effects that working with peer counsellors had on the PMTCT programme. Other studies have identified community dialogues as critical for the facilitation of communication about health issues and encouraging collective action by the community (Figueroa, Kincaid, Rani & Lewis, 2002). Some studies also found that community discussions and training awareness assisted with the reduction of stigma (Vincent,

2006). The Department of Health South Africa (2009) recommended that ministerial events should be exploited for the promotion of HIV or PMTCT education.

7.2.5.2 Language improvement

The second sub-theme which was reported to as a PMTCT programme solution by the HCPs was the language improvement used in PMTCT programme, especially in the written medium of communication to the community. The excerpt below shows the current situation related to written PMTCT information at some of the healthcare facilities in the Nkangala district.

> *"If most of the messages that come from the Department of Health can be in different languages because you will find that they are in English and we do not have so much educated people. Posters should come [written in the following languages] English, Setswana, Nguni so that they [patients] can read and understand them" (**female, 56 years, maternity ward manager**).*

There seems to be dearth of literature on PMTCT language improvement. As indicated in Chapter Five and Six, the consideration of linguistic factors is vital for effective HIV prevention, diagnosis and treatment (Penn & Watermeyer, 2012).

7.2.5.3 Healthcare systems/ structural/ policy change

The third sub-theme which serves as a PMTCT programme solution recommended by the HCPs was healthcare systems/ structural and policy change. The HCPs mentioned the importance of improving infrastructure, to allow more space for rendering PMTCT services *"…at least if they can add the consulting rooms in order to have a place to work and have privacy…"* They also indicated the need to increase PMTCT staff in the healthcare facilities "*another problem is the shortage of staff*." Furthermore, they expressed a need for capacity building for the PMTCT staff "*I think for now half of the staff are the ones who have done it [trained on PMTCT]…We are waiting for the invitation so that we can check those who are still behind [need training]*." Although the peer counsellors have been found useful by the HCPs and the PMTCT clients, they work on a contract basis and thus only provide services for a limited amount of time. The HCPs thus recommended that the issuing of contracts to peer counsellors should be reviewed *"…otherwise this person [name of peer counsellor] we [wish] she was employed*

permanently because isn't pregnancy is an on-going thing. She should not be on contract. Because of her presence, pregnant women are testing [for HIV]. They have seen her [live with HIV] so it is a good thing to target HIV positive people." Availability of drugs for PMTCT clients was also mentioned as a key to the success of the PMTCT programme **"***... the government is supposed to make sure that the patients comply, we should not run out of treatment*." The HCPs proposed a change in PMTCT guidelines, particularly those relating to grandmothers' care for children. They reported that PMTCT guidelines should allow grandmothers to continue bringing children for treatment/ prophylaxis to prevent HIV infection, as the mothers of the children often migrate to cities to seek employment (Barratt & Penn, 2009) or die, due to HIV. Since grandmothers are the primary caregivers of children, they should also be allowed to participate in activities that facilitate the child's well-being *"[One] particular law [that needs] to be changed is that if a child is remaining with the grandmother, she must be able to continue with the treatment [for the child]*." Therefore, grandmother involvement on the PMTCT programme is important *"It is important to involve grandmothers because many times, they are the ones remaining with children. They are the ones remaining with children. They have to been involved 100% from the onset [especially]. With regard to infant feeding they have to know that there should not be mixed feeding for the child. They have to know when the child is due for the tests [because] the mother would have gone to work, they have to bring the child to the clinic."* The HCPs further recommended that a supermarket approach (an approach where patients may receive PMTCT services on any day of the week) to PMTCT service provision be adopted five days of the week. This suggests that instead of having fixed days for providing varying healthcare services (for example chronic patient day, antenatal day, postnatal day etc.), all services should be provided whenever patients come to consult *"Anyone who comes presenting with a problem of missing periods, we have to test her and book her [immediately]. We are not supposed to turn them back*."

The data presented in this Chapter suggested much needed interventions relating to infrastructure, staff load and staff capacity, which have already been recommended by other studies (Delvaux et al., 2008; Sprague, Chersich & Black, 2011). Drug availability is crucial for the effectiveness of the PMTCT programme. Any drug shortages have the potential to hamper PMTCT service provision, and might lead to treatment non-adherence. Similarly, other studies have emphasised that for the PMTCT to be improved, critical PMTCT supplies are needed (Rujumba et al., 2012b). It was observed that peer counsellors seem to have a remarkable impact on women's HIV testing, HIV disclosure and treatment adherence. Putting peer counsellors on contracts, which are renewable subject to funding, seems to threaten the

efficacy of PMTCT service provision. Unlike the situation in Vietnam, where peer counsellors are not considered effective because of low education levels (Nguyen et al., 2009), the HCPs in the current study seemed impressed with the peer counsellor services, mostly because they assist in retaining PMTCT clients.

Family involvement has also been emphasised as key in PMTCT service provision. This is indicated by the recommendations to amend PMTCT guidelines to allow grandmothers to initiate child treatment, as they are already practising the caregiving role in most families. Other studies have shown that families lead to better adherence of PMTCT processes (Magagula & Mkhatswa, 2004; Peltzer et al., 2007). The HCPs seemed eager to provide PMTCT services that make a significant difference.

7.2.5.4 On-going capacity-building

The fourth and final sub-theme which was recommended as a PMTCT programme solution relates to the provision of on-going capacity-building to PMTCT staff. The data presented in this Chapter suggested that some HCPs require clarity on how to proceed with certain PMTCT processes. For instance, they needed to know the period of enrolment in the PMTCT programme. The excerpt below attests to this.

> *"…truly speaking, we do not have direction as to how do we sustain these people using this method. Maybe if we can get guidance as to when the person has started PMTCT being pregnant, how do we sustain her, how do we know what to give her for discharge [exit] from the PMTCT programme?" (**female, 47 years, health facility manager).***

Although the HCPs are aware of steps required to encourage participation in PMTCT, they have however expressed the need for a protocol stipulating the amount of time for which a person may be enrolled in the PMTCT programme. According to the HCPs, having a protocol outlining how long a person can be on the PMTCT programme is critical. The HCPs also expressed the need for assistance in involving men in the programme.

> *"[with regard to] the men, I do not know whether [is because of] negative response or negative attitude, I do not know. It is rare to find a man*

accompanying the woman [to the clinic]. I am just asking that please help us with the men…" ***(female, 43 years, professional nurse).***

The HCPs identified the need for interventions that target male involvement in PMTCT. This suggests that the issue of male involvement remains as a factor that may impact negatively on the PMTCT programme.

7.3 Conclusion

This Chapter consisted of five key themes which emerged from the thematic analysis of the healthcare workers' data. The first theme was the overview of the PMTCT services, which covered the history of PMTCT emergence in the area of study and the general services provided by the HCPs. The second theme related to the barriers affecting the healthcare system. The barriers identified were mainly linked to the non-utilisation of antenatal and postnatal care. With this particular barrier, the challenge arose with pregnant women's movement from one healthcare facility to another, as well as with non-disclosure of HIV status. Infant feeding was also mentioned as a barrier, which included issues such as mixed feeding, association of formula milk with HIV and formula milk shortages. The other barriers which were reported to affect the PMTCT programme were male non-involvement in PMTCT, lack of interest in support groups, health systems barriers and structural barriers.

The third theme identified was PMTCT barriers beyond the healthcare system. This theme encompassed the following challenges: teenage pregnancy, unemployment, lack of schooling by most of the young women and the HIV disease burden which is mostly carried by grandmothers. The fourth theme related to the success of PMTCT. The following successes were highlighted: PMTCT acceptance by women, the infant HIV PCR testing and mother-infant follow-up success and good understanding of the language used PMTCT by HCPs. The fifth theme related to suggested solutions for the PMTCT programme. These included: health education provision, community involvement, improvement of language used in PMTCT and changes in the health system, structure and policy. HCPs also indicated the need for guidance in some of the PMTCT services, such as male involvement strategies and period of enrollment on PMTCT programme.

CHAPTER 8
PMTCT NARRATIVE INTERSECTIONS AMONG HIV POSITIVE WOMEN, GRANDMOTHERS AND HEALTHCARE PROVIDERS

8.1 Introduction

This Chapter aims to formulate a response to one of the main research questions about the intersecting narratives of PMTCT lived experiences, posed in Chapter One. The data which emerged from the three groups of participants are compared according to themes. These thematic comparisons show intersecting and concurring viewpoints emerging from the three groups of participants. The intersecting PMTCT narratives refer to narratives which overlap or coincide among the three groups of participants. The intersections and concurrencies in this study were brought about by participants raising similar issues, which cut across their PMTCT lived experiences. For example, the views of PMTCT services non-utilisation raised by one group might suggest barriers relating to service provision by one group, and even more the influential role played by another group even though they are not providing the service. The narrative intersections show that although multiple views exist, some constructions are shared. The multiple constructions in this Chapter are reflected by the narrative variations which show that reality about health seeking and utilising PMTCT can be "resized and reshaped" (Denzin & Lincoln, 1994, p.125) according to the social context. The findings extrapolated in this Chapter are cross analysed, discussed and interpreted from a social constructionist point of view, which argues that there is no "single truth" but that there are "multiple truths" (Merriam, 2009, p. 10) which are not necessary equal in the construction of reality. This Chapter also presents some discordant views amongst the three groups of participants which assists with further interpretation of reality of the PMTCT lived experiences and how it's perceived. At the end of the Chapter, a conclusion is provided to link the critical issues raised with the ensuing Chapter.

8.2 Thematic narrative intersections

This section highlights seven key themes with some intersecting/ concurrent/overlapping sub-themes that have emerged from the preceding Chapters (Five to Seven). The seven themes

which emerged from the thematic analysis reveal the lived experiences of the three groups of participants (HIV positive women, grandmothers and HCPs) in terms of the following three aspects: being in the PMTCT programme; playing the role of a family support system to ensure adherence to PMTCT services and providing PMTCT services. The identified seven themes are: 1) Fear of stigma as a trigger for late antenatal care attendance, 2) HIV testing stigmatising behaviour and fear of HIV burden, 3) Silent voices about HIV disease, 4) fear of stigmatisation and women disempowerment on infant feeding, 5) health services stigma and cultural stereo types affecting male involvement on PMTCT and 6) structural violence, tradition and healthcare system as PMTCT blockages and 7) enhancement of PMTCT programme through health education, community participation, individual and health system change. These themes were generated by looking at the intersecting and concurrent narratives amongst the three groups of participants. Table 8.1 below shows the study findings in terms of themes and sub-themes, indicating the narrative theme intersections.

Table 8.1 Thematic narrative intersections

THEMES	SUB-THEMES		
	HIV positive women	**Grandmothers**	**Healthcare Providers**
1. **Intersecting PMTCT narratives showing fear of stigma as a trigger for late antenatal care attendance**	Avoidance of long periods of antenatal care attendance		Avoidance of long periods of antenatal care attendance
	Previous child-birth experience	Concealing pregnancy	Previous child-birth experience
	Laziness	Laziness	
	Time defer		
	Fear of healthcare providers		Patient movements
	Non-preference of healthcare facility	Health messages and family advise ignorance	Non preference of HBC
	Myths about pregnancy medication		
2. **Intersecting PMTCT narratives showing HIV testing stigmatising behaviour and fear of HIV burden**	HIV testing acceptance for baby protection	HIV testing acceptance for baby and mother protection	HIV testing acceptance
	Fear of HIV testing	Fear of HIV burden	HIV disease burdens for grandmothers
		Fear of HIV infection	
	Fear of HIV disease	Fear of HIV testing	
3. **Intersecting PMTCT narratives showing silent voices about HIV**	Non-HIV disclosure reasons • Compassion • Non-readiness	Non-HIV disclosure	Non-HIV disclosure to grandmothers

diagnosis	• Stigma • Partner unknown status		
4. **Intersecting PMTCT narratives showing fear of stigma and women disempowerment on infant feeding**	Breastfeeding promotion		Breastfeeding promotion
	Mixed feeding practices	Promotion of mixed feeding	Mixed feeding
		culture vs. health system	,
	Lack of trust	Transparency	Milk shortages
	Formula feeding practices -Stigma - Cleanliness	Infant feeding confusion	Association of formula milk HIV
5. **Intersecting PMTCT narratives showing health services stigmatisation and cultural stereo types affecting male involvement on PMTCT**	HIV testing obstacles	No participation in antenatal care	Non-participation in PMTCT
	Self- mirror HIV	Men do not follow orders	Partner non-HIV disclosure
		Clinic not for men	Men dislike of health education
6. **Intersecting PMTCT narratives showing structural violence, tradition and healthcare system as PMTCT blockages**	Community ignorance and uncertainty	Drugs & alcohol use	HIV disease burden
	HIV misconceptions		Unemployment
	Transactional sex	HIV orphans	Lack of schooling
	Teenage pregnancy	Teenage pregnancy and early sexual debut	Teenage pregnancy
	Beliefs on traditional & religious treatments	Beliefs on traditional & religious treatments	Beliefs on traditional treatments
	PMTCT language challenges	PMTCT language challenges	PMTCT language challenges
7. **Intersecting PMTCT narratives showing enhancement of PMTCT programme through health education, community participation, individual and health system change**	HIV education	HIV disclosure	Health education & community involvement
	Community mobilisation	Forceful antenatal care & grandmother involvement	PMTCT language improvement
	Individual changes (self-drive and knowledge of HIV status)	Improvement of HIV risk reduction strategies	Health systems and structural change
	Health systems changes (High compassion and non-judgmental by HCPs; good reception ; PMTCT language comprehension; Peer counselling (self-worth; open communication)	Improvement of male involvement strategies	Guidance on PMTCT provision
		PMTCT language simplification	
		Health systems improvement	
		Promotion of abstinence or condom use	

8.2.1 Theme 1: Intersecting PMTCT narratives showing Fear of stigma as a trigger for late antenatal care attendance

The first theme reveals views of the three groups of participants about the triggers of late antenatal care attendance. Table 8.1 shows the intersecting narratives for late antenatal care cited by each group. For instance, the HIV positive women cited long periods of antenatal care attendance, previous child-birth experience, laziness, fear of healthcare providers, non-preference of a healthcare facility and myths about pregnancy medication and time defer. The grandmothers cited laziness, concealing pregnancy and health messages and family guidance ignorance by the pregnant women. Lastly, the HCPs cited long periods of antenatal care attendance and previous child-birth experience, non-preference of HBCs and patient movement/relocation as the root causes of late antenatal care attendance. Table 8.2 below shows the intersecting and differing narratives among the three groups of participants.

Table 8.2 Late antenatal care triggers as perceived by participants

HIV + women	Grandmothers	Healthcare providers
Intersecting narratives on late antenatal care triggers		
Avoidance of long periods of antenatal care attendance		Avoidance of long periods of antenatal care attendance
Previous child-birth experience		Previous child-birth experience
Laziness	Laziness	
Varying PMTCT Narratives		
Fear of healthcare providers	Concealing pregnancy	Non preference of HBC
Non-preference of healthcare facility	Health messages and family advise ignorance	Patient movements
Myths about pregnancy medication		
Time defer/ postponement of action-taking		

8.2.1.1 Avoidance of long periods of antenatal care attendance

The study reveals late antenatal care practices by HIV positive women, despite the numerous benefits provided to the pregnant women, which include services such as pregnancy screening

for problems, pregnancy risk assessment, information provision and physical and psychological preparation for the child-birth (Department of Health, South Africa, 2007). Table 8.2 illustrates the intersecting and discordant narratives among the three groups of participants, in an attempt to explain triggers of late antenatal care attendance. For instance, the HIV positive women and the HCPs provided similar narratives on late antenatal care triggers, which are avoidance of long periods of antenatal care attendance and previous child-birth experiences whilst grandmothers and HIV positive women indicated 'laziness' as a trigger. Although from different contexts, the interconnectedness of views on late antenatal care triggers suggests shared knowledge on health issues, and the existence of conversation between the HCPs and HIV positive women about late healthcare seeking behaviour. From the point of view of the HIV positive women, the triggers of late antenatal care attendance were explained as a lived experience which shows that participating in antenatal care is onerous, because it involves multiple visits to the healthcare facility. However, from the HCPs' context, this barrier is something that was learned through being community members and interacting with the HIV positive women while providing PMTCT services. The finding seems to suggest that although HIV positive women are knowledgeable about the importance of adhering to PMTCT cascade processes, such as utilisation of antenatal care services, the long sessions of antenatal care seem unnecessary to them. This finding is in line with a study conducted by Mrisho et al. (2009) in a rural setting in Tanzania, where it was found that antenatal care attendance was avoided due to long sessions. Similar causes of poor attendance of antenatal care services were found in Ugandian study, where there was 96% antenatal care attendance, with most of the women attending only once (Tann et al., 2007).

Although the HIV positive women, HCPs and findings from other studies (Mrisho et al., 2009; Tann et al., 2007) suggest the long sessions as the root cause of late antenatal care, it could be argued that such behaviour seems to be promoted by community beliefs or community behaviour regarding pregnancy. This suggests that the health-seeking reality of the HIV positive women may have been influenced by the social world in which they reside. Therefore, it implies that local beliefs and witnessing similar behaviour by others shape the health-seeking behaviour for some individuals in a rural setting. Other studies have shown that health seeking behaviour can be influenced by individuals, but are mostly influenced by the environment which is dominated by local beliefs, cultural norms and practices (Feldacker, Ennett & Speizer, 2011). Busza et al. (2012) also argued that most barriers affecting utilisation of PMTCT services stem from the local communities in which the women reside. Unlike other studies that

have shown that the decision making power for the mother to seek medical help for the child was also controlled by the father of the baby (Tolhurst et al., 2008) this study seems to suggest that the decision to utilise or not to utilise healthcare services is influenced by the societal norms. If the women in the community are practicing late antenatal care, such behaviour is normalised so much that whenever there is a different practise, it raises curiosity (about the health status) among fellow women. The belief that antenatal care attendance is too time consuming does not seem to support the fact that antenatal care assists with improving the health of the child and the mother (Tann et al., 2007) and that pregnancy provides an opportunity for preventing HIV (Kershaw, Magriples, Westdahl, Rising & Ickovics, 2009). It also contradicts the notion of self-love, which some HIV positive women alluded to in Chapter Five. Hence, this suggests that the construction of knowledge about antenatal care in a rural context is governed by actions which are socially constructed and which might not necessarily be beneficial to the mother and child. As an insider researcher who is from a similar rural background, I find the study results surprising especially with regard to the reasons given for late utilisation of antenatal care services. I saw antenatal care utilisation as part of the norm when one is pregnant, however, for the participants the experience seems different. The issue of avoidance of long periods of antenatal care does not provide a clear understanding about why the women behave that way. It seems to lack an answer to the question: what is it about the long periods of attendance that makes the women feel a need to delay attendance of the antenatal care services? This finding seems to suggest that there are other underlying factors which may be causing such behaviour. The consideration of this avoidance action seems to suggest that there is something disturbing the utilisation of antenatal care service. This claim is supported by the next sections, which succinctly identify the root triggers for late antenatal care attendance.

8.2.1.2 Previous child-birth experience

Another intersecting narrative of late antenatal care trigger demonstrated by the HCPs and the HIV positive women was related to ‘previous child-birth experience’. This finding suggest that women, who previously had an experience of child- birth, appeared to seek antenatal care late. Upon the observations of the HCPs over the years of PMTCT service provision, late antenatal care by women who already had children was noted. For the HIV positive women, the findings show that a lived experience of having had a child before influenced their late antenatal care attendance. This finding concurs with that of Hanh, Gammeltoft and Rasch (2011) who argued

that lack of participation in PMTCT services, such as antenatal testing, was linked to having two children. Although the HIV positive women and HCPs in this study, and other studies (Hanh, Gammeltoft & Rasch, 2011), viewed child-birth experience as a trigger for late antenatal care, it is not completely clear as to why having child-birth experience' is causing such behaviour. What is clear is that previous self-experience or observation of the experience of others has an influence on subsequent behaviour regarding healthcare usage.

This suggests that the meanings and actions taken by HIV positive women are constructed through experiences (Simon, 1996) of self and others. For instance, it may be argued that if one has a lived experience of giving birth, one can either attach a positive or negative meaning to it, based on the care she received during the child-birth process. If the previous services were good enough in terms of reception and information provision, the mothers might come to the healthcare facility early a second time. As discussed in Chapter Three, the reality of antenatal attendance in this instance has been reshaped in such a way that "purposeful human actions" (Denzin & Lincoln, 1994, p. 125) of late health-seeking are observed. The results, therefore, seem to suggest that the previous lived experience of giving birth causes women to be disinterested in utilising antenatal care services. This finding is similar to that of avoidance of long periods of antenatal care attendance, because it does not have a clear explanation related to how having a previous child-birth experience affects early antenatal care utilisation. Hence, this finding suggests that there might be other underlying causes which lead to such a behaviour.

8.2.1.3 Laziness triggers late antenatal care attendance

Another intersecting narrative of late antenatal care trigger demonstrated by the grandmothers and the HIV positive women was related to 'laziness'. Chapter Six showed that grandmothers described two types of laziness observed in the women in the study setting: laziness to utilise antenatal care services and laziness to communicate the child's delivery date. Even though studies have shown that attendance of antenatal care assists with early screening of pregnancy risks (Department of health South Africa, 2007), the current study revealed that the non-utilisation of early antenatal care services is a common practice, which is concerning for the grandmothers. They viewed avoidance of long periods of antenatal care and experience of child birth as excuses for laziness by women in the study setting. The narrative intersections shows that although the grandmothers come from an old school of thought, which allowed women to

give birth at home, their perceptions and understanding of antenatal health-seeking behaviour differed compared to those of some of the HIV positive women in the study. This means that the reality about the antenatal health seeking behaviour is self-renewing (Guba and Lincoln, 1989). As the new constructions about the benefits of timeous health-seeking emerge, the traditional ways disappear, especially for the older generation. This suggests that the change from grandmothers' views of health-seeking behaviour was brought about by the social processes, interactions and lived experiences that people had in relation to the HIV disease. As a result, grandmothers perceived their daughters and grandchildren as being lazy because PMTCT services exist (which are new and were not available to the grandmothers) to assist them, and yet they do not wish to utilise them.

Conversely, poor socio-economic status may contribute to some of the behaviours mentioned by the grandmothers. For instance, because of the poor socio-economic status and the fact that the younger women in the study are unemployed, they appear lazy. The absence of health-seeking behaviour seems to emanate from impoverished conditions in rural areas, which facilitates a lack of motivation and inertia among HIV positive women. These individuals seem to rely on the belief that grandmothers have "gems of wisdom" (Penn et al., 2010, p. 9) and therefore will know how to manage various issues including those related to reproduction. Varga and Brookes (2008b) found that the implementation of PMTCT processes is easier for urban than rural women. This might hold true, considering that rural areas are negatively impacted upon by poverty. According to Soskolne, (2003) rural women's experiences of the HIV disease are worsened due to vulnerable and subordinate positions that they hold in society. Gilbert and Walker (2002) also argued that the HIV burden is gendered and classed. Because of the lower socio-economic status of rural areas, women in these areas are more likely to experience more health-related difficulties (Gilbert & Walker 2002).

On the other hand, the HIV positive women's laziness was described in terms avoidance of long periods of attendance and the fear of starting antenatal care services. As shown in Chapter Five, one HIV positive woman said "*people do not want to go to the clinic…many people still have fear…*" This seems to suggest that according to the HIV positive women the fear to go to the healthcare facility actually causes them to appear 'lazy' when it comes to antenatal care utilisation. The fear of healthcare facility might be due to community stereotypes which include not utilising antenatal care services. Therefore, this suggests that laziness might be

mistaken for what is actually fear of the healthcare services. The fear of healthcare services will be discussed in subsequent sections of this Chapter.

Interestingly, grandmothers have also indicated that the silence surrounding the discussion of the child's delivery date shows laziness of the young women. Although grandmothers view this behaviour as laziness, it could be argued that cultural constructions of the communication of sexual and reproductive issues might be a cause of this behaviour. Even though language is a vehicle that is used to communicate agreements in the world (Gergen, 2009), it may occur that certain constructions are difficult to express through language. Another study in Zambia showed that cultural taboos of sex communication could limit communication about sex education (Zambia Central Board of Health, 2004). Other studies have also suggested that sexual taboos are the cause of non-communication (Homsy et al., 2007). In concurrence with other studies, the current study argues that the laziness of non-utilisation of antenatal care services and limited communication could be due to fear of receiving healthcare services.

8.2.1.4 Myths about pregnancy medication

As indicated earlier in Chapter Five by the HIV positive women, another trigger for late attendance relates to myths about pregnancy medication that is received from the healthcare facility. This is a different view which shows one of the unfortunate realities that were socially constructed by some of the HIV positive women through their interactions with women in the community, regarding receiving services at the healthcare facility. One woman said "*When I take those tablets, my stomach becomes big…"*Other women say "*the medication causes dizziness*."

Due to previous pregnancy experience, the tablets or medication given during pregnancy are believed to cause the stomach to bulge and to cause dizziness. From the context of the HIV positive women, such beliefs trigger late antenatal care usage. It could be argued that such a belief is based on community constructions, which might not be beneficial to the mother and child. The myth about pregnancy medication possibly indicates the lack of knowledge among constructors about the functions of medication, which may be due to the poor scope of information available in their setting. Furthermore, the myths about pregnancy medication imply a lack of emphasis on and addressing of pregnancy myths in the healthcare setting. It also suggests miscommunication between patients and HCPs about treatment and its function (Watermeyer & Penn, 2009). Although these explanations might be the case, the myths about

pregnancy medication seem to not provide a clear link with late antenatal care attendance. The belief that medication affects the stomach seems to suggest that there are other underlying factors that might be related to the healthcare facility. This possible link is discussed in the subsequent section of this Chapter.

8.2.1.5 Fear of the healthcare facility and HCPs

The HIV positive women further suggested another varying trigger for late antenatal care attendance, which seems to provide an explanation as to why women avoid having longer periods of antenatal care attendance especially if they have given birth before, appear lazy and why they have issues with some pregnancy medication. For instance, the women mentioned the fear of healthcare services, the healthcare facility and HCPs as another cause. This particular trigger seems to be the underlying cause for all of the previously mentioned late antenatal triggers (avoidance of long periods of antenatal care attendance, previous child-birth experience, laziness and myths about pregnancy medication) because it provides reasons for not wanting healthcare services. In addition to the four, another varying late antenatal care trigger which seems to support what other participants said about fearing healthcare facility and HCPs was deferring time for initiating antenatal care. Chapter Five indicates that some participants deferred time by wanting more "time to think" about utilising antenatal care services. This also seems to suggest that some pregnant women had less interest in utilising the healthcare facility services. Another varying trigger mentioned by grandmothers for non-utilisation of antenatal care services was pregnancy concealment by the women. Even though such concealment could be due to wanting to respect parents or fearing parents as indicated by grandmothers, it could also be that some women fear to utilise antenatal care services once pregnancy has been discovered. This is because once the family discovers the pregnancy, the next level would be to encourage antenatal care utilisation. The fear of the healthcare facility and HCPs accounts for why there is reluctance to participate in early antenatal care services. It suggests that 'fear' is the one prohibitor of the usage of services. The women's disinterest in early antenatal care attendance may be attributed to their previous lived experiences of the healthcare facility. In this context, this suggests that experienced mothers may avoid going to the healthcare facility early during their subsequent pregnancies because of the previous lived experiences of antenatal care services which were ineffective. Thus the negative lived experiences of healthcare facility and HCPs instigate fear among women for utilising antenatal care services early. The excerpt below, taken from Chapter Five provides an explicit explanation of the women's late antenatal care

attendance because of the HCPs who are known to shout at patients "*I was afraid [because] they [community people] say they [healthcare providers] shout at patients in the clinic."*

The use of pronoun "they" should be noted. It is used to refer to other sources of information (other community members/ other women) which claim that HCPs shout at patients. This finding implies that the HCPs in this study setting are portrayed by community as being unfriendly towards patients, because they shout at women for being pregnant. This suggests that the community has painted a negative picture of HCPs and their profession especially when it comes to patient management. This is reflected by one HIV positive woman who said "*…you can arrive in the healthcare facility feeling very very very sick. The nurses …would just pass you just like that and help other patients who are not very sick*." Another woman showed the bad attitude of the HCPs by saying "they forced her to do hysterectomy." This finding shows that the social construction of reality relies on shared views of a particular situation (Creswell, 2007). This negative thinking about the healthcare facility may stem from the experiences of being familiar with the health facility or from the multiple realities constructed by the community about services (including the PMTCT services) that are provided there. At the same time, this finding suggests that the shouting at women in healthcare facilities might be due to the age of the pregnant women (for example, if the women are young girls). This element seems to account for why the community members do not seem to trust health care system interventions. Similarly, a study conducted in rural and urban Limpopo in South Africa, found that one of the challenges to antenatal care attendance was the view of HCPs as being unfriendly people (Varga & Brookes, 2008a). They also found that healthcare workers' attitudes contributed towards women's fear of HIV testing. The current study also found that women feared HIV diagnosis "*I was scared of going to the clinic because they might say I am HIV positive*." Therefore, fear in this study seems to disempower women from acting early on healthcare utilisation.

The findings of the current study further revealed that the HIV positive women feared HCPs because of the suspicion that they (HCPs) gossip about them behind their backs especially if they test positive. This belief caused the women to fear a breach of confidentiality, with regard to their HIV positive status. Similarly, paranoid beliefs and mistrust of the HCPs has also been found to lead to the non-utilisation of the PMTCT services in another South African study (Doherty et al., 2006). Other studies have also suggested that women feared clinic attendance because of confidentiality issues (Nguyen et al., 2008). The findings of the current study suggest that the healthcare facility is seen as a gossiping hub related to HIV positive women.

Data also reveal a very important factor which points that the fear of HIV is actually a form of disempowerment which stops women from seeking early antenatal care attendance. The fear of being morally judged is some form of disepowerment towards adherence to PMTCT services (Brickley et al., 2009). These findings possibly suggest that HIV positive women construct negative meanings, perceptions and understandings through their relationship with people in the community. Their responses reflect how meanings are constructed when it comes to antenatal care attendance. The findings of this study reflect the multiple constructions of reality of the HIV positive women, relating to the dislike and disinterest of attending the healthcare facility at the early stages of pregnancy. The findings show that based on the previous experience of interacting with the HCPs at the healthcare facilities, some HIV positive women prefer not to use any PMTCT services. Because nothing exists without relationships, this experience is shared and becomes known by many people. As a result, certain individuals become influenced by others who have had the experience, causing them to develop the same fear. Burr (1995) indicates that, the generation of meanings happens through the use of language. The different constructions, including the fear of healthcare utilisation, are expressed through language. One participant shared her fear which revealed an emotional clutter that led to healthcare non-utilisation:

> "*I came to the clinic late. I was not able to come to the clinic [early], I was afraid. I am told that they [nurses] shout [patients] at the clinic. I was afraid, they [community people] say they shout at people at the clinic…" (**Mother who had just given birth, 21 years, single, one child)***.

This suggests that language facilitates the understanding of the reality of factors affecting the utilisation of PMTCT services. In the above excerpt, the participant articulated the fear of HCPs, because she was told that they shout at people. The current study thus supports the findings of previous studies which seem to suggest that healthcare attitudes affect the utilisation of the PMTCT services. At the same time, Guba and Lincoln (1989, p. 143) argued that some constructions are regarded as "malconstructions" because they are "uninformed" and "inconsistent". It could thus also be argued that the above excerpt is an example of a malconstruction because it shows that the fear emerged from what others said, and thus reflects that the fear of HCPs was anticipated. The findings thus reveal that "malconstructions" are valuable at a community level, because they explain particular actions, such as late antenatal care attendance. The current study suggests that psychosocial factors, such as fear of HCPs,

have the potential to damage the reputation of the PMTCT programme. Fear is a behavioural consequence of the psychosocial effects of stigma (Turan & Nyblade, 2013). The results seem to suggest that some women in the current study anticipated stigma from the HCPs. For this reason, they utilised the PMTCT services late. These findings differ to those of Watermeyer (2012), who found that caregivers were satisfied with services provided at a healthcare facility. These findings are thus worrying considering that the HCPs are the first point of contact in PMTCT services, and can thus determine mothers' acceptance or rejection of the programme. Due to late attendance of antenatal care, women miss the opportunity of receiving prophylactic regimes, and other crucial PMTCT services (Pai et al., 2008; Morch et al., 2006). Other studies have found that besides HCPs' attitudes towards patients, some of the women coming for antenatal care wished to discuss HIV testing with their husbands before attending the healthcare facility (Homsy et al., 2007). In the current study, there was no mention of women having to acquire permission to test from their partners. This could be due to the fact that most of the participants in the current study were single. The avoidance of long periods of antenatal care attendance, having had child-birth experience, women's laziness and myths about pregnancy medication all seem to reflect a fear of HCPs and healthcare facility.

8.2.1.5 Health messages and family advise ignorance as triggers of non-antenatal care Attendance

Contrary to some narrative intersections that were discussed earlier, the grandmothers expressed that ignoring health messages and family advises were the causes of late antenatal care attendance. The health messages are ignored by not listening to HCPs and media which emphasises healthy living whilst for family, the ignorance is shown by not following advises on early antenatal care including avoiding risky behaviours. It could be argued that the young women's ignorance of health messages and family advices may be because of the plight of poverty. The young women seem to find it difficult to listen to what the elderly women and HCPs advise because they are trying to evade poverty, however, in the process they are becoming infected with HIV (Farmer et al., 1996). As discussed in Chapter Four, the majority of HIV positive women was single, unemployed and had one to two children, with the exception of a few (four women) that had four to six children. All of these traits might lead the women to engage in risky behaviours, which leads to infection with HIV. The argument of poverty as a cause of risky behaviour was supported by grandmothers who expressed that

women in the area of study continue to have children in order to receive child grants, which are used as a source income.

> "*I think it is this [child] grants they are getting, you know they finish giving birth, then there is another child, 123 [immediately], when the child starts walking, she is pregnant with another child. But I think it is this money for [child] grants that they are getting" (**FGD4, grandmother 2, 59years**).*

The above excerpt suggests that listening to the grandmothers and HCPs becomes almost impossible because the reality is that these women require survival strategies as they are unemployed and unmarried. This point will be further discussed in subsequent sections which discuss PMTCT barriers beyond the healthcare system. In addition to factors highlighted by other studies, such as low risk perception (Wringe et al., 2008), fear of HIV testing (Musheke et al., 2013) and long antenatal sessions (Mrisho et al., 2009) as contributing to the non-utilisation of PMTCT services, the current study also found that ignoring health messages and family advise are further perceived to be contributing factors.

8.2.1.6 Non-preference of home-based care workers and patient movement

The other varying triggers of late antenatal care attendance are mainly individual factors. For instance, the HCPs indicated non-preference of the home-based care services and patient movement and relocation as reasons for the non-utilisation of healthcare services by the HIV positive women. From the HCPs' point of view, HIV denial is causing the HIV positive women to show disinterest in the assistance offered by the home-based carers. However, the HIV positive women believe that the HCPs gossip about them, which causes them to avoid antenatal care services. Hence, they move from one healthcare facility to a different healthcare facility. The varying views on health-seeking behaviour point to the existence of multiple realities on healthcare utilisation which are socially constructed (Denscombe, 2003) in a rural context. The varying views also demonstrate that different people might interpret a lived experience differently in different contexts (Denscombe, 2003). The fact that HCPs see the cause of such behaviour as being HIV denial and HIV positive women see HCPs as obstacles, demonstrates the multiple truths that exists in the construction of such reality.

The narratives from the HCPs further showed that close to the time of child-delivery, the pregnant women move to the homes of their grandmothers to receive child support post-delivery. It could be argued that this behaviour is informed by the women's view of grandmothers as child caregivers and experts in childrearing, even in circumstances involving HIV. This is an additional finding to those discussed above, which claim that women fear the HCPs and healthcare facilities. However, in this particular instance, it suggests that women fear local healthcare facilities and HCPs. Because of the suggestion that 'fear' reduces the health-seeking behaviour of the women, it could be argued that relocation to their grandmothers' home might seem precarious, because the woman probably will not disclose her HIV status to her grandmother. Secondly, she will present as a new patient at a different healthcare facility, where she will be regarded as a new patient who tested HIV positive at delivery (despite already having been tested previously in another healthcare facility). Thirdly, the infant follow-up (three day, seven day, ten day, infant HIV PCR testing) might not be strictly adhered to because the woman did not attend the antenatal care services in her grandmother's hometown. There might also be a lack of home-based care workers to follow-her up because she would be in a new area. Patient movement and relocation might also be due to stigma of not wanting to be assisted by the HCPs who know the patient's HIV status (Turan & Nyblade, 2013; Merten et al., 2010; Selin et al., 2007; Nam et al., 2008; Nguyen et al., 2008). Therefore, the movement and relocation suggests that fear of HIV stigma is a reality for pregnant HIV positive women. Such movement and relocation is done as a wish of ensuring the well-being of their new born babies. The assistance of the HBCs has been constructed by the HIV positive women to be that of workers providing HIV services only. The views given by each group of participants cannot be judged as wrong or right, but it should be stated that "social selves" are involved in the creation of such realities or beliefs (Boghossian, 2001). The reason why HBC workers are rejected in women's homes could be due to the fact that they are linked to the HCPs and healthcare facilities, which the women have expressed their fear for.

Furthermore, the dislike of HBCs could also be due to the fact that the HIV positive women are afraid that the HBCs will disclose their HIV statuses to others. This implies that the fear of anticipated stigma by the women could affect how PMTCT services are used. For instance, Turan and Nyblade (2013) found that social factors such as stigma and discrimination affect PMTCT service utilisation. Other studies also found that HIV non-disclosure and stigma affected PMTCT programme negatively (Turan et al., 2008; Laher et al., 2012). Varying

theoretical frameworks have shown how HIV stigma affects the lives of HIV positive individuals and the utilisation of health services (Turan & Nyblade, 2013; Steward et al., 2008; Earnshaw & Chaudoir, 2009; Holzemer et al., 2009; Brickley et al., 2009; Turan et al., 2011; Brown et al., 2010). In the current study it appeared that the anticipated stigma most commonly occurred from the HCPs, which thus seemed to make utilisation of PMTCT services difficult.

Finally, the dislike of HBCs might also be due to the women not disclosing their HIV statuses to their families. Obermeyer et al. (2011) argued that HIV disclosure facilitates stigma reduction, whilst at the same time, HIV non-disclosure prohibits HIV positive women from participating freely in the PMTCT programme. The negative reaction towards HBCs is worrying considering that they are considered to be anchors for the HIV positive women and their infants (Kim et al., 2012). The results of the current study thus suggest that the 'fear' of HCPs and healthcare facilities, presented through patient movement and previously discussed behaviours in other Chapters, needs to be addressed in order for the PMTCT programme to be effective.

8.2.2 Theme 2: Intersecting PMTCT narratives showing HIV testing stigmatising behaviour and fear of HIV burden

The second theme reveals the narrative intersections and contrasting narratives about the general HIV testing beliefs and understanding from the three groups of participants. Table 8.3 shows the HIV testing beliefs cited by each group. For instance, all the three groups of participants supported HIV testing for varying reasons while the fear of HIV testing and fear of HIV disease was also raised by both HIV positive women and grandmothers.

Table 8.3 Intersecting narratives on HIV testing beliefs and constructions

HIV positive women	Grandmothers	Healthcare Providers
Intersecting narratives		
HIV testing supported for baby's sake	HIV testing acceptance for mother and baby's sake	Support HIV testing
	Fear of HIV burden	HIV disease burden for grandmothers

Fear of HIV testing (Wait for pregnancy to be tested; forced to test)	Fear of HIV testing (HIV testing is scary)	
Varying narratives		
Fear HIV disease (eat blood; witchcraft; no mention of HIV; premature birth; abortion attempts)	Fear of HIV infection	

8.2.2.1 HIV testing acceptance: Baby and mother protection and fear of burden and HIV Infection

As discussed in Chapter Five, the findings showed that most HIV positive women support HIV testing in order to avoid transmitting HIV to the baby. The results suggested that the women lacked knowledge about the importance of HIV testing for their own health. Other studies have also found that mothers were tested because of the strong belief of a possibility of transmitting HIV to the child (Adedimeji et al., 2012; Rothpletz-Pulgia & Storm, 2012; Etiebet, 2004; Hardon et al., 2012). Unlike the current study, participants in the study of Levy (2009) had knowledge that HIV testing would preserve the mother's health as well. The lack of knowledge about the importance of HIV testing for the mother's own health might be due to the fact that for a long time, South African PMTCT interventions have been concerned with perinatal infection, where the infant's health was the main priority. This was until recent global commitments and local policies emphasised the importance of keeping the mother healthy (UNAIDS, 2011; UNAIDS, 2012; Department of Health South Africa, 2013). This finding suggests a need for local educational messages which places emphasis on the importance of the mother's health when conducting HIV testing. Such education could facilitate adherence to the PMTCT cascade processes highlighted in Chapter Two in figure 2.2.

The narrative intersections further highlight that unlike the HIV positive women who support HIV testing for benefiting the child only, the grandmothers support the act of HIV testing for protection of both mother and child. Similar to Levy's study (2009), grandmothers wanted healthy mothers and children. However, unlike Levy, such wish by grandmothers was based on wanting to avoid the burden of caring for the sick mother and child and of being infected with HIV. This suggests that grandmothers were afraid of being burdened by the AIDS orphans, and of being infected with HIV when looking after the orphans. The HCPs attest to what the grandmothers said as shown in Table 8.3. They report that the grandmothers are truly

burdened by the sick grandchildren. The grandmothers' fear of being infected with HIV indicates avoidance of social stigma especially because they are the older generation. The findings thus show that 'fear' dominates the HIV positive women and the grandmother's thinking about HIV. The fear mentioned by the HIV positive women is related to the HCPs, the healthcare facility, HIV testing and how HCPs treat the women. On the other hand, the grandmothers' fear is related to self-protection and of being burdened by AIDS orphans. Although grandmothers wanted to avoid MTCT of HIV for burden removal, they seemed less knowledgeable of the full PMTCT cascade processes and its benefits. This was confirmed by the fact that HIV testing was constructed as a mechanism for protecting themselves. Whilst it is important for the grandmothers to protect themselves and have the healthy mother and child in the context of PMTCT, burden removal is not a key message. It could thus be argued that the prevailing fear amongst both the grandmothers and the HIV positive women is generally caused by lack of PMTCT knowledge of the cascade processes and HIV stigma.

8.2.2.2 Fear of HIV testing

Although HIV testing was supported as discussed on section 8.2.2.1, further intersecting narratives were found between HIV positive women and grandmothers about the 'fear' of HIV testing. For some HIV positive women, the fear of HIV testing was expressed by having views that they "*are scared of HIV testing but were forced because of pregnancy*" and "*the fear of HIV testing by young girls especially if not pregnant."* These findings suggest that some women in the area of study portray HIV testing as a practice that only needs to be adhered to when one is pregnant. HIV testing is perceived as an action that can only be committed by pregnant women. This indicates that social perspectives influence the meaning that people construct about the phenomenon (Crotty, 1998, pp. 42-43), such as HIV testing. In this case, the common local practice has been for women to be tested for HIV only when they are pregnant. This is unclear considering the previous discussion under the first theme of this Chapter, where the HIV positive women indicated various reasons for starting antenatal care late with 'fear' being the main reason. It could thus be argued that being pregnant does not necessarily imply that the women would want to start antenatal care early in order to be tested for HIV.

The action of waiting for pregnancy to happen before HIV testing could jeopardise the PMTCT programme because if women only test when they are pregnant, on-going risky sexual behaviour is more likely to occur. The HIV pandemic will thus be difficult to control. This

finding suggests the lack of understanding about HIV and MTCT of HIV. It shows the impact of societal and individual beliefs on HIV issues. Testing for HIV only when one is pregnant could be detrimental because it might cause an influx of HIV positive cases to be identified during antenatal care. Prior knowledge of HIV status may assist in having many HIV positive cases identified before pregnancy. In this way, lives could be saved. For the grandmothers, the fear of HIV testing was expressed by one grandmother who said "*HIV testing is scary and a positive HIV result breaks souls*". The fear of HIV testing could greatly hamper the effectiveness of PMTCT services, since HIV testing is seen as a gateway to PMTCT (Hardon et al., 2012; Department of Health, South Africa 2009). A review conducted by Obermeyer and Osborn (2007) also found that fear resulted in the non-utilisation of HIV testing services. The women's fear of HIV testing is perpetuated by the social construction of HIV in their community, the grandmothers' fear is exacerbated by how HIV is perceived by the community. As a result of how HIV is socially constructed in communities, some women feared HIV testing. This finding suggests that the societal and cultural beliefs in a rural context affect acceptance of some of the PMTCT cascade processes, such as HIV testing. The descriptions, perceptions and explanations of fear given by both the grandmothers and the HIV positive women suggest a need for change of some of the traditional social constructions of HIV.

8.2.2.3 Fear of HIV disease

Furthermore, the results reveal intersecting narratives of 'fearing HIV disease' by both grandmothers and HIV positive women. It could also be argued that the fear of HIV testing stems from how HIV is perceived in the area of study. For instance, the HIV positive women in this study humanised HIV and equate it to something that consumes blood *"if you test after a long time, it [HIV] would have already eaten your blood…"* The fear of HIV disease for the HIV positive women in this study was further shown by believing that they are "*bewitched, premature births, abortion attempts*" whilst for the grandmothers it was reflected by them "*not wanting to be infected with HIV"* while looking after grandchildren. This study therefore supports other studies which indicated the importance of understanding context specific barriers (Thompson et al., 2012) and cultural norms (Roura et al., 2010; Wanyama et al., 2007) in order for PMTCT programme to be effective.

The fear of HIV is also demonstrated by the euphemistic terms used to refer to '*HIV*'. For instance, the participants used pronouns and words such as "it/ that (disease)/ this (disease)/

positive" to refer to HIV positive. This could be due to denialism of HIV disease which is shown by non-acceptance (Heywood, 2004). Other studies found that communication about health including HIV is not always easy and, as a result, euphemisms are often used (Watermeyer & Penn, 2008; Ware et al., 2009). Therefore, the findings in this section also describe fear of HIV testing by the HIV positive women as a reason for reluctance towards utilising healthcare services. This is worrying considering that there have been on-going health education messages about accepting HIV like any other chronic disease.

8.2.3 Theme 3: Silent voices about HIV disease

The third theme reveals the narrative intersections amongst the three groups of participants which show the lack of HIV disclosure by HIV positive women. Table 8.4 shows that all the three groups of participants indicated HIV non-disclosure as one factor that leads to PMTCT non-effectiveness. HIV positive women provided the reasons for such behaviour.

Table 8.4 Intersecting PMTCT narratives showing silent voice about HIV disease

HIV positive women	Grandmothers	Healthcare Providers
Intersecting narratives		
Non-HIV disclosure reasons • Compassion • Non-readiness • Stigma • Partner unknown status	Non-HIV disclosure	Non-HIV disclosure to grandmothers

Intersecting narratives between HIV positive women, HCPs and grandmothers also emerged on the issue of HIV disclosure, which is viewed as another root cause for the late antenatal care attendance. The results reveal a very interesting finding in that both the HCPs and the grandmothers suggested individual factors that cause HIV positive women to fail to adhere to the PMTCT services. In contrast, the HIV positive women reported the HCPs, the healthcare facility and the other individual factors as the root causes for their behaviour.

The data in Chapter Seven also showed that HIV non-disclosure is closely related to anticipated stigma, as already mentioned. The current study found that because of the HIV

non-disclosure, HIV treatment is taken under false pretenses to avoid stigma. One healthcare provider said:

> ***"…****when you arrive at the bus stop, you would often find empty containers of tablets [which belong to] people who are from the wellness [clinic] at this hospital. One day [i decided] to ask another sister [that i work with] as to why do people throw [away the medication]and she said they are exchanging their medication containers; they do not want people to know that they are taking these tablets…" (****female, 56 years, maternity manager****).*

It could be argued that this kind of behaviour not only puts partners at risk, but also family, for example, if there is an open wound as a result of injuries. It is unlikely that women would disclose their HIV positive status to their partner if they were pretending to take pain killers. This seems to be a perilous practice which denies the women family support in dealing with the HIV positive status. The findings suggest that this kind of behaviour is not sustainable and demonstrates that HIV stigma is still a huge challenge, which needs to be tackled at community and individual level. On the other hand for the HIV positive women, the reasons for HIV non-disclosure as stipulated in Chapter Five include: compassion for family, non-readiness, avoidance of stigma and not knowing partner's HIV status because of non-disclosure. The non-disclosure to family reflect that some HIV positive women did not want to disrupt their family (Medley et al. 2004) and that participants used avoidance goal (Chandoir, 2009; Chandoir & Fisher, 2010) especially when they were not anticipating support. The findings show that some women anticipated stigma, therefore, they remained silent about their status. This point is made by one pregnant woman who said "*she is not comfortable to disclose because people judge and therefore, she will remain silent*." On the grandmothers' side because of the lack of understanding of the HIV positive womens' non-disclosure reasons, they saw such behaviour as burdening them because of the pressure of caring for the sick mother and child and not wanting to be infected. PMTCT barriers are specific to different contexts and therefore it is crucial to understand them as the initial step of dealing with them (Thompson, 2012). These multiple realities provides an understanding of rural context which suggest a need for open communication at these three levels (service recipient, community and healthcare facility levels) in order for the PMTCT services to be fully utilised.

8.2.4 Theme 4: Intersecting PMTCT narratives showing fear of stigma and women disempowerment on infant feeding

The fourth theme reveals intersecting narratives amongst the three groups of participants about infant feeding perspectives. Table 8.5 below shows the infant feeding perspectives expressed by the three groups of participants. The HIV positive women focused on breastfeeding practises, mixed feeding practises, lack of trust in infant feeding messages, and formula feeding practises. The grandmothers shared their views on the promotion of mixed feeding, cultural beliefs that diverge from recommendations of the health system, transparency on infant feeding issues and infant feeding confusion. The HCPs raised the following areas of concern: mixed feeding, association of HIV with formula milk and milk shortages in the healthcare facilities.

Table 8.5 Infant feeding beliefs, observations and interpretations

HIV positive women	Grandmothers	Healthcare Providers
Intersecting narratives		
Mixed feeding practices	Promotion of mixed feeding	Mixed feeding practices
Breastfeeding promotion vs. coercion		Breastfeeding promotion
Association of formula milk with HIV		Association of formula milk with HIV
Varying narratives		
Lack of trust	Culture vs. health system	Milk shortages
	Transparency	
	Infant feeding confusion	

8.2.4.1 Mixed feeding practices and promotion

In this study, intersecting views about mixed feeding practices and perspectives were found amongst the three groups of participants. Although there were a few HIV positive women who indicated that they were exclusively breastfeeding, because of the knowledge of the benefits of breastfeeding, the most common infant feeding practice in this study was found to be mixed-feeding. The findings suggest that grandmothers in this study condoned the behaviour of mixed-feeding because of the belief that the child remains hungry if only receiving breast milk.

Because of the grandmothers' position within the family and the fact that they have been practicing mixed feeding for decades, condoning such behaviour seemed normal. The results show that the HIV positive adhered to the mixed feeding advises offered by the grandmothers without questioning it. Similarly, Doherty et al. (2006) and Thairu et al. (2005) found family pressure, fear of family rejection (Cames et al., 2010), and socio-cultural factors as reasons for mixed feeding. Bezner-Kerr et al. (2008) also found that because of the belief that the child is born with hunger, grandmothers give children water mixed with herbs to stop them from crying. Aubel (2012) found that grandmothers provide advice on infant feeding, including the introduction of solid foods.

The findings of the current study differ from those of Goga, Doherty, Jackson, Sanders, Colvin and Kuhn (2012) where better adherence to infant feeding practices among the HIV positive women compared to HIV negative women was noted. Both grandmothers and HIV positive mothers in the current study feared the concept of having a hungry, crying baby because of the lack of solid foods. Unlike other studies which have not described how the process of mixed feeding is handled, the two groups (HIV positive women and grandmothers) of participants in this study confirmed the dual practices engaged in during infant feeding. For instance when the mothers are at the healthcare facility, they practice breastfeeding and when at home, the mixed feeding behaviour resumes. The findings for this study reveal the differences of women's status/positions within a household. For instance, the infant feeding decisions are dominated by grandmothers because they occupy higher positions in a home. Whereas the younger women because they occupy lower positions in society and at household level, they are unable to adhere to the recommended infant feeding methods. One study indicates that women would choose to adhere to paternal grandmothers' advise on infant feeding instead of adhering to HCPs advises (Bezner-Kerr et al., 2008). This is a sign of women disempowerment (Besser, 2010a; Besser 2010b) in relation to infant feeding which is bound by a system which seems to be difficult to change through the normal PMTCT campaigns.

Mixed feeding in this study was also reported to result from the use of traditional medicines for the infants' fontanel and for strengthening the baby's navel. Similarly, Sibeko et al. (2005) found that traditional medicines such as '*muthi*' were used from one month of birth. The HCPs in the current study also confirmed the finding that mixed feeding is engaged in to curb the child's hunger and relieve the family pressures to do so. This study found that both the HIV

positive women and grandmothers were adamant that mixed feeding is part of their culture and that they have always practiced it.

It is interesting to note that the grandmothers did not seem to wish to keep the practice of mixed feeding a secret, as they seemed to show a desire for partnership with healthcare workers to promote appropriate mixed feeding habits. This is a reflection of the superior position occupied by grandmothers when it comes to infant feeding. The grandmothers compared the infant feeding habits in their times to current practices and indicated that there is confusion about the length of time for which infants should receive exclusive feeds only. For both the HIV positive women and the grandmothers, mixed feeding was not a practice associated with fear or concern. In fact, the fear of the child's hunger and crying was a greater concern for them. This suggests a lack of knowledge on the dangers of mixed feeding by both the grandmothers and the HIV positive women. It also shows that in the context of PMTCT, how reality is constructed could have a negative effect on the programme. Burr (1995) suggests that the way in which the world is understood, it is mostly embedded in the history and culture. The mixed feeding habits and support of this practice in this study stems from the historical belief and cultural practice of infant feeding. It is for this reason that mixed feeding is seen as the one true reality. It is promoted by the social processes, interactions and communication that occur around it. Infant feeding practices seem to be informed by grandmothers' previous infant feeding experiences. Mixed feeding, is a shared reality amongst community members. This needs to be addressed as a matter of importance.

This finding suggest that the knowledge about recommended infant feeding procedures exists, however, it is outweighed by the traditional and cultural beliefs related to infant feeding. The excerpt hereunder supports this argument:

> "*We do not like the issue that the child is supposed to eat [solids] when he/she is 6 months [old]. [This is] because the child will keep on crying due to not being full. When the child is 3 weeks old he/she must start eating porridge so that it can stay for longer in the tummy" (**FGD1, grandmother 2, 40years**).*

The current study suggests that the traditional infant feeding practices inhibit the PMTCT programme mandate of preventing children from being infected with HIV. The on-going mixed feeding practices noted in numerous studies, suggest that the current infant feeding

messages are known but not clear to the society at large. Furthermore, the infant feeding messages might not be reaching the relevant people who actually practise or influence mixed feeding. Even though grandmothers have been shown to play a significant role in caring for grandchildren, (Penn et al., 2010; Barrett, 2008; Bezner-Kerr et al., 2008; Mumtaz & Salway, 2007; Aubel et al., 2006, Barrat & Penn, 2009), the current study also portrays them as obstacles to the recommended infant feeding procedures. Falnes et al. (2011) also identified grandmothers as barriers to appropriate infant feeding.

This finding is worrying considering that the grandmothers alluded to the fact that their children and grandchildren do not disclose their positive HIV status, and yet the practice of mixed feeding prevails. The findings suggest that grandmothers lack information about infant feeding (Petrovic et al. (2009), and if they have the knowledge, traditional infant feeding practices seem to be clouding their understanding of the matter. These findings call for powerful interventions that would focus on changing the system that has existed for decades which places grandmothers as superiors of infant feeding. Such system should encourage grandmothers to change their mindset on the practice of mixed feeding.

8.2.4.2 Breastfeeding promotion and poor policy change communication

Some of the HIV positive women, grandmothers and the HCPs raised a similar recommendation of enforcing breastfeeding as the best method for infant feeding. Due to the lack of explanation from the HCPs about the reasons for the promotion of breastfeeding, some HIV positive women reported that they felt coerced into exclusive breastfeeding. This suggests the existence of poor communication between the HCPs and the HIV positive women related to critical messages on infant feeding that are in line with policy changes (WHO, 2010). In the study by Sibeko et al. (2009), most women indicated that HCPs influenced their choice of infant feeding. The current study suggests the HCPs' limited communication to HIV positive women about the new infant feeding policy change that encourages breastfeeding for all, could be a contributing factor to stigma amongst HIV positive women and in the community at large. On the other hand, grandmothers' support of breastfeeding was not done exclusively. Because of the promotion of breastfeeding by HCPs, the HIV positive women who opted to feed with formula milk were reported to have been chased away from the healthcare facility premises when they wanted to feed their children. Ijumba et al. (2013) similarly found that community members were not knowledgeable about the reasons for the free formula milk (FFM)

discontinuation, suggesting limited communication about policy change issues at the community level. The current study found that HIV positive individuals stigmatise each other especially when an individual is known to formula feed, because of the promotion of breastfeeding. This finding suggests that in order to avoid stigmatisation related to choice of feeding amongst HIV positive women, effective communication about infant feeding guidelines is vital at a societal and individual level. At the same time, the lack of communication about policy change on infant feeding, and discontinuation of the FFM might have resulted from the HCPs' lack of knowledge about these changes at the time of the study. This also has implications for the government in terms of policy change communication in rural healthcare facilities.

The current findings therefore suggest that the coercion of the HIV positive women into selecting a particular feeding method without communicating that policy changes encourages their lack of interest in healthcare services and in the messages of the HCPs, as already discussed in earlier section of this Chapter and Chapter Five. It could also be argued that the act of chasing away the HIV positive women from the healthcare facility when formula feeding might exacerbate fear of HCPs in a rural context. Although the recommendation of exclusive breastfeeding for all would reduce the stigmatisation of HIV positive women by the community, multiple questions continue to arise. What happened to the HIV positive women who chose to formula feed before FFM was discontinued? How were their children fed if they relied on receiving FFM free from the healthcare facility? Did they start mixed feeds? If they did not disclose their status, did they get family support to continue with formula milk feeding? Another question raised by the fact that one group of women appeared to not trust PMTCT messages related to infant feeding. Such group would normally opt for formula milk feeding, therefore, how were their children fed? Did they opt for mixed feeding? This array of questions highlights the impact of FFM discontinuation, even though in the end it is beneficial to the newborn baby.

8.2.4.3 Formula milk feeding practices and associated challenges

Another intersecting narrative was found from both the HIV positive women and the HCPs who indicated that FFM is associated with HIV. Thairu et al. (2005) also noted the stigmatising association of HIV with formula feeding. Unlike Thairu's study which only identified the social stigma directed at HIV positive women, the current study has revealed

HCPs intervention attempts to reduce social stigma. For instance, the HCPs assisted women in changing the milk packaging to avoid questions from the community and family members. Although this practice was reportedly done to protect the mothers, it could be argued that the HCPs were promoting HIV non- disclosure. The people in the community constructed the knowledge of linking HIV with FFM. Simon (1996) writes that meanings are constructed based on experience. This suggests that the linking of FFM with HIV is based on an individual experience which was shared by many (Denzin & Lincoln, 1994). This implies that infant feeding messages are not comprehended at a community level, as the reasons for not breastfeeding may involve factors unrelated to HIV, such as lactation difficulties or mastitis etc. This highlights the importance of comprehensive infant feeding education which addresses infant feeding issues at all levels, including issues that are specific to this rural context.

8.2.4.4 Lack of trust in PMTCT interventions

Another interesting finding revealed by the HIV positive women was the lack of trust in the infant feeding messages which emphasise exclusive breastfeeding. The lack of trust explains why women continue to mixed feed, even though they are told about the importance of avoiding this practice. This suggests that HIV positive women lack knowledge of the PMTCT programme messages, particularly those messages related to infant feeding. The lack of trust could also be due to fear of infecting the child with HIV through breastfeeding. A lack of trust in the PMTCT programme may be attributed to maternal age and economic factors. If a woman is young and working, for example, formula milk feeding might appear to be the best option. The lack of understanding of the PMTCT programme and the absence of disclosure of HIV status may also heighten such fear.

8.2.5 Theme 5: Intersecting PMTCT narratives showing health services stigma and cultural stereo types affecting male involvement on PMTCT

The fifth theme reveals intersecting narratives related to male involvement in the PMTCT programme provided by the three groups of participants. Figure 8.1 shows similar opinions by the three groups of participants about the challenges related to male non-involvement.

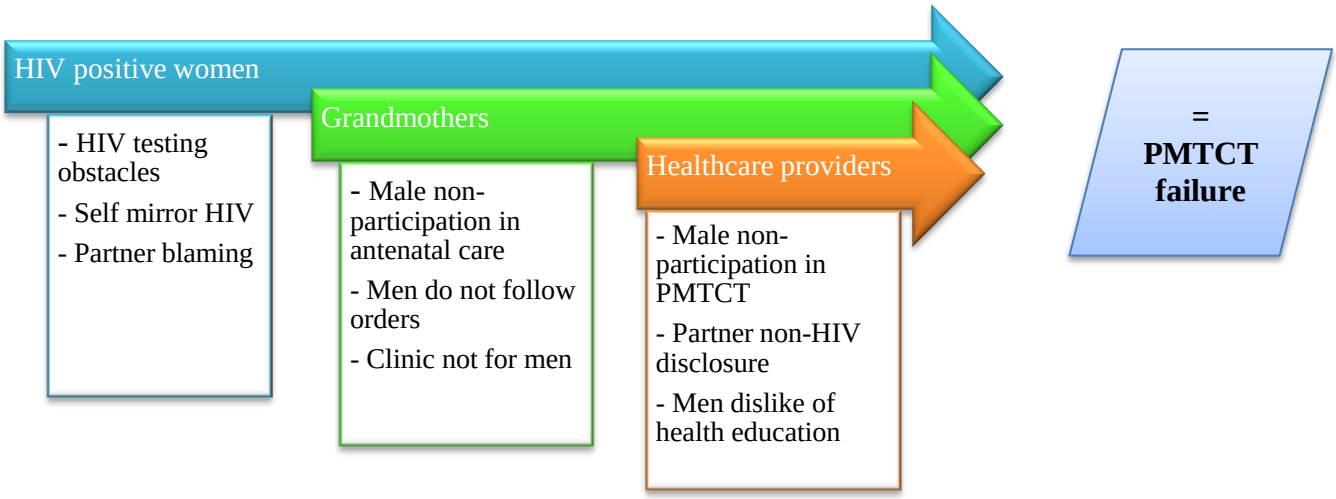


Figure 8.1 Intersecting narratives on PMTCT male non-involvement

For the current study, male non-involvement in the PMTCT cascade processes was found to be a cross-cutting issue, mentioned by the three groups of participants. Varying reasons based on the participants' experiences were given as to why men do not want to be involved in any healthcare services, including the PMTCT programme. A single intersecting narrative which was reported to influence all the other factors was the belief that 'men do not like going to the healthcare facility' in general. This suggests a lack of interest in the healthcare facility, as was noted to be the case with some of the HIV positive women. This behaviour was emphasised by the HCPs who indicated that men do not want to be part of antenatal care regardless of the efforts made to involve them. For example, there was an intervention whereby women were told to invite their partners to the healthcare facility to attend antenatal care services, and were given written invitations to take home. However, men did not respond positively. Again, as part of mother-friendly services, men were invited to be present at child-birth, but still they did not attend. The reason why such interventions failed might relate to the stubbornness and community ignorance that was discussed earlier in this Chapter. Such stubbornness is shown by the grandmothers' belief that despite anything that could be done, a healthcare facility is not a place for men. Similarly, other studies have also noted the belief that antenatal care is a woman's issue (Mbonye et al., 2010). Unlike Mohlala et al. (2011), who indicated that facilitators of male involvement include sending letters to male partners, the findings for the current study showed that such initiatives were not effective in this study setting, as suggested by the HCPs.

The HIV positive women shared some of the reasons given by men for not wanting to test for HIV, such as drinking tea from church, inference of HIV status based on that of the partner, the belief that HIV tests lie and the perception that HIV tests cause AIDS. These reasons reflect the multiple realities that men have constructed around HIV testing. Their beliefs seem to reflect the cultural traditions of how men respond to health issues. The reasons given also reflect fearful thoughts associated with HIV testing. Considering the multitude of campaigns that are provided through the media and within communities, it could be argued that hiding behind religious beliefs poses a great threat to the women, because they are most likely to continue engaging in risky sexual behaviour because their male partners do not know their status. It was also suggested that men do not want to participate in the PMTCT programme because of the self-perception of good health (Kizito et al., 2008). Such self-perceptions might affect women's decision making, regarding the utilisation of the PMTCT services.

Another reason expressed for not testing was that men infer their own HIV status from that of their female partner. Similarly, other studies found that if the female partner is HIV positive, the male partner assumes to have the same HIV status (Rujumba, et al., 2012a; Mbonye et al., 2010; Parker, 2012). The current study also suggests that men did not like to test because they believed that the test lies or the test infects them with HIV. These misconceptions might seriously inhibit the utilisation of PMTCT services, because it suggests that HIV is acquired by HIV testing. This is contradictory to the main messages about HIV testing, which relates to reducing the HIV pandemic in the country. This indicates that HIV testing messages should be tailored according to the cultural and community beliefs in different settings. This finding also suggested that the existence of multiple truths might be harmful, especially if the truths endorse not testing for HIV.

In a similar vein, the HCPs expressed that men dislike health education. The findings indicate that this behaviour is mostly influenced by the way in which men are culturally perceived by women in the study setting. The men's dislike of HIV education could be attributed to their traditional gender roles which do not encourage them to attend healthcare facilities (Nkuoh, et al, 2010; Reece et al., 2010; Theuring, 2009). The men's realities revolve around providing for their families, and not around seeking medical help. The HCPs also emphasised that men do not share their HIV status after testing. This may be due to the social construction of HIV. The underlying cause of male non-involvement in PMTCT might be the fear of HIV testing. The report that men infer their own HIV status from their partner's status, believe that HIV

tests are inaccurate and infect them with HIV clearly suggests a fear of HIV testing and that of the healthcare facility. The findings demonstrate that the men's construction of negative meaning associated with HIV testing is a reality shared by many people. The lack of interest in PMTCT participation by men could be due to socio-economic factors, healthcare system barriers and poor communication between men and women (Ditekemena et al., 2012). This seems to suggest that interventions aimed at involving males in the PMTCT programme should address a variety of factors, such as low socio-economic status, healthcare system barriers and non-peer sensitisation activities. The traditional beliefs related to male participation in health programmes needs to be addressed at a policy level.

8.2.6 Theme 6: Intersecting PMTCT narratives showing structural violence, tradition and healthcare system as PMTCT blockages

The sixth theme refers to the narrative intersections concerning the PMTCT barriers which fall within and beyond the healthcare system. As reflected in Table 8.6 below these narrative intersections are mostly governed by the cultural and socio-economic barriers. These barriers provide a foundation for understanding the crux of the non-utilisation of the PMTCT services by the women in the area of study.

Table 8.6 PMTCT barriers beyond and within the healthcare system

HIV positive women	Grandmothers	Healthcare providers
Intersecting narratives		
Transactional sex and teenage pregnancy	Teenage pregnancy and early sexual debut	Teenage pregnancy
Beliefs on traditional & religious treatments	Beliefs on traditional & religious treatments	Beliefs on traditional treatments
	HIV orphans	HIV disease burden (orphans)
PMTCT language challenges	PMTCT language challenges	PMTCT language challenges
Varying narratives		
Community ignorance and uncertainty	Drugs & alcohol use	Lack of schooling
HIV misconceptions	Crime and parental stress	Unemployment
	Parental non-unity	

8.2.6.1 Early sexual debut, teenage pregnancy and transactional sexual relationships

The first intersecting narratives showed teenage pregnancy, early sexual debut and transactional sexual relationships by young girls as socio-economic factors which contributed to the non-effectiveness of the PMTCT programme. The findings showed varying views and interpretations for such behaviour. From the grandmother's point of view, teenage pregnancy and early sexual debut is believed to be brought about by the provision of social grants by the government. According to the HCPs, teenage pregnancy is caused by the lack of schooling and unemployment, whilst for the HIV positive women, transactional sexual relationships are caused by the lack of provision of living materials (such as clothes) by the parents for the young girls. For the HIV positive women, teenage pregnancy seems to be influenced by a need to improve one's self-esteem in order to fit well amongst the peers (Jewkes, Dunkle, Nduna & Shai, 2012). Although put differently by the three groups of the participants, the findings show that the young girls in the community indulge in early sexual activities in an attempt to boost their socio-economic status. The statement made by grandmothers in Chapter Six about boyfriends accompanying their young girl friends to receive childcare grants, seems surprising considering that the very same partners were reported to be reluctant to accompany their female partners to health facilities for the antenatal care services. As indicated in Chapter Five, Six and Seven these boyfriend, seem to avail themselves when it comes to money issues. It could be argued that due to the poor socio-economic situation in the area of study, money matters gain importance over health-seeking practices. It could also be argued that young women allow the men to accompany them to get grants, in order to continue having children with them, whilst at the same time they continue receiving money. This suggestion is supported by the excerpt below:

> "*You should see the fathers of their children at the pensioners/grants pay point; you will find them waiting outside for their little women when they get [child grants] money…" (**FGD2, grandmother 4, 61 years**).*

This study also showed that gender relationships play an important role towards improving the poor socio-economic status of women in the study setting. For instance, the young women yearn to live an extravagant lifestyle, because they feel that parents do not support their lifestyle desires. The excerpt below provides a scenario of how improving ones socio-economic status can lead to HIV infection.

> *"…her mother buys poor quality clothes…older people [men] will buy clothes for her and then she [has] contracted the disease…" (**Pregnant woman on AZT, 30years, single, 1 child)*.

It could be argued that such behaviour is mostly influenced by the social relationships (societal) that young people have. For instance, Burr (1995) indicates that the social relationships that individuals have, shape the reality of how they view certain aspects in life. The narrative intersections show that young people considered being pregnant or having a partner who is older as methods of improving their socio-economic status, hence the high rate of teenage pregnancy and early sexual debut in the area of study. Another factor contributing towards the poor socio-economic conditions was found to be the lack of education and unemployment. Chapter Six also conveyed the issue of learners giving birth at school. This finding suggests that learners are not aware of PMTCT messages. This is most likely because teachers are not exposed to PMTCT training and therefore find it difficult to address learners' sexual challenges at school. For the PMTCT programme to be effective, it is imperative to strengthen the communication channels between parents and teachers, as the current study reveal a high prevalence of teenage pregnancy. This also calls for interventions to deal will gender relation issues to encourage further success of the PMTCT programme.

The findings suggest that unemployment and the lack of education as causes of HIV prevalence is a cause for concern. This explains why certain interventions which did not consider socio-economic status have not been successful in reducing the HIV prevalence. Unlike the study by Squire (2007), which found that burdensome responsibilities prevented women from obtaining education and employment, this study found that poor socio-economic conditions form the causal factors. This study found that poor socio-economic status increases the women's vulnerability to HIV infection (Kako et al., 2012). It seems that a lack of "sufficient resources" needed to maintain a minimum standard of living, forces women in the study area to depend on men for daily survival (May, 2000, p. 5). These findings suggest that the survival strategy of young women in the rural communities, puts them at risk of HIV infection (van Donk, 2002; Farmer et al., 1996). PMTCT interventions should take this into consideration, as one may infer that poverty places women at risk of HIV infection. This inference suggests that the PMTCT programme is affected negatively by structural violence barriers which are inescapable for many women living in rural areas. Even in the midst of HIV/AIDS campaigns

the behaviour of the youth does not seem to be changing (USAIDS, 2005) because of the structural barriers imposed by poverty. It is for this reasons that until such barriers are addressed, the HIV prevalence might continue rising and PMTCT utilization might continue to be poor.

8.2.6.2 Community ignorance, uncertainty and HIV misconceptions

The findings demonstrate another view raised by the HIV positive women which suggest that community ignorance, uncertainty on health matters and HIV misconceptions as contributing factors towards early sexual debut, teenage pregnancy and substance abuse (drugs and alcohol use). For the HIV positive women, community ignorance on health issues, and HIV misconceptions are the key societal barriers affecting the utilisation of the PMTCT services. As already discussed in Chapter Seven, ignorance is also demonstrated by older women in the area of study who engage in sexual activities without testing for HIV first. HIV testing prior to having sex could reduce the spread of HIV among the youth. Hence, this calls for a combination of community oriented interventions to address societal barriers, which may lower vertical HIV transmission, such as HIV testing interventions (Marcos et al., 2012). It is for this reason that a change is needed. This change could be brought about by changing the traditional ways of constructing PMTCT messages.

Community stubbornness related to health matters was also noted as another issue which might affect the PMTCT programme. This is demonstrated by one of the participants who said *"the community is very stubborn, I am not sure how to think of them…things have changed."* Community stubbornness seems to suggest that the community has certain ways of constructing the realities of dealing with health issues. Hence, this study suggests that people in the community construct their own versions of reality (Burr, 1995) and insist on these when it comes to health and specifically on PMTCT issues. This implies that even when PMTCT messages are stated, in this study setting, people rely and insist on their beliefs. Their stubbornness might be due to the lack of understanding of the PMTCT messages, because of their clinging onto existing beliefs. The above excerpt illustrates that this participant believed that we are living in times where diseases like HIV exist, and thus the behaviour needs to change. Although the terms "ignorance and stubbornness" differ in explanation, the current study shows that because of the stubbornness and the persistence in clinging onto old ways of living (multiple partners, no HIV testing, poor healthcare utilisation), PMTCT messages are ignored by the community.

At the same time, from the HIV positive women's perspective, community ignorance related to health messages leads them to have misconceptions about HIV and develop stigma towards people living with HIV. Examples of some of the misconceptions stated by the HIV positive women include the perception that HIV affects certain people and the belief that they are bewitched. This belief is attached to cultural constructions of sickness, which are spread through social interactions within the community. This also reflects the shared reality among community members, related to health issues. Citing witchcraft as a possible cause for HIV infection demonstrates community ignorance related to the HIV messages that have been shared for many years by activists. This finding thus questions the content of the current PMTCT and HIV messages that are given to the community.

One could argue that the way in which HIV positive women describe their community's behaviour is the result of the interactions and relationships they have with each other (Gergen, 2009). Community ignorance thus seems to be one of the key barriers to the utilisation of the PMTCT services. This finding suggests that PMTCT messages have not been well comprehended by the people in the resource-poor settings such as the Dr JS Moroka sub-district. Community ignorance might be detrimental, because it suggests that interventions to elicit change in sexual behaviour will not be successful until people come to realise the important of such interventions. As pointed out by another participant earlier, this finding suggests that women will not adhere to PMTCT as long as they are not infected by HIV. Community ignorance could also be due to the lack of trust in the PMTCT programme. Since individuals generally do not ignore messages alone, it could be argued that the social network barriers contribute to ignoring of such messages (Thorsen et al, 2008; Kebaabetswe, 2007). Hence, alongside the fear of healthcare facilities and HCPs, community ignorance which is fuelled by social networks, was also found to be one of the contributing factors to poor utilisation of the PMTCT services.

This is worrying considering that Mpumalanga Province has a high HIV prevalence compared to most other South African provinces (South African Department of Health, 2012) as shown in Chapter Two. The beliefs and behaviours related to health seem to stem from cultural and individual experiences. It could thus be argued that culture forms one of the factors that influences human thinking (Somma & Bodiang, 2003). Studies have shown that HIV positive women are generally reluctant to practice any behaviour which is outside of their cultural

terrain (Buskens, Jaffe & Mkatshwa, 2007; Eide et al., 2006). The current findings, therefore, suggest that cultural beliefs coupled with human experiences affect the utilisation of PMTCT services. The members of the community where the study participants reside, appear to fail to see the seriousness of HIV and its negative impact on their lives and children's.

8.2.6.3 Usage of drugs and alcohol

Another different view raised by the grandmothers related to substance abuse by male youth and its repercussions. This highlights intersecting narratives on PMTCT barriers beyond the healthcare facility which were already discussed. Grandmothers insistently mentioned that the youth usage of drugs and alcohol culminates into advice ignorance from them and HCPs. From the grandmothers' point of view, the use of drugs and alcohol are a societal problem which affects the utilisation of healthcare services, including the PMTCT programme. In this study context, it could be argued that the irresponsible behaviour expressed by the grandmothers, also reflects the impact of poverty in rural areas. The young people abuse alcohol and subsequently, ignore grandmothers' and HCPs advises on health issues. It is suggested that these young people try to escape poverty by abusing drugs and alcohol. It could thus be argued that such behaviour demonstrates the negative consequences of the low socio-economic status in the area of study. The current study revealed multiple realities which involve acting in certain ways (including healthcare utilisation) to improve the socio-economic situation.

This finding suggests that for the PMTCT programme to be effective in the rural areas of Mpumalanga, community barriers need to be carefully considered. The behaviour practiced by the youth in the area of study highlights poverty as an inhibiting factor. The factors mentioned are all markers of poverty: alcohol use, drug use, being primary school child, unemployed and the provision of financial support by older people. How people act in response to poverty is influenced by their environmental context (Francis, 2006). Therefore, because of the poor environmental arrangements in which young boys find themselves in, they resort to other ways of escaping poverty which place other people at risk of contracting HIV (Farmer et al., 1996). The behaviour of stealing reflects the need to boost their own socio-economic status and the act of rape demonstrates misconceptions about HIV. It is believed that HIV misconceptions, community ignorance and fear of poor socio-economic status cause fear of the utilisation of the healthcare services.

The results suggest that poverty as an obstacle to development should be removed (Sen, 1999). Poverty has negative consequences for grandmothers (Squire, 2007) who are already burdened by caring for their grandchildren. This suggests that PMTCT interventions should focus on context specific barriers (Busza et al., 2012), whereby obstacles such as poverty are considered in ensuring the effectiveness of the programme. This further suggests that for the PMTCT programme to be effective, a holistic approach is needed to tackle the PMTCT barriers according to that particular societal context.

8.2.6.4 Beliefs in traditional and religious treatments

Additional intersecting narratives were expressed by the HCPs and grandmothers on the issue of beliefs in traditional and religious treatments. This study reveals that the belief in two systems (traditional and religious) seems to cause a dismissal of the use of healthcare system. One grandmother explained this as shown by the excerpt below.

> "*You find at home we have been given these things [treatment from clinic], but people stop using them and go to the traditional healers who uses "ditaola" [bones for diagnosing the ailments] and church treatments…" (**FGD3, grandmother 5, 56years)***.

The utilization of PMTCT services is sometimes clouded by the use of traditional and religious treatments. Believing in these treatments seems to cause women to ignore health messages provided by the HCPs. For instance, the excerpt below provided by a HCP shows some of the practices which cause women to ignore HCPs' messages.

> *"during antenatal care, we educate them that they should not apply anything to the baby's umbilicus/navel, [however], we educate them today [but] tomorrow when she comes for postnatal care, she comes having applied mouse faeces/ excretion on the [baby's] umbilicus"(**female, 51 years, professional nurse).***

This point suggests a high preference for the traditional system over the healthcare system. Once could argue that such treatment misconceptions and non-adherence is mostly influenced by the individual, societal and cultural factors. The individual factors indicated in Chapter Six

(such as treatment side effects and the belief that treatment is made from the human brain) suggest the lack of knowledge on the impact of treatment. As such, the continual use of traditional and religious medications could impact negatively on the PMTCT programme. This is because the findings seem to suggest that the stubbornness related to health beliefs seems to blur the health messages shared by HCPs in this context. One could argue that another factor that contributes to the ignoring of health messages, including PMTCT, is the existence of strong beliefs in traditional and religious treatments. This suggests that PMTCT interventions should address such beliefs. At the same time, the current findings add to literature which suggests that the misconceptions about the HIV treatment might cause a lack of adherence to medical treatment.

8.2.6.5 PMTCT language barriers

Additional intersecting narratives expressed by grandmothers and HIV positive women were on PMTCT language barriers. For both of them, the PMTCT language challenges were expressed in terms of grandmothers 'low literacy level which makes it difficult for them to comprehend PMTCT terminology and PMTCT processes. Other HIV positive women highlighted that they are not really interested in knowing PMTCT terminology but that they are more concerned with the baby's well-being. The lack of grandmothers' literacy points to a need for the development of PMTCT programme messages that are context specific and caters for the relevant literacy levels of the people in the community. The findings for the current study points that a one size fits all approach for delivering PMTCT messages leads to actions that affects the effectiveness of the PMTCT programme such as mixed feeding practices. Interesting in this study is that although the interest is on the baby's well-being, there is less concerns about PMTCT terminology. It could be argued that the comprehension of PMTCT terminology has the potential to increase the understanding of PMTCT processes that facilitates the baby's well-being. PMTCT campaigns to take note of this.

8.2.7 Theme 7: Intersecting PMTCT narratives showing enhancement of PMTCT programme through health education, community participation, individual and health system change

The seventh theme relates to PMTCT solutions proposed by the three groups of participants to facilitate an effective PMTCT programme. Table 8.7 below shows that HIV positive women

indicated HIV education, community mobilisation, PMTCT language simplification, individual changes and health system changes as key solutions. For the grandmothers, the following were seen as key solutions: HIV education on prevention strategies and male involvement strategies, HIV disclosure, forceful antenatal care and grandmothers' involvement, PMTCT language simplification, health systems improvement. Lastly the HCPs proposed the following key solutions: health education and community involvement, PMTCT language improvement, health system and structural changes and further capacity building for HCPs on the PMTCT programme.

Table 8.7 Suggested ways of enhancing PMTCT programme and factors facilitating PMTCT processes adherence

Suggested ways of enhancing PMTCT programme and factors facilitating PMTCT processes adherence		
HIV positive women	**Grandmothers**	**Healthcare providers**
	Intersecting narratives	
HIV education and Community mobilisation	HIV education on reduction strategies and improvement of male involvement strategies	Health education and community involvement
Comprehension of PMTCT language	PMTCT language simplification	PMTCT language improvement
Health systems changes (High compassion and non-judgmental by HCPs, good reception)	Health systems improvement	Health systems and structural change (supermarket service provision; data recording)
Peer counsellor participation in PMTCT		Peer counsellor participation in PMTCT
	Varying narratives	
Individual changes (self- drive and knowledge of HIV status)	HIV disclosure	On-going capacity building for PMTCT HCPs
	Forceful antenatal care & grandmother involvement	
	Prayer	

The results in Table 8.7 demonstrate narrative intersections regarding proposed PMTCT programme solutions raised by the three groups of participants (HIV positive women, grandmothers and the HCPs). These include HIV education and community involvement, (which seems adequate to address psychosocial factors such as fear and confusion, especially related to infant feeding), antenatal care attendance, HIV testing, HIV prevention strategies and solutions to societal barriers including challenges of men's involvement on the PMTCT programme. The proposed strategies (education and community mobilisation) could greatly

enhance the PMTCT knowledge of the community members, if the identified societal and individual barriers are addressed. There seems to be a need to address the social constructions of HIV and PMTCT as part of education provision. Such education provision might also assist in keeping the HCPs informed of new PMTCT information. Another intersecting narrative existed between the HIV positive women and the HCPs, on the involvement of peer counsellors in the PMTCT programme. Most HIV positive women endorsed the work by peer counsellors especially because they were experiencing a similar situation, their involvement could create increased adherence to PMTCT processes. The education and community mobilisation related to PMTCT services is in line with the goals of the South African National Strategic plan which indicates a need to reduce the rate of new HIV infections by 50% in 2016 and reduce new HIV infections by 90% by the year 2016. This calls for an intense review of the current community mobilisation strategies, especially in rural South African settings such as the Dr JS Moroka sub-district in Mpumalanga Province. Such a campaign would assist in changing some of the cultural and societal beliefs about HIV and living with the disease. It would also demystify some of the misconceptions of grandmothers, including that they cannot be infected with HIV because of their age.

Additional narrative intersections were also found between the three groups of participants which reflect the following key solutions to facilitate PMTCT programme improvement: PMTCT language improvement, health system and structural changes. The proposed solutions suggest that PMTCT language needs to be simplified in order to be fully understood by everyone. The health systems changes would include grandmother involvement in the PMTCT programme to ensure forceful antenatal care attendance, centralising the ARV treatment administration system, providing transport for elderly people to attend clinic services, longer hours of operation and structural improvement. These changes would involve improved infrastructure, which is PMTCT user friendly. The findings of this study suggest that grandmothers are eager to be part of the PMTCT programme and also to enforce antenatal care attendance. Therefore, educating grandmothers would enable them to provide appropriate guidance to their pregnant children and grandchildren. Their silence in the discussion of mixed feeding was interesting, as they seem very passionate about it. None of the three groups of participants indicated a need for change in infant feeding practices. This suggests that the best-known method, mixed feeding, is deeply rooted in participant behaviour. Participants also proposed the improvement of HIV risk reduction strategies and male involvement strategies. Grandmothers also believed that although not a panacea or solution, HIV disclosure is

necessary for the PMTCT programme to be effective. Having self-love was also seen as another necessary individual trait that could encourage adherence to PMTCT processes. Self-love might be demonstrated by taking the first step, which is HIV testing. This study showed that individual factors are also critical for the success of the PMTCT programme. Personality and belief change, including the development of self-love could be a strong tool for the PMTCT programme, because it might reduce the sole reliance on societal, religious and cultural beliefs when it comes to seeking treatment and healthcare.

All of the PMTCT solutions proposed by the three groups of participants suggest the need for a collaborative effort from the women who are HIV positive, grandmothers, the community (including men), HCPs and the government (in terms of resources), in order for the PMTCT programme to be effective. This collaborative team effort would assist in combating the fear and stigma that inhibit an effective PMTCT programme.

8.3 Conclusion

This Chapter discussed the six dominant themes that are emerged from the three Chapters (chapters five, six, and seven) of data analysis. It identified the intersecting and varying narratives indicated about the factors that inhibit the proper functioning of the PMTCT programme. The key themes that dominated the current study revolved around PMTCT barriers (individual, personal, societal, structural and cultural) that are hindering the effectiveness of the programme, and possible solutions to these barriers, including the facilitators of PMTCT adherence. For the HIV positive women, the barriers mentioned showed their lived experiences of being a part of the healthcare system previously and the negative societal influences that exist with regard to health-seeking behaviour. This Chapter also outlined the various views related to infant feeding and highlighted that the grandmothers condoned mixed feeding. Although this was the case, grandmothers were fearful of the HIV burden. The HCPs reported that they observed mixed feeding habits by both the HIV positive women and grandmothers, and advocated for change. The findings of this study further suggested that HCPs need assistance with regard to formulating and implementing male involvement strategies, context specific infant feeding guidelines to reduce mixed feeding and general PMTCT guidance.

CHAPTER 9
SMALL STORY ANALYSIS: UNDERSTANDING THE CONTEXT OF PMTCT NARRATIVES

9.1 Introduction

Departing from the thematic analysis, which provided a general understanding of the construction of triangulated thematic issues, this Chapter (the fourth pertaining to data analysis) focuses on the analysis of small stories. As discussed in Chapter Four, small story analysis is a data analysis framework used to examine narrative structure differently, by allowing the inclusion of some of the underrepresented stories within the analysis of narrative research. Hence, this Chapter presents the analysis of small stories that do not embody a conventional narrative structure which generally comprises of a beginning, middle and an end. This Chapter brings attention to the hidden small stories that formed part of the interview data that were collected in this study. Unlike thematic analysis, small story analysis focuses mainly on how a story is told as opposed to the themes within the small story. The use of small story analysis provides an opportunity to identify and explore the context in which the narratives are told. In the context of this study, it provides a unique way of unpacking and analysing the lived experiences, which could not be achieved via thematic analysis or any other data analysis method.

In the current study, one small story from each of the three groups of participants (HIV positive women, grandmothers, HCPs) was selected for analysis. The stories were chosen according to Georgakopoulou's (2007) four types of small stories. As discussed in Chapter Four, the selected small story excerpts were analysed according to three different levels. Firstly, the small stories were analysed according to the four types of small stories (stories to be told, breaking news stories, future projections of storytelling and shared stories) introduced by Georgakopoulou (2007). In addition to the four types of small stories given by Georgakopoulou, the data that emerged in the current study also generated supplementary small story types and sub-types. For instance, one broad category called PMTCT affective small stories was developed and it included the following two sub-types (motivational/ inspirational and lived experience small stories). Furthermore, one broad category for shared

story sub-types was developed and it included the following: shared stories on treatment adherence, shared stories on conditional HIV disclosure and shared stories on antenatal care practices. These small stories are discussed later in this Chapter, together with those introduced by Georgakopoulou (2007). Secondly, small story analysis was done by focusing on the positioning levels, which examined how characters and the speaker were positioned within an interactive situation. Of equal importance was the examination of how the speaker positioned her sense of self in relation to the dominant discourses. Lastly, small story analysis involved focusing at small story compositions, which concentrates on the way in which the story was told, sites of the story (places where the stories took place) and tellers of the story. The subsequent sections focus on the three levels of analysis by small story type, positioning levels and small story compositions. Figure 9.1 below shows the small story types described by Georgakopoulou.

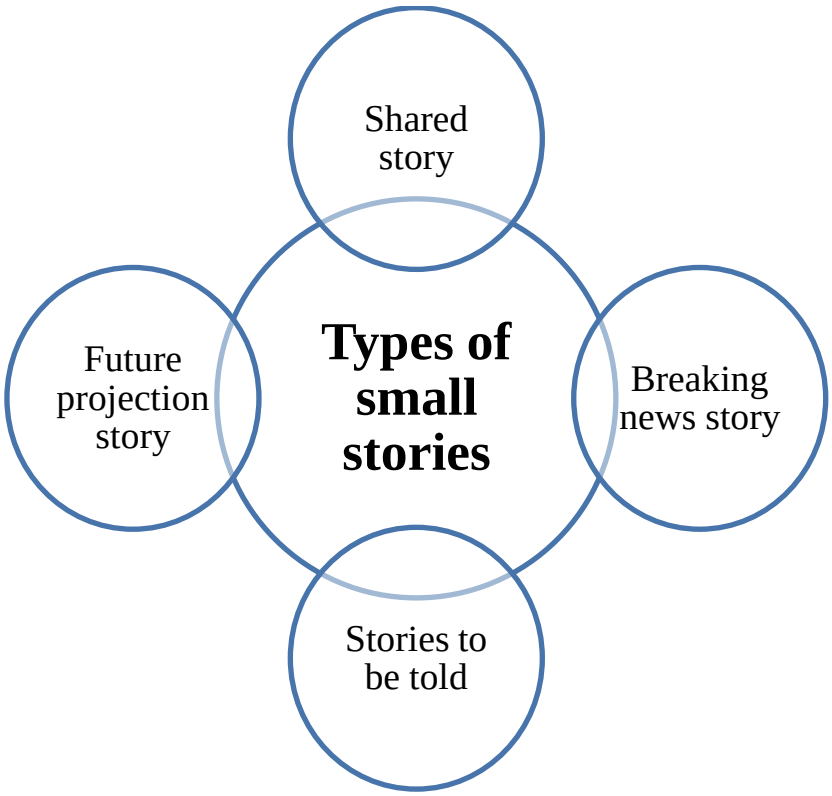


Figure 9.1 Small story types

9.2 Small story analysis by story type, positioning levels and compositions

9.2.1 Breaking news small story analysis: *"My family is supporting me, they show me love."*

Excerpt 9.2.1 below is an example of a 'breaking news' story-type one, showing the events that were shared straight away or as they were unfolding (Georgakopoulou, 2007). In this context,

the breaking news of the small story was related to HIV disclosure by one of the HIV positive women in the study. The discussion below outlines how characters are positioned within the small story, how the woman who had just disclosed her HIV status positioned herself in relation to the issue of HIV disclosure, and how she viewed herself in relation to how the community perceives disclosure. The use of the small story allows for a deeper understanding of what happens when one breaks the news about being HIV positive. The HIV positive women in Chapter Five mentioned the importance of HIV disclosure because it facilitates family support. Grandmothers in Chapter Six and HCPs in Chapter Seven also highlighted that HIV non-disclosure impedes the success of the PMTCT programme. Excerpt 9.2.1 below demonstrates the context in which the 'breaking news small story' about the HIV positive status occurred. The thematic analysis done in Chapter Five only provided themes related to HIV disclosure, without giving the context of the lived experience. Hence, the small story analysis of a breaking news story provides a unique way of understanding the context in which HIV disclosure occurred.

Excerpt: 9.2.1 Example of a breaking news small story

Line #	Participants	Breaking news small story (Infant HIV PCR test results received, 33 years, single, 3 children)
1	Participant	My family is supporting me, they show me love.
2	**Researcher**	**How did you tell them [about your HIV status]?**
3	Participant	I started [disclosing my HIV status] with my sister the day I got weak.
4	Participant	I explained to her and she said ok my sister, if it's like that you have to accept because you are not the first one.
5	Participant	There are many people who are like that [HIV positive].
6	Participant	Then I told my mummy, she also said my child accept what you are, you must be proud of yourself.
7	Participant	We will give you support.
8	Participant	And for real, they showed me love and they supported me.
9	**Researcher**	**Now when you got pregnant with your second and third child, was your status already known by the family?**
10	Participant	Yes they already knew my status
11	**Researcher**	**How did they feel about you continuing to have more children considering your HIV positive status?**
12	Participant	They were busy talking saying my child, when you are busy bringing children being like this, what will the people say?
13	Participant	Then I said if it is God's will that I have children, there is nothing I can do
14	Participant	As long as the father of my children is showing me love and support me,

Line #	Participants	Breaking news small story (Infant HIV PCR test results received, 33 years, single, 3 children)
		there is no problem
15	**Researcher**	**Oh you had told your partner about your HIV status, please explain how it went?**
16	Participant	I told him because he also used to have a big body
17	Participant	So he told me that he is losing weight, he is not eating alright, and when he is with his friends he does not feel free anymore
18	Participant	Then I advised him to go for the test [HIV] to check [his status], perhaps he might find that he has [sickness]
19	Participant	Then he went to test and found that he is positive [HIV]
20	Participant	Then I also told him that I am like that and that he must disclose his statu order to get love and support that people can give.

The news-worthiness in the small story conveyed in excerpt 9.2.1 is on the actual telling of the new discovery of being HIV positive. Thus, the breaking news plot line revolves around HIV status disclosure at different levels of relationship. Excerpt 9.2.1 shows that the narrator has revealed the news about her HIV positive status to a number of people. It even demonstrates the sequence in which she disclosed her HIV status. For instance, she started with her sister, followed by her mother. In both circumstances, she observed love and support from the characters which she stipulated (see line 3-8). Although the narrator did not mention how she disclosed the news to her partner, line 16 and 20 convey that she also shared the news about her HIV status with him. Line 16 further suggests that the reason for breaking the news to her partner was because his physical body changes began to suggest that he might also be HIV positive. Line 20 confirms the narrator's suspicion of her partner also being HIV positive. Hence, the small story context shows that HIV disclosure occurred as a result of the HIV positive diagnosis of the participants' partner. Excerpt 9.2.1 further showed the participants' eagerness to break the news about her HIV positive status to multiple people, in order to obtain the necessary love and support. This suggests that breaking news in this instance served as a mechanism for seeking and obtaining support.

This small story suggests that the narrator possesses a number of characteristics. Firstly, she portrayed the characteristic of desiring multiple pregnancies, regardless of her HIV positive status (see line 12). This shows where she is located in the story (Freeman, 2006). For instance, it is clear that she has a passion for children irrespective of being HIV positive. The narrator appeared to be comfortable with experiencing multiple pregnancies, as long as the

father of her children supported and loved her. Secondly, the narrator positioned herself as being fragile, because of her recent HIV diagnosis. Given the breaking news about her status, she positioned herself as one who was in need of support, whilst her mother and sister were positioned as having the ability to improve her situation by showing her love and support. Lastly, the narrator portrayed the characteristic of being emotionally strong, as suggested by the advising of her partner to test for HIV (see line 18-19 of Excerpt 9.2.1). She also encouraged her partner to disclose his HIV positive status, in order to obtain love and support from others (see line 20 of Excerpt 9.2.1). Based on this scenario, it could be argued that the positioning levels of this 'breaking news small story' revealed the participants' character in relation to HIV disclosure and external factors, such as family. In terms of how the narrator viewed herself in relation to dominant discourses, Excerpt 9.2.1 suggests that her family was concerned about the views and thoughts of others regarding the participants' on-going pregnancies and the fact that she is HIV positive (see line 12), whilst the participant was not. The results suggest that 'breaking news small stories' to family or even to the community has the possibility of raising HIV stigma of HIV positive women who continue to give birth despite their positive HIV status. Line 12 demonstrates that although the HIV positive status of this participant was known to her family, they continued to worry about the community's perceptions of HIV and pregnancy.

Concerning the small story compositions, with a specific reference to the sequence of the story, Excerpt 9.2.1 indicates that the story starts by suggesting the love and support that was received from the family after the breaking news. It also ends with the narrator emphasising the importance of HIV disclosure to her partner in order for him to obtain family love and support. Regarding the sites of the story, Excerpt 9.2.1 demonstrates that the spaces in which HIV disclosure took places included the home and the healthcare facility. This suggests that breaking news of an HIV positive status might often takes place at home, where one anticipates receiving unconditional support. In this instance, the teller of the breaking news portrayed multiple traits (strong and weak, about her HIV positive status) that were both negative and positive. The teller conveys the fears related to non-disclosure, which included the lack of love and support from family. This excerpt showed the "habitual practices such as the likes, dislikes fears" of the narrator (Rampton, 2007, p. 3), related to HIV disclosure.

Unlike thematic analysis, which is more concerned with themes, the small story analysis of breaking news shows the context in which the small story took place, by unpacking the

positioning levels of characters and the teller of the small story. It also provided a sequence of how the breaking news was revealed, by showing how the news was introduced and how the story ended, as well as the various people who were told the story. The small story compositions revealed the feelings of the teller about breaking the news and the spaces in which the news was broken. The analysis of this small story reflects the positive outcomes of telling a breaking news story of being HIV positive. Breaking the negative news was accompanied by love and support, especially because the news was expressible. This type of small story in the context of the PMTCT programme suggests the need for mechanisms to assist with breaking news stories (for example breaking the news of one's HIV status) at the family, and community level, including between partners. Breaking news is instrumental in the context of PMTCT and HIV, because it seems to promote love and support of HIV positive women, which might facilitate adherence to PMTCT cascade processes.

9.2.2 Shared small story' analysis: "… *Yes we all agree that the child must be given porridge at 3 weeks!"*

Excerpts 9.2.2 to 9.2.7 are examples of a 'shared small story' (type two) which shows the group views on infant feeding. These Excerpts (9.2.2 to 9.2.7) were taken from one of the four grandmothers' FGDs in the study. The selected FGD consisted of six grandmothers who shared a common view on the issue of infant feeding, as discussed in Chapter Six of this thesis. The issue of infant feeding has been discussed in the background Chapters Five to Eight which also revealed some intersecting narratives between the three groups of participants about infant feeding habits. The background Chapters provided key themes related to the issue of infant feeding. This Chapter provides the context in which some infant feeding habits occurred. This information could not be clearly obtained by thematic analysis, as thematic analysis concentrates solely on themes, rather than context. Excerpts 9.2.2 to 9.2.7 below are an example of a shared story which demonstrates a common topic that is known to all the participants is being discussed (Georgakopoulou, 2007). As discussed in Chapter Four, shared stories may also be labelled as 'group stories', which in the current context suggests group views on infant feeding. The punch line for this shared story is: "*the child must eat porridge!*" This quote suggests a widely known story about how an infant is supposed to be fed. The 'shared small story' consists of mini-stories told by a group related to a known issue, in this context, mixed feeding.

Excerpt: 9.2.2 Example of a 'shared small story': FGD1

Line #	Grandmother	Shared small story- FGD 1
1	G1	Yes the child should eat porridge. We raise him/her with porridge. He/she should eat porridge
2	G4	When he/she turns three weeks old, we start with the porridge,
3	G4	We make it [porridge] a bit watery until he/she grows and start walking.
4	G2	When he/she starts walking, the porridge and milk would have long being there.
5	G1	Is not like we give him/her porridge the whole day, we only give him/her in the morning, during lunch and at night.
6	G1	In the morning I make the porridge and then he/she eats, then later I make formula milk.
7	G1	At night I make the porridge again and then he/she eats and sleeps.
8	G5	The child must eat porridge!
9	**Researcher**	**The child must eat porridge**
10	G2	The child must eat porridge!
11	**Researcher**	**Okay granny**
12	G3	Yes when you have a child at home, you give him porridge and then after porridge you make lukewarm water for him/her.

Line 1 of Excerpt 9.2.2 illustrates the authority that grandmothers possess within the topic of infant feeding. The use of the pronoun 'we' shows the position of grandmothers in relation to the mixed feeding experience. They seem to portray the attribute of being masters of infant feeding. Such an experience is clearly shown by line 1 of Excerpt 9.2.2, which emphasises how a child should be raised. The multiple uses of the pronoun 'we' in lines 1, 2, 3, 5, and the expressions of grandmother two (line 10) and three (line 12), also demonstrate the prevalent belief in mixed feeding by grandmothers, as well as the authority that they hold in practising it. The shared story in Excerpt 9.2.2 seems argumentative, as the grandmothers are trying to justify to the researcher that mixed feeding is a shared behaviour.

With regard to the small story composition, Excerpt 9.2.2 shows that the small story starts with emphasis on mixed feeding (line 1) and ends with advice on how mixed feeding should be practised (line 12). Lines 3-8 of Excerpt 9.2.2 provide an example of how mixed feeding should be practised "*is not like we give him/her [child] porridge the whole day we only give him/her in the morning, during lunch and at night*…"

Excerpt 9.2.2 suggests that the punch line of the shared story remains the same "… *the child must eat porridge*!" (Georgakopoulou, 2006). In terms of the sites of the story, the mixed feeding practices appear to take place in the home environment, where the behaviour is shared

and known to everyone. With regard to tellers of the story, it could be argued that grandmothers see themselves as masters of mixed feeding, as suggested by their knowledge on the early introduction of food to the infant (lines 3-8). The punch line "*the child must eat porridge*" reflects the grandmothers' habitual practice of mixed feeding. This habitual practice does not support the key PMTCT message against mixed feeding, because mixed feeding is promoted by culture.

In Excerpt 9.2.3 below, the grandmothers further shared their mini-stories on the time-frame for mixed-feeding, (see lines 14-20). The excerpt suggests that mixed feeding begins as early as two or three weeks after birth. Emphasis is further placed on the type of the water that is given to the child, with the Setswana name called "*ntsu*". As described by grandmother three in Excerpt 9.2.3 of FGD1, '*ntsu*' means lukewarm water. Similar to Excerpt 9.2.2, mixed feeding in this excerpt is portrayed as a reasonable and acceptable practice. The grandmothers are portrayed as being highly skilled in practising it. They also appear to be highly knowledgeable on the amount of solid food that a child should be given during mixed feeding (see line 19 of Excerpt 9.2.3).

Excerpt: 9.2. 3 Example of 'shared small story': Continuation FGD 1

Line #	Grandmothers	Shared small story: Continuation FGD 1
13	**Researcher**	**I: When do you start giving him/her porridge?**
14	G3	When he/she is two or three weeks old.
15		And you also make him/her boiled water and give him/her with the bottle.
16		They call that water 'ntsu'
17		But it should have boiled previously
18		After that he/she would be growing
19		even the amount of porridge goes according to how big he/she is
20		until he/she grows and start eating the real porridge
21	**Researcher**	**So do you all agree that the child must be given porridge?**
22	All	Yes we all agree that the child must be given porridge!

Similar to Excerpt 9.2.2, the sequence of Excerpt 9.2.3 starts with the grandmother providing the age at which mixed feeding starts and ends with all grandmothers agreeing with mixed feeding practices. It could be argued that the shared mini stories demonstrate dominant cultural beliefs and habits.

Lines 23-29 of Excerpt 9.2.4 below is a continuation of the shared story, which also provides reasons for mixed feeding. For example, one grandmother indicated that mixed feeding is caused by the baby's cry, which is assumed to be a sign of hunger (lines 24-29). For the grandmothers, a crying child signifies the need for solid food over and above breast or formula milk. Grandmother three suggested that mixed feeding is a part of their culture. As such, the grandmothers adhere to their own ways of feeding children (see lines 36-39 of Excerpt 9.2.4). The belief that children are born with hunger is raised (suggested in lines 40-46). Excerpt 9.2.4 (lines 41-46) demonstrates another mini- telling, where the grandmothers share the eating habits of mothers while they are pregnant "*their mothers eat atchaar [mango vegetable mix]*." A metaphor is used in line 43: "…*even their children are born hot* [spicy]!" This small story suggests that the child's cry is assumed to stem from the hot food that their mothers eat while pregnant.

Excerpt: 9.2. 4 Example of 'shared small story': Continuation FGD1

Line#	Grandmothers	Shared small story: Continuation FGD 1
23	**Researcher**	**At the clinic you have been told that the child will eat [porridge] after six months and it is clear that at home you are practising something else. Why is that?**
24	P6	We do not agree with that because the child would be crying
25		Because of not getting full from the milk. When the child is three weeks
26		he/she has to eat porridge so that it can stay a bit long in the stomach.
27		Because you will find the child already sucking fingers and crying
28		uncontrollably and we would not know how to make him/her stop crying.
29		Only to find that, the child is hungry.
30	**Researcher**	**So what you mean is that even when you have been told at the clinic about infant feeding, when you go back at home you still do things the way you see fit?**
31	P1	Yes
32	**Researcher**	**Hmm?**
33	P5	27. P5 Yes that is what we do
34	**Researcher**	**Hmm?**

Line#	Grandmothers	Shared small story: Continuation FGD 1
35	P2	It is our culture
36	P3	It is our culture, if we are told to do that by the clinic,
37		when we enter the clinic, we do what the clinic recommends,
38		however, when I arrive at home, I also do what I need to do at home
39		because this children are born with hunger
40		Their mothers eat atchaar [mango vegetable mix] and this and that.
41		Therefore the children cry at night.
42		When their mothers are pregnant, they eat anything
43		that is hot, even their children are born hot, they cry on us.
44	**Researcher**	**they [children] come hot!**
45	P2	They are hot, they cry on us, so we make them porridge [when they cry] [everyone laughing]
46	**Researcher**	**I you make porridge?**
47	P1	Yes

This shared story in Excerpt 9.2.4 related to the reasons for mixed feeding (line 45) which appeared argumentative. In this story the grandmothers argued that children were born 'hot' because their mothers ate atchaar (mango vegetable mix) whilst pregnant. It was believed that children would cry as a result of the hotness. Hence the introduction of solid food to prevent crying, would justify the practice of mixed feeding. Excerpt 9.2.4 shows that the argument within shared stories makes it difficult for PMTCT processes to be adhered to. For instance, line 24 of Excerpt 9.2.4 explicitly demonstrates that this grandmother disagreed with the PMTCT programme requirements because she seems to believe that the programme will not solve the problem of the child's crying: "*we do not agree with that because the child would be crying…"* Studies on PMTCT have not addressed how to soothe a crying child, especially in the context of HIV in a rural South African setting.

Georgakopoulou (2007) also suggested that an argument in shared stories is brought about by the personal experience. Line 49-52 of Excerpt 9.2.5 demonstrates a personal experience of grandmothers four. She shared her experience of infant feeding to argue against the other five grandmothers' views on early infant feeding. Her argument was that regardless of the perceived importance of mixed-feeding, she still followed the recommended infant feeding

guidelines with her three children. Although she did not explicitly express it in the small story (excerpt 9.2.4), it is suggested that the absence of mixed feeding has become possible for her because she has practiced exclusive feeding with her three children.

Excerpt: 9.2. 5 Example of 'shared small story': Continuation FGD1

Line #	Participants	Shared small story: Continuation FGD 1
48	**Researcher**	**Okay, you also want to add something madam?**
49	P4	I have three children, and with all of them,
50		I followed clinic guidelines.
51		I was breastfeeding them the whole six months.
52		And after six months I would wean them and start giving them porridge.

The argument in the 'shared small story' also presents a conflicting view of infant feeding brought about by the view of the healthcare system and the opposing traditional or cultural beliefs (see line 54-66 of Excerpt 9.2.6) of the grandmothers. The argument is brought about by divergent views regarding the requirements for a child to have a healthy umbilicus. The shared assumption (Georgakopoulou, 2007) of the participants is that porridge strengthens the baby's umbilicus (navel) (line 62, 63) and stops him or her from crying. The health of the umbilicus seems to be of concern for both mixed-feeding habits and non-mixed feeding ones practices. The 'umbilicus' is portrayed as being sensitive to early infant feeding by the health system, but traditionally according to the grandmothers, the umbilicus needs to be strengthened by the early introduction of food. This study shows that in a rural context, the child's umbilicus is believed to be strengthened by the early introduction of solids and failure to introduce solids causes the umbilicus to cramp and thus causes the child to cry (line 64 and 65), Excerpt 9.2.6.

Excerpt: 9.2. 6 Example of 'shared small story': Continuation focus group 1

Line #	Participants	Shared small story: Continuation FGD 1
53	**Researcher**	**Have you ever asked yourselves why the clinics are giving such a message that a child must only start eating at six months? Have you not wandered why are they saying the child must be fed solid food at six months? What is going on in your minds?**
54	P1	I thought when they say the child must eat at six months,
55		I thought perhaps the food disturbs the child's navel, that is what I thought

Line #	Participants	Shared small story: Continuation FGD 1
56	**Researcher**	**The baby's navel?**
57	P1	Yes
58	**Researcher**	**Grandmother this side, why do you think they say the child must eat solids at six months?**
59	P6	Ai, I do not know why because eating strengthen the baby
60		He/she has to eat [solids]
61		We are not refusing clinic advises but we have to feed the child.
62		The navel is strengthened on the inside by eating [solids]
63		He/she has to eat, if the child does not eat, the navel becomes painful and then the child will cry.
64		The reason for him/her to cry i.e. because of hunger
65		when the baby is starving, the navel becomes painful
66		He/she [child] has to get something that will help on the inside
67	**Researcher**	**Hmm, what do you think madam this side?**
68	P5	I also see it that way that the child has to eat [solids]
69		because the navel has to be strengthened

The 'shared small story' in Excerpt 9.2.6 illustrate an argument which is repeated by the grandmothers, emphasising the importance of mixed feeding. The above excerpt portrays the umbilicus as needing to be fed constantly to avoid cramping, which will cause the baby to cry. As line 59 indicates above, there seemed to be lack of knowledge about why mixed feeding should not be practised. This suggests a need to inform and educate the grandmothers on PMTCT processes, as it could provide them with a clear explanation of the reasons why mixed feeding should not be practiced.

Excerpt 9.2.7 is another mini-telling/story which shows the sites of the small story which relate to the change in the infant feeding practice by the grandmothers in different settings (home versus healthcare facility (see lines 70-73 of Excerpt 9.2.7). The participants believed that adhering to infant feeding guidelines, while at the healthcare facility and practising their own infant feeding habits at home was deemed appropriate. Finally the shared story among the grandmothers was the request for harmonisation of the two differing practices of infant feeding. Acceptance of traditional infant feeding habits was emphasised.

Excerpt: 9.2.7 Example of 'shared small story': Continuation FGD 1

Line No	Participants	Shared small story: Continuation FGD 1
70	P5	We do follow what they say at the clinic
71		but when we get home, we deal with it [infant feeding] according to our culture
72		We do listen when they talk to us at the clinic
73		but when I get home I give the child whatever I want to give.
74	**Researcher**	**I have heard what you said about the infant feeding advice they give you at the clinic. And what you are saying is that when you get home you practice your cultural habits relating to infant feeding. What do you think should be done to have good collaboration with the clinic since you are the ones who are looking after these children at home?**
75	P5	I am asking the clinic that they accept our culture
76		that we spoke about as grandmothers and that we should work together.
77		That whatever we do with these children at home
78		they should not shout at us when we get here.
79		Because we are always with these children, we live with them.
80		We do bring the children [to clinic] at the times that they give us [for immunization].
81		They should not shout at us. We need to work together.
82	**Researcher**	**You just indicated that you do not want the healthcare professionals at the clinic to give you advices about infant feeding. So what are you saying as grandmothers about infant feeding? Are you saying you know it better?**
83	P1, P2, P3, P5, P6	Yes, yes, [we know] about how they have to be fed, yes
84		We also need to work with them
85		We are also the nurses at home

Excerpt 9.2.7 places emphasis on the grandmothers' belief that mixed feeding is associated with cultural inclinations. As such, grandmothers are portrayed as having multiple attitudes towards infant feeding, suggested by the practice of both mixed and non-mixed feeding at home and at the healthcare facility respectively (see lines 70 and 73). Grandmothers emphasised the reason for this combinatory practice as being to avoid being reprimanded by the HCPs (see line 78 of Excerpt 9.2.7). This is an important finding which seems to suggest why the continuation of mixed feeding exists. Chapters Five to Eight indicated that the HIV positive women started antenatal care late, because of the fear of being shouted at by the HCPs. This small story analysis also shows that grandmothers avoided practicing mixed feeding in

front of the HCPs, because they did not wish to be shouted at by them. This finding suggests that the HCP-patient relationship in this rural South African context seems to be dominated by reprimanding, mostly from the HCPs. As shown in Excerpt 9.2.7, it could be argued that such reprimanding aggravates undesirable behaviour and practices, such as late antenatal care attendance and mixed feeding practices by HIV positive women and grandmothers.

The small story conveyed in Excerpts 9.2.2-9.2.7 provide an explanation for mixed feeding practices, including hunger and the baby's cry, and perhaps even the cultural fondness of grandmother as child carers. The grandmothers also portrayed a character of being home nurses, hence the presence of mixed feeding practices (see line 85 of excerpt 9.2.7). Regardless of the mini-tellings within the shared story, the punch line and the wording remained the same throughout the small story: "*the child must eat porridge*." The shared story in this case, suggested that healthcare system and community need to harmonise infant feeding practices. It was also very clear that there is lack of information as to why mixed feeding is not ideal for an infant. The small story in Excerpts 9.2.2-9.2.7 showed the context in which mixed feeding occurs. Through the small story analysis of a shared story, a repetitive argument about the importance of mixed feeding was noted. Unlike thematic analysis which is only concerned with the generation of themes, this analysis showed that grandmothers are activists for mixed feeding, as they provided guidelines for its practice, reasons for it and guidelines regarding time-related aspects of mixed feeding. A clear context of why mixed feeding occurs was presented in Excerpts 9.2.2-9.2.7, which eventually highlighted a fear of HCPs as a contributing factor towards mixed feeding.

9.3 Future projection small stories: *"… So then this PMTCT will save the economy because children will not get sick"*

Excerpt 9.3.1 is an example of a small story type showing future projections that would result from the success of the PMTCT programme. This excerpt is taken from an interview that was conducted with the HCP who was the manager of the PMTCT programme at one of the healthcare facilities. According to Georgakopoulou (2007), 'future projection small stories' involve planning actions for future events. The analysis of 'future projection small stories' brings about new information, which could not be revealed by thematic analysis, such as unpacking the context of a future projection of PMTCT narratives. For instance, the HCPs outlined actions that need to be taken in order for the PMTCT programme to be successful.

Examples of the actions outlined include: Every woman must go for HIV counselling; every woman must be given information and receive treatment (see lines 1-5 of Excerpt 9.3.1). These actions are the future projections that will make the PMTCT programme successful. The other actions include partner notification in order to protect the child from being infected (see lines 6-9 of Excerpt 9.3.1). This small story further outlined that the action of HIV treatment will ensure that the PMTCT programme protects the economy from the negative effects of HIV (see lines 10-15 of Excerpt 9.3.1)

Excerpt 9.3. 1 Example of 'future projection small story': Female, 51 years, professional nurse

1. The success of the PMTCT comes from the action of
2. every woman going for [HIV] counselling
3. and will be given the information
4. and from there, if she is positive, depending on her CD4 count,
5. She will get the treatment.
6. And the other success [of the PMTCT] is that the partner will be notified.
7. Mostly they do tell their partners because they have this thing
8. that they will infect and re-infect the children and all that.
9. So, the success is that the partner will know
10. and the child will get the treatment
11. And then in the long run depending on her CD4 count she will also get ART for life.
12. So then this PMTCT will save the economy
13. because children will not get sick
14. And they will be saved during delivery.
15. So, it is 100% good because we will have a generation free of HIV because of this PMTCT programme

This type of a small story projects the near future of events that would aid the success of the PMTCT programme. Projections in a small story involve planning in detail, for example, including details such as a time and place. As expressed by Georgakopoulou, (2007, p. 48), the plotline of future projections in a small story is governed by "event planning and interacting verbalism". The composition of the small story in Excerpt 9.3.1 suggests that the HIV positive women are central to the success of the PMTCT programme. Adherence to treatment is also portrayed as being central in achieving an HIV-free generation.

The HCPs provided the future projections in an ordered sequence of events (see lines 1-5 of Excerpt 9.3.1) which might lead to the success of the PMTCT programme. The above small story starts by indicating the action that needs to be taken by women (line 1) and ends by indicating the impact of such action (an HIV-free generation). Regarding the sites of the small story in Excerpt 9.3.1, the story is told from the point of view of the HCPs who manage the HIV positive women. Hence, the site of this small story would take place at the healthcare facility where the women and their partners test for HIV and receive treatment (lines 2, 3, 6). Excerpt 9.3 shows that further success of PMTCT might occur through planning the action of partner notification (see line 6 of Excerpt 9.3.1). In this context, partner notification appears to be a verbal interaction which would involve women's sexual partners in a discussion about preventing the child from contracting HIV (see lines 6-9 of Excerpt 9.3.1). Partner notification is an example of a social arrangement mentioned by Georgakopoulou (2007).

Event planning in this small story is the action of obtaining or seeking treatment should the child be HIV positive (see lines 10-11 of Excerpt 9.3.1). Excerpt 9.3.1 shows that the important future projection in this story relates to saving or preserving the economy and having an HIV-free society as a result of the PMTCT programme (lines 12-16). Hence, this small story on future projections emphasises the key Millennium Development Goal (MDG) (UNAIDS, 2012) of having an HIV-free society. It could therefore be argued that the actions indicated in this future projection small story are critical for the success of the PMTCT programme. The HCPs would thus be responsible for providing a service that would lead to an HIV-free generation.

9.4 Stories to be told: "*…It will depend with how I will feel after some advices, for now, no HIV disclosure [to family]*"

Excerpt 9.4.1 is an example of a small story analysis (type four) showing 'stories to be told' within the PMTCT programme, by the HIV positive women. As discussed in Chapters Two and Four, 'stories to be told' involve deferring news for future telling. Although Chapter Five revealed the theme of HIV disclosure challenges, it failed to unpack the reasons for HIV non-disclosure and to provide a clear context. Hence, the analysis of small stories to be told (Excerpt 9.4.1) suggests reasons why there is a lack of readiness to disclose HIV status. The punch line for this small story is "*not now*", which indicates that the message has been deferred to the unknown future.

Excerpt 9.4.1 Example of 'stories to be told' small story: Mother who had received infant HIV PCR test results, 23 years, single, 1 child

1.	**Researcher:**	**Did you tell them at home [about your HIV status]?**
2.	Participant:	(disagreeing) [with a very low voice]
3.	**Researcher:**	**You haven't told them?**
4.	Participant:	(agreeing) [with a very low voice]
5.	**Researcher:**	**How do you feel about telling them?**
6.	Participant:	(disagreeing), not now.
7.	**Researcher:**	**Why is that? [Do you perhaps] feel] it is early?**
8.	Participant:	I will just be careful.
9.	**Researcher:**	**What do you mean by saying you will be careful?**
10.	Participant:	That there won't be things that will infect them.
11.	**Researcher:**	**Okay, or [when would you like to disclose?] you want to disclose when the baby is how old then?**
12.	Participant:	Haa... it will depend.
13.	**Researcher:**	**Do you feel its fine to not disclose like this? Is it okay like this? What do you think?**
14.	Participant:	It will depend with how I will feel after some advises.
15.	Researcher:	For now, no?
16.	Participant:	(agreeing)

Excerpt 9.4.1 illustrates that the discussion about issues related to HIV disclosure to family recorded between the researcher and the participant was mostly conversational. The character of the HIV positive woman in this excerpt is portrayed as a shy person. This small story also suggests the non-readiness of the participant to disclose her HIV status to her family. The emphasis on the non-readiness is suggested by her response "not now" (see line 6 of Excerpt 9.4.1). In this small story, HIV disclosure is deferred to the non-specified future. The teller of the story is portrayed as having a fear of disclosing HIV status.

Although HIV disclosure to her family was deferred, of interest was that the participant indicated that she would be careful of anything that could negatively affect her family (see lines 8-10 of Excerpt 9.4.1). This implies that even though HIV disclosure did not occur, the participant was constantly aware of her status and always acted carefully to prevent the risk of her family contracting HIV. In this small story, HIV disclosure to family is deferred until such

a time that the narrator receives advice from external individuals. Her disclosure would also depend on whether the advice of others is good enough or not (line 14). This small story suggests that for some women, HIV disclosure is not a tellable/ expressible action. This could be due to the perceptions of HIV in the narrator's community or due to the narrator's lack of trust. Kramer and Cook (2004) link tellability to trust. Only if the teller trusts a person, they will tell their story. The excerpt above seems to suggest that some participants regard being HIV positive as something that is not worth telling, immediately after they have been diagnosed (see line 6 of Excerpt 9.4.1).

9.5 Other small stories generated from the data of the current study

Although there are four existing types of small story that have already been introduced by Georgakopoulou (2007), the current study data allowed for further analysis according to sub-types. To complement Georgakopoulou's (2004; 2007; 2013) 'shared small story', the current study has introduced a single shared story type with sub-types, which are relevant to the PMTCT programme. The current study data also enabled the generation of one additional small story type, which is also more relevant to the PMTCT programme. The next section commences by discussing the 'shared small story' type and ends by discussing the additional small story type.

9.5.1 PMTCT Shared small story type

The new 'shared small story' type in this study was analysed according to the broader type termed the 'PMTCT shared small story'. This term was used to allow for the inclusion of any 'shared small stories' related to the PMTCT programme. The 'PMTCT shared small story' type was also defined using Georgakopoulou's (2007) description that they are group stories which are well known in the study setting, which involve retelling future and past event stories. The generation of this new category of 'PMTCT shared small stories', might be of use to researchers studying PMTCT to understand the context in which the lived experiences occur. Figure 9.1 shows that 'PMTCT shared small stories' consist of the following three sub-types: 1) 'treatment adherence stories', 2) **'**conditional HIV disclosure stories' and 3) 'antenatal care practice stories'.

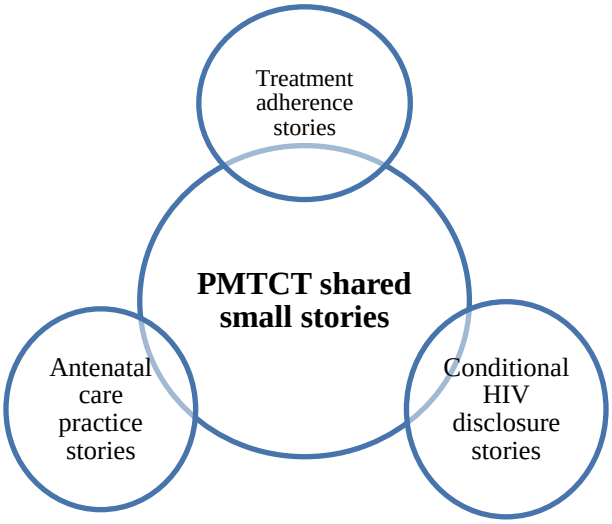


Figure 9.2 'PMTCT shared small stories'

A description of PMTCT shared small stories, which is supported by the participants' excerpts, is provided hereunder. The PMTCT shared small stories are discussed according to the small story positioning levels and small story compositions (Georgakopoulou, 2007).

9.5.1.1 Treatment adherence shared small story': "*Mummy, have you taken tablets…?"*

The first type of 'PMTCT shared small story', which focuses on treatment reminders for an HIV positive patient, is called 'treatment adherence shared small story'. It focuses on the actions needed to be taken by people who support HIV positive patients. It indicates that the lack of reminders from those people may have serious repercussions for the HIV positive patient. Thematic analysis could not provide an analysis similar to this type, which provides the context of the PMTCT shared story. Excerpt 9.5.1 is an example of a 'treatment adherence shared small story', which is about a mother who receives reminders from her son to take ARV treatment. This 'PMTCT shared small story' consists of two characters: the story teller, who is the mother, and her son.

Excerpt 9.5.1 Example of a 'treatment adherence shared small story': Infant HIV PCR test results received, 43years, single, 5 children

1.	Researcher:	So you don't skip medication?
2.	Participant:	No, when its 8 o'clock, you will see him [son] with a glass of water
3.		Mummy, have you taken tablets?
4.		He would even fetch it, mummy have you taken tablets?
5.		Then I would say yes I have taken it
6.		Then he would say, but I didn't see you
7.		He is the one who gives me [medication]every evening
8.		You see even this baby they gave him his medication [at the clinic]
9.		He makes sure before he goes to school that the child has taken syrup medication [Nevirapine]
10.		He is so small [son]… he does not even know what it does, he just sees medication

The punch line for this small story is "…*mummy have you taken tablet?* (see line 3 of Excerpt 9.5.1). The punch line reflects the habitual practice of the son providing the mother with tablets which help to keep her healthy. The narrator positioned herself as being adherent to the treatment because of the help she receives from her son (see lines 3-7 of Excerpt 9.5.1). The son is portrayed as being conditioned to remind his mother to take her medication even though he does not know what it is for. The known shared story is that the mother is sick, but the information about her sickness is not known. The teller in this context sees herself as being blessed to have a family treatment supporter, who is small, and yet very aware of the routine that his mother has to follow (line 10). In terms of the small story compositions (the way the story is told), the narrator begins by giving a description of what happens when it is time for medication. For instance, line 2 provides the time at which the mother takes her medication, and suggests that her son is aware of this time. For the son, this act seems to continue to happen on a daily basis. The narrator further emphasises that her son makes sure that her and her baby have taken the medication (see lines 4-9). This shared story ends with the mother describing that although her child is so small, he plays a vital role.

Looking at the sites of the story, the mother experienced treatment support in her home environment. Even though details of her sickness are not discussed, constant reminders are given by her child (see line 10 of excerpt 9.5.1). The story suggests that the verbal sharing of the details of the mother's sickness was not possible because the support was received from a

child. The findings suggest that treatment adherence shared stories are critical for the effectiveness of the PMTCT programme. It is clear from the study that PMTCT shared stories facilitate adherence to treatment in the case of HIV positive women in the PMTCT programme. However, this shared story suggests that huge responsibilities are given to children, who are not knowledgeable about the disease.

9.5.1.2 Conditional HIV disclosure shared story: "*Until he had chicken pox…*"

The second 'PMTCT shared small story' sub-type which emerged from the current study data is called a 'conditional HIV disclosure shared story'. This is a type of 'PMTCT shared small story' which demonstrates that sometimes HIV disclosure happens on the condition that the partner shares his/her own HIV status. This seems to be a common shared practice in a rural context. The delays in sharing HIV status suggest that this small story could be delayed for a long period time, which is often unknown. This kind of story would involve disclosing a past event which has been known for some time only when the partner decides to do the same. It could also suggest that the positive status is known by both partners and other people, but has not been formally disclosed or discussed, especially if it is a sensitive disease such as HIV.

Excerpt 9.5.2 Example of 'Conditional HIV disclosure shared small story': Mother received infant HIV PCR test results received, 25 years, single, 2 children

1. I did not want to tell him [partner] straight
2. Until he had chicken pox and went to the clinic and they tested him first
3. Then he called me saying they are saying he is [HIV] positive
4. But I already knew [my status] isn't?
5. So I went to him and he explained that they are saying he is [HIV] positive
6. That's when I told him that they also said I am [HIV] positive.

Excerpt 9.5.2 is an example of a 'conditional HIV disclosure shared small story', provided by an HIV positive mother who had just received her infant HIV PCR test results. The narrator positioned herself as not being able to tell her partner about her HIV positive status until he discloses his (HIV status) to her (see lines 1 and 6 of Excerpt 9.5.2). Line 1 demonstrates that the narrator felt uncomfortable to disclose her HIV status to her partner in a straight forward way, suggesting that she might feel more comfortable with using other less direct methods of

disclosure. The narrator's character is portrayed as being selfish (see lines 1 and 4 of Excerpt 9.5.2). For instance, Excerpt 9.5.2 suggests that the way the story was shared was based on the partner sharing their story (see line 6 of excerpt 9.5.2). The telling of this small story took place after the news had been shared by the partner. It also suggests that the telling of the story could not happen in a straight forward, conventional way (see lines 1 and 2 of excerpt 9.5.2). The small story suggests that sharing the story was based on discovering the same HIV status of the partner. This implies that conditional sharing was embedded in a previous experience of being diagnosed with HIV.

In terms of the sites of the story, it took place at the clinic where the partner was diagnosed with HIV, and at the female partner's home. This suggests that the narrator and the male partner lived separately because he had to call her to inform her of his HIV positive status (see line 3). Furthermore, Excerpt 9.5.2 shows gender differences in the HIV disclosure process. For instance, it portrays the male partner as feeling free to disclose his status once he discovered he was HIV positive (lines 2 and 3), and the narrator as feeling reluctant to share the news of her HIV status over the phone. She reported to prefer disclosing her status to her partner in person (lines 5 and 6). The data thus suggests that there are two types of disclosure, which could be referred to as 'face-to-face' and 'telephonic disclosure'. 'Telephonic HIV disclosure' could happen at anytime, anywhere, whilst 'face-to-face' disclosure seems to involve waiting to receive the partner's HIV status. Excerpt 9.5.1 shows gender preferences on how HIV disclosure could happen in a rural setting.

It could therefore be argued that for the PMTCT to be effective, 'conditional shared small stories' might be an obstacle, because they promote on-going risky behaviour whilst one waits to share their disclosure story. One of the recommendations suggested by participants, noted in previous Chapters was that HIV disclosure would facilitate adherence to PMTCT services. Hence, PMTCT interventions should discourage conditional shared stories at all levels.

9.5.1.3 Antenatal care practice shared story: *"They just decide to come towards the end…"*

The third 'PMTCT shared small story' sub-type generated from the current study data is the 'antenatal care practice shared story'. This type of small story is based on what is observed as a common practice in a particular setting. It is concerned with past practices related to health-

seeking. For example, past practices might include community beliefs on issues affecting men and women, regarding their participation in the PMTCT programme. They might also include shared cultural beliefs related to antenatal care practices in the particular context. An antenatal care practice shared story, provided by a mother who had received the infant HIV PCR test results is provided hereunder. The participant shared some of her observations of antenatal care practices in her community.

Excerpt 9.5.3 Example of 'antenatal care practice shared small story': Mother received infant HIV PCR test results, 33 years, single, 3 children

1. **Researcher: And what about many other women?**
2. Participant: A lot of women do not attend [antenatal care] early
3. A person would come this month knowing that she is giving birth next month
4. **Researcher: What makes them do that?**
5. Participant: I am not sure, what makes them [women] do that. They just decide to come towards the end
6. Knowing that the following month they will be giving birth.
7. They [HCPs] tell us to come to the clinic on time, they [HCPs] teach us
8. They [women] do not do that, I do not know what their problem is

Excerpt 9.5.3 is an example of a small story analysis of an 'antenatal care practice shared story'. This Excerpt begins and ends with a statement highlighting the problem of late antenatal care attendance by women in the community (lines 2 and 8). The narrator in this excerpt, portrays herself as someone who has been observing the inappropriate behaviour of late antenatal care attendance by the women in her community (see line 2, Excerpt 9.5.3). Her character is portrayed as a woman who understands the importance of early antenatal care attendance, whilst the other women do not (lines 5-6). The knowledge she is in possession of comes from the education that was provided at the healthcare facility (see line 7 of excerpt 9.5.3). The way the story is told shows that it is a well-known, shared practice for women to attend antenatal care services late in the rural community (see lines 3 and 5 of Excerpt 9.5.3). In the context of the narrator, attending antenatal care in the last month of pregnancy is a common practice (see line 3 of Excerpt 9.7.1). Because this is a common practice, the narrator is able to provide the particular times that women in the community attend antenatal care services (lines 5 and 6). The narrator seems to disapprove of the practice of her fellow community members, because they are taught to attend antenatal care early. This disapproval

is similar to that of the grandmothers' noted in Chapter Six, which suggested that grandmothers would like their children to listen to the HCPs. Similar to the ignoring of health messages discussed in Chapter Eight, this small story seems to suggest that the ongoing practice of ignoring health messages exists amongst women in the community. The sharing of this story is embedded in the previous observation of this behaviour by the women in the community. This small story suggests that some women acknowledge the importance of early antenatal care, whilst others dismiss it. The 'PMTCT shared stories' revealed narratives that would not be easily be revealed by thematic analysis. It provided the context in which PMTCT shared stories occur. The next section provides an additional small story type.

9.6 PMTCT affective small story types

Over and above the 'PMTCT shared story type', the current study data generated a small story type called the 'PMTCT affective small story'. This type of small story includes PMTCT stories which display the emotions related to living with HIV. Figure 9.2 below shows 'PMTCT affective small story' sub-types such as 'motivational/ inspirational' and 'lived experience small stories'.

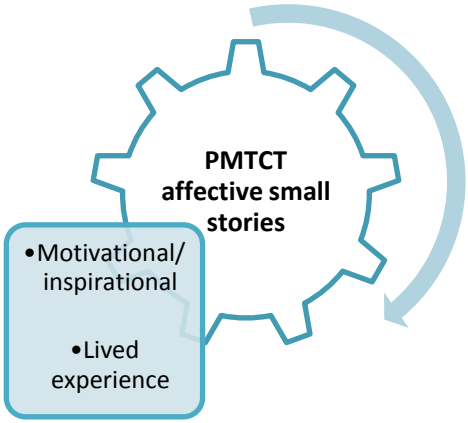


Figure 9.3 'PMTCT affective small stories'

9.6.1 'Motivational/ inspirational small story'

The 'motivational/ inspirational small story' is based on the negative and positive feelings about oneself in relation to a past or current situation. This type of story demonstrates the

characteristics of an individual and the way in which the individual deals with or has dealt with an emotional situation. This type of story dictates how people should behave in certain situations. It provides them with advice to live a positive life, especially when they are suffering from concealable stigmatised disease, such as HIV. This small story type is also discussed according to the small story positioning levels and small story compositions proposed by Georgakopoulou (2007). Excerpt 9.6.1 is an example of a motivational small story, which encourages people to develop self-love, which may translate into love shown by other people. The motivational small story type suggests factors that facilitate adherence to PMTCT cascade processes, which were also discussed in Chapters Five to Seven.

Excerpt 9.6.1 Example of 'emotional' small story': Mother received infant HIV PCR test results, 25 years old, single, 2 children

1. I feel fine…I feel fine because this is the type of disease that anybody can have
2. There is no way that I can say I have HIV, then I start stressing because I have that disease.
3. I accept that I am positive, there is nothing I can do
4. I got counselling, they counselled me…

Excerpt 9.6.1 is a typical example of a 'motivational/ inspirational small story', revealing positive feelings about oneself in relation to one's current situation, which in this case is the situation of being HIV positive. The narrator in Excerpt 9.6.1 is portrayed as being a strong and confident character, who has accepted her HIV positive status. The narrator positioned herself as being accepting of her HIV positive diagnosis, because it is a disease that anybody could contract (see line 1 of Excerpt 9.6.1). In terms of the sequence for this small story, it begins with the expression of feeling good despite having been diagnosed with HIV, and it ends by suggesting counselling as the source that led to her acceptance of her HIV status. The experience of the HIV diagnosis and counselling took place at a healthcare facility. The way in which the narrator tells her story, shows a lack of stress and anxiety (see lines 2-3 of Excerpt 9.6.1). The calmness of the story, which lacked elements of stress and anxiety, was suggested to have been brought about by balanced counselling (see line 4 of Excerpt 9.6.1). The small story is therefore tellable because of the fact that the narrator has accepted her HIV positive status. This 'motivational/ inspirational small story' suggests that receiving counselling helps with acceptance of a positive HIV status. It is evident that HIV acceptance by the narrator was facilitated by the HIV counselling she received. As indicated in Chapter Eight, other participants also recommended ongoing peer counselling and self-love (shown by the action of

HIV testing). The use of the 'PMTCT affective small story' analysis assisted in understanding the contexts which bring about the acceptance of one's HIV status. Another 'motivational/ inspirational small story' is shown in Excerpt 9.7.1 below.

Excerpt 9.7.1 Example of 'motivational/ inspirational' small story: Mother who had just given birth, 41years, divorced, 5 children)

1. So I want those who are like me to have an enduring heart
2. They must have love; I mean they must start by loving themselves.
3. You know if you are like this, in a situation like this, then you love yourself,
4. Even other people will love you. They will love you without pointing fingers at you…
5. But when you belittle yourself, they will also belittle you.

Excerpt 9.7.1 suggests that the narrator positions herself as a character that has accepted her HIV status and gives advises to others who have not yet accepted their status. This small story starts with advice on how to behave when HIV positive (having self-love) and ends with more advise of not demeaning oneself. The narrator's character is portrayed as being a positive thinker who has an enduring heart (see line 1 of Excerpt 9.7.1). The narrator positioned herself as having self-love, which might influence others to love her too. The manner in which this small story is told signifies the narrator's self-love and self-acceptance (see line 2 of Excerpt 9.7.1). The narrator emphasises the habitual practice of self-love. This small story is embedded in previous experiences of the narrator that showed that the lack of self-love causes negative reactions by other people (see line 4 of Excerpt 9.7.1). This 'motivational/ inspirational small story' promotes self-motivation for people living with HIV. As such, the success of the PMTCT programme requires self- motivated individuals, who will adhere to its services.

9.6.2 'Lived experience small story'

The second 'PMTCT affective small story' generated from the current study data is called 'lived experience small story'. This type of a small story demonstrates the importance of a lived experience in understanding the situation of those living with an illness. This type of small story emphasises the difference between hearing about a situation and actually being in the same situation. It suggests that a lived experience in the context of PMTCT makes

messages even clearer. This small story type is also discussed according to the small story positioning levels and small story compositions, proposed by Georgakopoulou (2007). Excerpt 9.8.1 below is an example of a lived experience small story which is given by an HIV positive mother who has just given birth.

Excerpt 9.8.1 Example of Experiential small story (Mother who had just given birth, 41years, divorced, 5 children)

1. …the main thing is that I understand, I am the one who is in this situation which is like this
2. I am the one who understands it more
3. But when you are not in this situation, you will not understand
4. You will not take it serious
5. So I understand, I fully understand because of certain reasons.

Excerpt 9.8.1 is an example of a 'lived experience small story' which emphasises the importance of experience in understanding a disease. The above excerpt illustrates that the narrator positioned herself as understanding the situation of being HIV positive better than anybody else. She portrays a character who is knowledgeable about HIV, which is reflected by the use of the pronouns 'I and you' in describing the lived experience. The narrator tells the small story as one who understands her own situation better than anyone else (see lines 1-3 of Excerpt 9.8.1). The narrator's claim to have abundant knowledge of HIV suggests that she is not willing to accept any advice. As a consequence of this, lived experience small stories might offer advantages and disadvantages. The disadvantages may stem from the ignoring of advice due to perceptions of self-sufficiency.

9.7 Conclusion

This Chapter involved the analysis of small stories based on the four small story types described by Georgakopoulou. It also revealed the analysis of small stories based on the new shared story sub-type called the 'PMTCT shared' small story. Finally this Chapter identified another additional small story type called the 'PMTCT affective small story', which emerged from the data of the current study. This Chapter demonstrated that small story breaking news of HIV positive statuses are necessary at both the family and community levels. This study also found that the shared story of mixed feeding amongst grandmothers was tellable, because

it was deeply influenced by culture, although they also blamed mothers for their eating habits while pregnant. Future projections of small stories in this Chapter draw attention to the fact that immediate action to encourage the success of the PMTCT programme is crucial. This Chapter also revealed that small stories that need to be told are mostly inhibited by a fear of telling them. Other types of PMTCT shared stories showed that reminders facilitate treatment adherence, whilst conditional HIV disclosure shared stories seemed to encourage risky behaviour. The PMTCT affective small stories also showed the importance of self-love and that a lived experience of HIV can only be understood by those living with HIV. The lived experience small story could have both negative and positive consequences for the PMTCT programme. One needs to be mindful of this.

The small story analysis presented new information in the context of PMTCT, which allowed for the classifying of narratives of participants' lived experiences according to the varying types. This kind of classification has not been done in any PMTCT study. However, this means of analysis assists in achieving a clearer understanding of the reasons for the lack adherence to PMTCT services. The additional small story types which emerged from current study created additional categories to understanding HIV lived experiences. These categories offer a new way of analysing a lived experience in the context of PMTCT.

CHAPTER 10
GENERAL DISCUSSION, CONCLUSIONS AND IMPLICATIONS

10.1 Methodological reflections

To understand the lived experiences of HIV positive women, grandmothers and HCPs related to their participation in the PMTCT programme, either through receiving service, supporting those receiving service or providing service, a qualitative narrative strategy was employed as the method of research inquiry. This study required an interpretive approach which assisted in providing information on how people understand the world and the experiences they had encountered in that world (Merriam, 2009). The qualitative narrative strategy provided rich descriptions of participants' lived experiences of the PMTCT programme and factors which led them to delay the utilisation of the services. The use of narrative inquiry allowed participants to freely narrate their experiences of being in the PMTCT programme (Marshall & Rossman, 1995), and thus helped to understand the experience better (Clandinin & Connelly, 2000). It could thus be stated that the qualitative narrative strategy revealed an important "aspect of human behaviour", which demonstrated the health-seeking practices of individuals living in a rural context (Ulin et al., 2005, p. 6). This study provided a unique way of understanding the PMTCT lived experiences of rural women, in terms of how PMTCT services transpired in that context. Thus, the results of the study might offer an important contribution to aid the prevention of the further spread of HIV from mother to the child. The methodology of this study offered a variety of unique aspects.

Firstly, the uniqueness of the study is brought by the use of the methodological triangulation principle (Creswell, 1998), which involved obtaining narratives about the PMTCT programme from the three groups of participants (HIV positive women, grandmothers and HCPs) in order for a holistic understanding to be achieved. The lived experience of receiving the PMTCT service, supporting those receiving the PMTCT services and the actual offering of the PMTCT services were all obtained and analysed. The approach of using three groups of participants, assisted with obtaining multiple perspectives and understandings of the PMTCT services in a rural context. The grandmothers' involvement assisted with obtaining

the shared or societal context of health issues, as well as their knowledge of HIV programmes (Richie & Lewis, 2003). It also facilitated an understanding of their role in the family, their cultural views of infant feeding and more insight into lay understandings of PMTCT. As such, the use of the FGD method allowed grandmothers to express a broader range of norms, values and opinions (Ulin, Robinson, & Tolley, 2005) about family dynamics, including infant feeding and antenatal care attendance by young women in their community. The lived experiences of the grandmothers provided new insight into critical areas of intervention related to the PMTCT programme. One critical intervention suggested was the inclusion of grandmothers in PMTCT, since they are often involved in postnatal care activities.

The HCPs' individual interviews demonstrated the lived experience of providing services to both HIV positive women and grandmothers in this rural context. The HCPs lived experiences also revealed some of the challenges to the PMTCT programme, such as late antenatal care attendance by women in the study setting. Chapter Seven demonstrated the activities that HCPs are engaged in to provide PMTCT services, such as pregnancy education, infant feeding education, treatment support and treatment adherence education. These activities expressed by the HCPs, corroborate with the views of the HIV positive women and the grandmothers. Conducting individual interviews with HIV positive women also elicited information about their understanding and decision-making and action-taking related to participation in the PMTCT programme. The inclusion of the five categories of HIV positive women (1) Women attending their second antenatal care visit, 2) women who are taking AZT, 3) women who had just given birth, 4) women who had brought their babies to be tested for infant HIV PCR, and 5) women who had received infant HIV PCR testing results) showed the different stages of involvement in the PMTCT programme, which provided rich and unique information about their lived experiences of each stage of the PMTCT cascade.

Secondly, the study provided a deeper insight into lived experiences by specifically probing rural women's perceptions of the following PMTCT related activities: initiation of antenatal care services, HIV testing, ARV treatment, HIV disclosure, infant feeding, family participation, PMTCT language-use and male-partner involvement in the PMTCT programme. This study allowed women to freely narrate their experiences and perceptions of all of the above mentioned PMTCT cascade processes.

Thirdly, the use of the social constructionism theory provided a deep understanding of the participants' social interpretation of the reality of healthcare service utilisation (Denscombe, 2003) in a rural setting. Moreover, the use of a phenomenological approach provided a clear understanding of a lived experience which was provided by individuals who had actually experienced the phenomena (Denscombe, 2003). The use of social constructionism how reality is constructed (Merriam, 2009) in relation to health-seeking. Furthermore, it showed that the meaning of a lived experience can be interpreted in "different ways by different people, in varying times and under different circumstances" (Denscombe, 2003, p. 100). Through the social constructionism theory, this study revealed a high degree of dependency on "social selves" in the creation of health-seeking reality (Boghossian, 2001). This dependency on social selves was revealed in relation to issues, such as antenatal care attendance, infant feeding and HIV disclosure. This study revealed that dependency on social selves might be detrimental towards an HIV intervention programme, such as PMTCT. Hence, it may be deduced that this study showed the perceptions about how the reality of participating in PMTCT services is constructed. The study revealed various linguistic elements used by participants (for example, the use of terms, such as 'this disease' and 'that disease' to refer to HIV) and symbols (such as the lack of action towards utilisation of PMTCT service). Behaviour construction in relation to those who have decision making powers on infant feeding was also noted. Hence, this theory revealed that knowledge of HIV and PMTCT programmes is constructed through social interactions. The social constructions of the PMTCT programme in this study revealed that anticipated and internalised stigma still persist as obstacles to the utilisation of healthcare services, such as PMTCT, in a rural South African context.

Fourthly, the use of narratives to explore the lived experiences provided a clear understanding of how PMTCT services were provided and utilised. It also revealed the rural women's voices, which seem to have been silenced and sidelined for a significant period of time (Gergen, 1997; Reinharz, 1994), especially in relation to health matters, such as PMTCT.

Fifthly, the uniqueness of this study stems from the utilization of two data analysis approaches, which greatly assisted in understanding the lived experiences of the PMTCT programme in this rural context. For example, this study revealed that thematic analysis and

small story analysis complemented each other, in that they focused on both the dominant themes and the context in which the lived experiences occurred. The thematic analysis was useful in understanding the content of the data (Riessman, 2003) and generating codes and categories which led to the development of key themes and sub-themes (Glesne, 2011). The participants' narratives in this study could not be analysed using traditional narrative methodology, which is more time bound and focused on chronological presentation of the information (showing a beginning, a middle and an end) (Riessman, 1993). Thematic sequencing was a useful tool in this study because the narratives were stitched together by a theme (Michaels, 1981), instead of a temporal sequence of plots (Riessman, 1993). In the current study, the narratives were focused on the topic of PMTCT and were later organised thematically. The presentation of results following the PMTCT cascade steps provided a clear sequence of understanding a lived experience. The data yielded detailed descriptions of the PMTCT lived experiences of participants, which were demonstrated in various excerpts within the Chapters of this thesis. The direct quotations from the participants' interviews allowed the researcher to generate themes (Graneheim & Lundman, 2004). Hence, the use of thematic analysis allowed for the generation of factors suggested to facilitate or inhibits participation in the PMTCT programme in a rural context.

To complement thematic analysis, which focused on themes and the content of the data (Riessman, 2003), small story analysis revealed important findings which demonstrated the context of the narratives (Georgakopoulou, 2007). The findings of this study revealed that the use of small story analysis, which looks beyond the narrative canon, highlighted some of the data that were embedded within the naturally occurring data. The small story analysis showed the context in which the lived experiences occurred, by focusing on the positioning levels of the teller, spaces and places in which the experiences took place (Georgakopoulou, 2007). Analysing PMTCT lived experiences according to types of small stories (stories to be told, breaking news stories, future projections of storytelling and shared stories) appeared to be the most relevant and unique way to understand the lived experiences. The utilisation of the small story analysis led to the development of additional shared small stories, such as 'PMTCT shared small stories' and 'PMTCT affective small stories.' These new small stories generated from the current study data provides a new way of understanding PMTCT lived experiences in a rural context.

Lastly, the uniqueness of this study was brought about by the cultural and linguistic advantage that the researcher possessed in relation to the study setting. The researcher's ability to understand Setswana and Sepedi languages (participants' native languages) enabled her to present the direct and original lived experiences of the participants' narratives, without having to alter any information due to a limited understanding of the native languages. Furthermore, the fact that the researcher is originally from a disadvantaged rural background similar to that of the participants placed her at the same level as the participants. The fact that she is educated and have employment served as a motivation for some PMTCT women that regardless of your background, it is possible to still progress in life. In addition to this, as indicated in Chapter One and Four of this thesis, the exceptionality for this study was brought by the fact that the researcher understood the context in which the PMTCT services were provided, because of her prior involvement in PMTCT research in the study setting. The researcher's publications in peer reviewed journals attest to this (**See Appendix A**). All the qualities described above, facilitated a clear understanding of the meanings and contexts through which the participants' lived experiences were shared.

10.2 Study limitations

One of the limitations of this study is that it was only conducted in one rural district of the Mpumalanga Province. As such, the findings are not necessarily generalisable to other South African rural districts. The various methodologies employed are, however, transferrable to other rural contexts and the findings may serve as a benchmark for other PMTCT studies conducted in a rural context. Furthermore, participants' excerpts used in the thesis were not constructed in their original languages (Setswana and Sepedi), due to challenges related to writing space and the length of the thesis. However, because the researcher is fluent in both languages, the translated versions of the excerpts were close to the original transcript versions. Again, only participants who came to the healthcare facility were involved in the study. This means that other individuals in similar situation might have been excluded, by virtue of not being at the healthcare facility during the course of data collection. Although the findings of the study revealed a wide variety of themes based on participants' lived experiences, obtaining narratives from one HIV positive woman from the time she started attending her second antenatal care visit until she had received her infant HIV PCR test results would have been useful in providing richer data. However, having the five categories of HIV positive women interviewed at different stages of antenatal and postnatal care also

provided a rich understanding of PMTCT service usage in this study context. Another limitation could be that the grandmothers who were involved in this study are not related to the HIV positive women participants. Involving immediate grandmothers could have provided the 'real' lived experiences of child-caring and the perceptions of PMTCT programme. Further limitations in this study stems from the overlap in ages between grandmothers and PMTCT mothers. Whilst grandmothers' ages ranged from 40-74 years, there were two PMTCT mothers whose ages were 41 and 43 years. This suggests that they could have been grandmothers, however, such role was not indicated during the interviews which required them to elaborate on members of their family as part of providing demographic information. The ages of the PMTCT mothers and the researcher also did not differ, this means that participants could have been biased in their responses. However, since responses were narrated to reflect the lived experiences, biasness would almost be impossible. It is also possible that the participants could have shared only age relevant information without detailing other information that would surprise the researcher. The insider role might have also hampered participants from sharing their full experiences because of the belief that the researcher understands the context. Again, due to over familiarity with the study setting, the researcher might have missed some aspects when doing data analysis. Lastly, although the researcher is not originally from the study setting, she was born in a similar rural background, this might influence some of her interpretations. However, unlike most participants, she has postgraduate degree which might have influenced her interpretation of the results. The next section provides an account of study findings and their implications.

10. 3 Intersecting narratives of PMTCT: Lived experiences of HIV positive women, grandmothers and HCPs

The researcher's interest was drawn by the existing gap and the lack of narratives from HIV positive women, grandmothers and HCPs in rural areas, about the poor utilisation of the PMTCT programme in this context. Such a gap demonstrated that it is critical to study and understand the lived experiences of PMTCT by looking at factors that facilitate and hinder participation in the programme, particularly in a rural South African context. The lack of understanding of the lived experiences of PMTCT has the potential to affect global targets set by UNAIDS for the elimination of new HIV infections and maternal death by 2015 (UNAIDS, 2012). It might also delay some of the South African Health Department's plans

to reduce the MTCT rate to <2% at 6 weeks by 2016 (SANAC, 2011). This study therefore, provided an account of narratives of lived experiences of receiving PMTCT services, supporting those receiving PMTCT services and the actual provision of such services. These lived experiences are critical for facilitating adherence to PMTCT cascade processes as discussed in Chapter Two, figure 2.2, which is the basis for achieving global and national goals related to HIV.

10.3.1. Factors hindering participation on PMTCT programme

This study found intersecting narratives on the lived experiences among the three groups of participants (HIV positive women, grandmothers and HCPs). These were related to factors that facilitate and hinder participation in the PMTCT programme. There are seven key themes that emerged from the study, which capture the lived experiences of the participants and also respond to the research questions posed in Chapter One of this thesis. The seven themes which emerged include: 1) fear of stigma as a trigger for late antenatal care attendance, 2) HIV testing stigmatisation and fear of HIV burden, 3) fear of HIV stigma and women disempowerment on infant feeding, 4) health services stigmatisation and cultural stereo types affecting male involvement, 5) structural violence, tradition and healthcare system as PMTCT blockages, 6) fear as a factor affecting adherence to PMTCT processes and 7) enhancing PMTCT programme through health education, community participation, individual and health system change. The cross-cutting theme in the data that emerged from this study was on factors that facilitate and hinder the effectiveness of the PMTCT programme. The participants' narratives provided an understanding of the challenges of late antenatal care attendance, HIV testing, treatment barriers and family involvement barriers, as well as the reasons for these barriers.

10.3.1.1 Fear of stigma as a trigger for late antenatal care attendance

What has emerged from this study is that the intersecting narratives on reasons for late antenatal care attendance, included the following: fear of HCPs and the healthcare facility, HIV non-disclosure and low socio-economic and structural factors.

- **Fear of HCPs and the healthcare as an agent of stigma**

Theme one showed that although there were a few participants who shared their lived experiences of the benefits of utilising PMTCT services, the key theme related to non-utilisation of the PMTCT services by the HIV positive women. The cross-analysis of the findings suggested different schools of thought, related to late antenatal care attendance. The study revealed that although there are benefits of participating in the PMTCT programme early, in a rural South African context, late antenatal care attendance continue to persist. The intersecting narratives were found between HCPs and grandmothers in this study, who continue to worry about late attendance of the antenatal care services by the women of child bearing age in the study setting. The results suggest that the health-seeking behaviour of young women differs from that of the grandmothers, as the grandmothers seemed to believe in maintaining regular contact with the healthcare facility and HCPs. Although the literature shows poor practices around healthcare utilisation and poor treatment behaviour such as mixing traditional with Western medicines especially by the elderly (Lutala, Kwalya, Kasagila, Watongoka & Mupenda, 2010; Case, Menendez & Ardington, 2005), the current study seems to suggest a different health-seeking behaviour by grandmothers in this rural context. Grandmothers' involvement in healthcare utilisation is necessitated by their role of child-caring whereby they have to take babies to the healthcare facility for immunization and other baby check-ups. Furthermore, because of their need for monthly chronic medication for high blood pressure and sugar diabetes (although adherence was not discussed) and conducting tests such as 'pap smear' as indicated in Chapter Six, they utilise the healthcare facility. Therefore, because of the above factors and their need to keep healthy unlike their grandchildren, they are yearning for their children and grandchildren to listen to HCP *"Let them [our children and grandchildren] listen to what the nurses are saying."* Baker and Silverstein (2008) found that grandmothers who had been raising children for at least two years were more likely to utilise healthcare services for influenza vaccination, monthly breast examinations and their probability for receiving pap tests was 63%. Poor health due to child-caring might be another motivation for wanting to keep healthy (Lee, Colditz, Berkman & Kawachi, 2003).

Chapter Five of this thesis reveals that fear affects decision-making and action-taking concerning the utilisation of the PMTCT services by the HIV positive women. Decision-making is an initial step prior to the engagement on the PMTCT cascade processes. Chapters

Five, Six and Seven of this thesis clearly indicated the individual and community factors that influence the decisions for late antenatal care utilisation in a rural setting. These included avoidance of long periods of attendance, previous child-birth experiences, laziness, concealing pregnancy, intentional defer of healthcare use and myths about pregnancy medication. Data revealed that such late antenatal care utilisation decisions were deeply embedded in psychosocial factor, such as fear of the HCPs and healthcare facility. This study therefore reveals that such fear which is caused by anticipated stigma disempowers women's decision-making and action-taking ability towards PMTCT services utilisation. The study findings provided evidence that suggests that fear of the HCPs is mostly instigated by the community's negative beliefs about healthcare utilisation. For instance, fear of being 'shouted at', 'fear of being diagnosed HIV positive' and fear of being 'asked too many question' seemed to cause some women to commence antenatal care late. Such fear was also suggested to be brought about by the fact that the healthcare system is seen as an agent of HIV stigma, especially for HIV positive women.

Furthermore, the findings attested that HIV positive women in this study anticipated great deal of stigma from the HCPs (Turan & Nyblade, 2013), especially in relation to adherence to the PMTCT cascade processes (discussed in Chapter Two, figure 2.2). Data in the current study revealed "multilevel stigma" from the individual, community (Smolak & Bassel, 2013) and healthcare facility level. This stigma seemed to form the source of non-utilisation of PMTCT services. For instance, the findings provided evidence which suggested that early antenatal care attendance was associated with anticipated stigmatisation by fellow community members (Merten et al., 2010; Selin et al., 2007; Nam et al., 2008) and the HCPs. This study found that the fear of accessing the healthcare services was also socially constructed. For instance, the women in the current study indicated that it is a habitual custom to seek medical help late, especially if one is pregnant in this community. This implied that early antenatal care was also viewed negatively by community members in the study setting. As such, it was perceived that pregnant women who utilises healthcare services early during pregnancy, are HIV positive. The findings suggested that the multiple constructions of antenatal care usage in the study setting are such that the attitude towards healthcare service remains negative and stigmatizing, although PMTCT has been portrayed positively as a programme that may save lives. This forms a significant barrier to healthcare service utilisation.

The study findings further revealed that the stigma anticipated from HCPs might be due to the belief that confidentiality is not maintained at a healthcare level. This suggested the existence of mistrust of the services provided by the HCPs which in turn promotes the lack of utilisation of PMTCT services (Doherty et al., 2006; Cunning et al., 2007). Chapter Seven provided additional factors which suggested that the healthcare facility is seen as an agent of stigma, such as the dislike of HBCs and patient movement to grandmothers' homes around the time of delivery. These findings appear to support the argument that patient movement is caused by stigma anticipated from HCPs (Merten et al., 2010; Selin et al., 2007; Nam et al., 2008; Nguyen et al., 2008). The relocation to the grandmothers' homes was reported to result from the traditional role grandmother have been known to play in childcare (Penn et al., 2010; Barratt & Penn, 2009). Chapters Six and Seven revealed that grandmothers play a significant role in the PMTCT programme, because they participate (often as primary caregivers) in postnatal care, which includes taking the child to the healthcare facility regularly for immunisation.

Although I had insider privilege which stems from being familiar with the setting because of working there previously, understanding the language and culture, this study revealed different antenatal care behaviour from what I expected. My own experience of antenatal care utilisation seems different from that of participants. As a mother of two, the idea of starting antenatal care early seemed like a norm and yet it appears that participants in this study context had so many barriers which include fear. My grandmother and my mother did not tell me that I should start antenatal care early, I made a decision to do so because I embraced the notion of motherhood. I really do not understand why participants in this setting start antenatal care so late and I wonder what differences exists between myself and them considering I originate from a similar geographical background as theirs. Perhaps the differences could be that they do not understand the consequences of late antenatal behaviour and what makes it worse is that they are also HIV positive. It could also be because I had a privilege of having good education and that I never had a bad experience of utilising healthcare services.

The findings presented in Chapter Five of this thesis therefore suggested that avoidance of healthcare facility utilisation by some participants was used as a coping mechanism to avoid the stresses associated with the healthcare facility. Hence, the avoidance strategy discussed in Chapter Two of this thesis was found to be utilised by the HIV positive women in this

study. The findings of the current study seem to contrast with Rosenstock's (2005) health-seeking behaviour model, which argues that healthcare utilisation depends on the state of readiness or believing that one would benefit from it. The current study found that even though women believed they would benefit significantly from early utilization of the healthcare facility, they still used the avoidance strategy because of how health services are perceived. This suggests that in the study setting, health-seeking behaviour is not really affected by what people believe or feel (readiness), but by their perceptions of the social world in which they live. The PMTCT messages provided in a rural context thus needs to take this factor into consideration. It is for this reason that the results for the current study imply that the HCPs should not behave in a way that is intimidating to the patients. Regardless of how the HCPs feel about the pregnant women's behaviour, including their late antenatal care attendance, their provision of information should always take place in the form of counselling and not in the form of reprimands about the women's mistakes. Improvement of the communication between the HCPs and the patients would assist with the retention of the women in the PMTCT programme. Women would be empowered to decide and act timeously towards healthcare utilisation.

- **HIV non- disclosure**

The findings of the current study further provided evidence that HIV non-disclosure was a motivating factor for late antenatal care attendance. Chapter Eight revealed intersecting narratives amongst the three groups of participants demonstrating that HIV non-disclosure perpetuates late antenatal care attendance. This study also revealed that the HIV non-disclosure not only affects early antenatal care attendance, but also the way in which HIV positive women administer their HIV medication. An interesting point was made by one of the HCPs in Chapter Seven, which suggested that women in a rural context change their treatment packaging to that of common medication used within the community. This finding suggested that treatment adherence is possible, even if done in discrete and secretive way. However, it implies the delay of HIV disclosure, which forms an obstacle to the PMTCT cascade processes (Wouters et al., 2009).

Although the grandmothers and HCPs viewed HIV non-disclosure as a hindrance to early antenatal care attendance and adherence to PMTCT cascade processes, the HIV positive women in this study indicated that this behaviour occurred because they were not feeling

ready, feared being rejected (Chandoir, 2009; Chandoir & Fisher, 2010) and wanted to protect their family from being emotionally troubled. The non-readiness and fear of rejection noted in this study suggested that anticipated stigma delays the disclosure process. As such, stigma messages need to be changed to address this issue. In terms of protection of family members, PMTCT communication interventions need to address this belief. This finding differs from the disclosure model of Chandoir and Fisher (2010), which argues that disclosure takes place when one anticipates support and avoids disclosure when negative reactions are anticipated. The current study demonstrated that non-disclosure also occurs to protect others, including family. Therefore, disclosure process model needs to include this unique finding especially for the concealable stigmatised disease such as HIV.

- **Low socio-economic and structural factors**

This study also found that low socio-economic and structural factors seem to affect early antenatal care attendance. The description provided by the grandmothers and HCPs in this study suggested that HIV positive women, seemed lazy and therefore ignore any health advice given to them by grandmothers and the HCPs. The descriptions also seemed to suggest unemployment as one of the markers of poverty. Women in this context are expressed as lazy because they do not work. UNAIDS (2012) also suggested that a low socio-economic status, unemployment and the lack of education render women more vulnerable to HIV. The data that emerged in this study attests that individuals' health-seeking is also influenced by structural factors, and hence, the implementation of PMTCT in a rural area will most likely be affected by factors such as poor socio-economic conditions (Skinner et al., 2005).

The current study further revealed gender related vulnerability because of the low socio-economic status of women in this rural context. As already demonstrated by other studies (UNAIDS, 2012; UNAIDS, 2010; Pettifor et al., 2004; Shisana et al., 2009), the current study showed that women continue to be infected with HIV as a result of their vulnerability. The HCPs in this study indicated that women engage in risky sexual behaviour with the hope of securing a better life, for example, by getting married. These women were reported to engage in transactional sexual relationships with young and older men. This suggests that poverty affects the way in which people behave, and in turn, affects their health and treatment-seeking behaviour. Farmer et al. (1996) argued that trying to escape poverty places women at

risk of contracting HIV. This implies that implementing a PMTCT programme in a rural context might not be as easy as implementing it in an urban area (Varga & Brookes, 2008b), because of the vulnerability of women in rural areas, which results from structural violence factors (Kako et al., 2012; Pettifor, MacPhail, Anderson & Maman, 2012). Therefore, implementing PMTCT services in a rural context should consider the vulnerability of women that is caused by structural factors into consideration.

10.3.1.2 HIV testing stigmatisation and fear of HIV burden

The findings of this study, discussed under theme two, revealed intersecting narratives related to HIV testing beliefs and constructions of the three groups of participants. Although HIV testing importance was acknowledged by all the groups, the lived experiences of the HIV positive women suggested that importance of HIV testing is only realised post HIV positive diagnosis. The findings suggested that prior to the women's HIV positive diagnosis, HIV testing was not seen as a vital practice, especially if one was not even pregnant. This belief suggests that some women in this rural context do not see the benefits of utilising healthcare services before pregnancy. This seems to be common knowledge which is fabricated through social interactions (Burr, 1995) by rural women in this study setting. Rosenstock (2005) argued that health-seeking behaviour is mostly influenced by the belief that such action would be beneficial. In this case, the late utilisation of healthcare services suggests that women do not regard it as being beneficial, or they are not ready (Rosenstock, 2005) to face challenges that accompany antenatal care attendance, such as HIV testing. While the model of health-seeking behaviour emphasise the state of readiness and assessing the benefit of attending the healthcare facility (Rosenstock, 2005), the data in the current study suggested that in a rural context, this does not occur. This study showed that societal and individual constructions about other's perceptions of health-seeking are more important. The action of only testing when pregnant appears to suggest that although HIV testing campaigns highlight the benefit of HIV testing, they do not discuss the possible negative effects of consulting peers about health issues and treatment-seeking. This finding has an implication for current communication strategies aimed at encouraging HIV testing.

Moreover, this study revealed multiple realities regarding why HIV testing is supported. As attested by HIV positive women, HIV testing is supported for the benefit of the child (Adedimeji et al., 2012; Hardon et al., 2012; Rothpletz-Pulgia & Storm, 2012). For the

grandmothers, the act of HIV testing was supported for the protection of both mother and child (Levy (2009). Such wish was based on wanting to avoid the burden of caring for the sick mother and child and of being infected with HIV. The HCPs attested to the fact that grandmothers are indeed burdened by HIV. The data which emerged in this study thus suggests that the participants (HIV positive women and grandmothers) lacked the knowledge that HIV testing also aims to preserve mothers' health (Levy, 2009; UNAIDS, 2011, UNAIDS, 2012; Department of Health South Africa, 2013). This finding suggests that current PMTCT education needs to be improved to facilitate a clearer understanding amongst community members. The study findings suggested that grandmothers' fear was two pronged: fear of structural violence factors, such as poverty, and fear of the local perceptions about being a grandmother who is HIV positive.

The current study further provided an understanding of why HIV testing is avoided in the study setting. Chapter Six suggested that HIV testing is avoided because of the belief that the same needle is being used to test various people for HIV. In essence, this implies that in this study setting, some community members believe they are being infected with HIV during HIV testing at the healthcare facility. A similar belief was raised by a participant in Chapter Five, who expressed that men believe that the HCPs infect them with HIV. The intersecting narratives between the grandmothers and HIV positive women suggested a need for change in the way that HIV testing messages are communicated, especially for the promotion of PMTCT processes.

The findings further revealed that the physical location of PMTCT services (such as HIV testing) within the healthcare facility appeared to promote fear of health facility. For instance, Chapter Five showed that in this study the patients stigmatised the rooms for HIV counselling and testing (HCT). As a result, they believed that being referred to room 'four' and 'five' suggested that one was already HIV positive. The study findings suggested that social constructions of HIV testing cause it to be associated with fear. Such fear was also demonstrated by the use of euphemisms used to refer to HIV. The study participants used pronouns and terms, such as "this disease" and "that disease" or "positive", without uttering the word HIV. The findings revealed that talking about HIV and receiving HIV related services, such as PMTCT, in this particular context is still mystified. This implies that communicating about health issues, including HIV and PMTCT, is not always an easy task (Watermeyer & Penn, 2008; Ware et al., 2009). Although stated differently by HIV positive

women and grandmothers, the findings support the fact that the fear of HIV stems from the community in which the participants reside, and dominates the minds of women in this context. The fear of using the word 'HIV' and the use of euphemisms to refer to it, suggest that part of community mobilisation should address communication about HIV.

10.3.1.3 Fear of stigma and women disempowerment on infant feeding

Theme four showed another aspect related to cultural and family dynamics, namely infant feeding. In this study, the most common infant feeding practice among HIV positive women and grandmothers was mixed feeding even though it is against the recommendations of the PMTCT programme (WHO, 2010). Although grandmothers have been found to play a significant role in childcare (Penn et al., 2010; Bezner-Kerr et al., 2008), this study revealed that grandmothers seem to form a source of confusion and a barrier to appropriate child feeding (Falnes et al., 2011). Grandmothers were found to practice and advise their children to mixed feed (Aubel, 2012), because of the belief that it is culturally acceptable (Thairu et al., 2005). Such adherence to culture seemed to disempower HIV positive women in making decisions on how to feed their children.

The use of small story analysis provided in Chapter Nine of this thesis, demonstrated the narration of mixed feeding practices by the grandmothers. The narratives portrayed the grandmothers as experts of infant feeding. The shared small story analysis presented a repetitive argument for the practice of mixed feeding, which were brought by grandmothers' personal experiences. For the grandmothers and some of the HIV positive women, the practice of mixed feeding was brought about by their previous mixed feeding experiences that had accumulated over the years. It was interesting to note that multiple views existed between HCPs and grandmothers related to the consequences of mixed feeding. Through the 'shared small story analysis' which reveal the context of a lived experience, grandmothers expressed that traditionally, the baby's umbilicus is strengthened by the early introduction of solids (mixed feeding), whilst medically, the HCPs believed mixed feeding is harmful to the umbilicus. The data from the current study showed that infant feeding is not an issue determined by mothers only. It also seems to involve family members, especially grandmothers. Given grandmothers' role of strengthening family systems (Bezner-Kerr et al., 2008; Barrett, 2008; Aubel, 2012), women seem to always adhere to their advice. HIV positive women are disempowered to make their own decisions about infant feeding because

of the cultural role assigned to grandmothers. They provide indigenous knowledge and cultural values that are believed to stabilise family relationships. This study revealed a continuation of mixed feeding practices, which appear to be mostly encouraged by the grandmothers as caregivers.

The narratives obtained in this study highlighted the effects of the social stigma on infant feeding choice (Thairu et al., 2005). This study also suggested poor communication related to policy change on formula feeding (Ijumba et al., 2013), which has caused HIV positive women in this context to stigmatise formula feeding. The mixed feeding practices and social stigma related to infant feeding choice seemed to suggest that there is lack of trust in infant feeding messages and that cultural beliefs still dictate infant feeding practices. The participants' narratives expressed uncertainty about the exclusive breastfeeding option that was communicated to them. Chapter Six further suggested that there is confusion related to infant feeding, especially pertaining to the length of breastfeeding. This implied that the communication on infant feeding is unclear in this context, hence the mixed feeding practices continue to occur.

This study also found that women experience vulnerability and disempowerment as a result of infant feeding. For instance, before women disclose their HIV status, they succumb to family pressure to practice mixed feeding (Desclaux et al., 2009). While the woman is still fragile after having been diagnosed with HIV, she finds herself having to deal with family pressures related to infant feeding etc. In most cases, the findings suggested that grandmothers place the most pressure on mothers to mixed feed (Aubel, 2012). As a result, women find it difficult to challenge them. Whilst the practice of mixed feeding suggested poor knowledge of infant feeding in this study, the problem relates to social norms which emanate from the family and community.

This study reveals intergenerational differences reflected by the opinions of grandmothers and HIV positive women with regard to infant feeding. HIV positive women in the current study were affected by their grandmothers' voice which they found difficult to ignore. As someone who was raised by my maternal grandmother from the age of three months, I have a different experience regarding infant feeding. I acknowledge that my grandmothers' perspectives about child-birth and infant feeding were different from my mother's and that yet again my experiences of child-birth and infant feeding are different from both my mother

and grandmother. My grandmother and my mother never assisted me to make decisions of how to feed my children, instead my own perspective about infant feeding was informed by reading and some general advises from the healthcare provider. Why am I different from my mother and grandmother? It is because I live in an urban setting and I have had the opportunity to study. Although I grew-up from a similar geographical setting as the participants, I am different from them because they struggle to make a living, unemployed and they are rural-based. It could be argued that the lack of awareness of appropriate infant feeding procedures promotes the continuation of infant feeding dilemmas. The lack of knowledge and lack of decision-making powers seems to disempower women from adhering to PMTCT cascade processes. This study indicates the lack of an alternative system of knowledge about how to feed the infants appropriately especially in the context of HIV disease. Such system should deal with internalised beliefs that place grandmothers as superiors of infant feeding. It should also identify strategies to empower HIV positive women to make their own decisions without feeling that they are disrespecting the elders. This finding suggests that there should be clear communication and education on infant feeding and PMTCT, which is aimed specifically at the grandmothers in a rural context. Education on women's vulnerability and disempowerment should also be incorporated.

10.3.1.4 Health services stimatisation and cultural stereo types affects male involvement

Theme five showed another aspect of family dynamics which was reflected by similar views expressed among the three groups of participants which related to the reluctance of men to be involved in the PMTCT programme. The data in this study revealed multiple efforts made by the three groups of participants to involve males in the PMTCT programme. However, due to the social and cultural perception of men's identity in the community, such efforts were futile. The intersecting narratives of the three groups of participants on the issue of male non-involvement in the PMTCT programme revealed that a healthcare facility is viewed as a place for females (Nkouh et al., 2010; Reece et al., 2010, Theuring, 2009). Like other studies, this study suggested that the perception of good health (Kiziti et al., 2008), health systems issues and poor socio-economic status (Ditekemena et al., 2012) seem to influence men's reluctance to participate in the PMTCT programme. This suggests that there is a need for strong and clear communication about the importance of male involvement in the PMTCT programme.

The common view among the three groups of participants (Chapters 5-7) was that it is difficult to convince men to test for HIV, hence they lacked interest in the healthcare facility. This behaviour suggested the lack of knowledge and understanding about HIV testing and its benefits in the context of PMTCT. It was interesting that the lack of HIV testing by men was associated with the refusal of their susceptibility to HIV infection (Rosenstock, 2005) and with religion. Hence, male intervention programmes within the PMTCT programme need to take this into consideration.

10.3.1.5 Structural violence, culture and healthcare system as PMTCT blockages

- **Structural violence factors**

Theme three demonstrated that the non-utilisation of PMTCT service stems from the negative societal constructions of HIV and PMTCT, which occur beyond the healthcare system. The study findings revealed that factors linked to poor socio-economic status, such as early sexual debut, teenage pregnancy, unemployment, and lack of education, seem to impact negatively on the PMTCT programme. It was interesting to observe the multiple interpretations of reasons for teenage pregnancy amongst the three groups of participants. All groups suggested poor socio-economic status as an underlying cause for this issue. This study revealed that a need for a financially secure life outweighs the need for a healthy life. The narratives about the high rates of teenage pregnancy also seemed to suggest that learners and teachers in the study setting do not discuss programmes, such as PMTCT. The findings, therefore, suggest that communication between teachers, learners and parents is imperative in reducing teenage pregnancy in a rural context. Furthermore, the findings emphasised the unbalanced socio-economic status of young women. Women were expressed to feel the need to depend on men for survival (May, 2000, p. 5). This suggested that structural violence barriers continue to affect women in the rural South African context (Parker et al., 2012; Farmer et al., 1996). This study suggests that women's vulnerability is due to their need of a balanced socio-economic status (Kako et al., 2012). This needs to be taken into consideration when implementing PMTCT programme in a rural context.

Other barriers beyond the healthcare system which were expressed by grandmothers included the use of drugs and alcohol, crime and lack of parental unity in guiding the youth. The

participants' narratives suggested that the non-utilisation of PMTCT is caused by substance abuse which leads to crimes against grandmothers, such as rape. The findings suggested that men in this context attempt to escape causes of structural violence, such as poverty, by committing crime, whilst women engage in risky sexual behaviour to improve their livelihood (Farmer et al., 1996). Gender related factors were thus found to cause women to be vulnerable to the HIV infection (because of their need to improve their socio-economic situation) (Kako et al., 2012; Farmer et al., 1996). This suggests that poor socio-economic status poses as a challenge to treatment adherence and healthcare service utilisation.

- **Cultural and family dynamics**

Another barrier which falls beyond the healthcare system which emerged is that belief in cultural and traditional treatment affects adherence to some of the PMTCT cascade processes. The participants' lived experiences attest that individual, societal and cultural factors often cause community members to mix traditional and western medications. One grandmother expressed that when the family observe that an HIV positive family member fails to physically recover, they terminate ARV treatment and opt for treatment that is provided by traditional healers or their church.

Although the HIV positive women suggested a preference for the late utilisation of antenatal care services, the data that emerged from this study also suggested that the lack of attention to health messages perpetuates this behaviour and as a result, affects the overall utilisation of PMTCT services. The findings also suggested that community inflexibility and the lack of attention to health messages, discussed in Chapter Five seem to be caused by the community's persistence to cling to traditional health-seeking behaviours. This study found that community ignorance and inflexibility towards PMTCT service utilisation seems to be highly influenced by socio-cultural social networks (Thorsen et al., 2008; Kebaabetswe, 2007; Somma & Bodiang, 2003), as individuals seem to dislike practices which differ from those in their culture (Buskens, Jaffe & Mkatshwa, 2007). The participants' narratives seemed to suggest that misconceptions and community reluctance to engage in appropriate health-seeking behaviours might be due to fear of the healthcare facility, HCPs and the lack of PMTCT and HIV knowledge.

- **PMTCT language use**

Findings that were related to PMTCT language use suggested that there was lack of PMTCT knowledge and understanding of language used in PMTCT messages, especially by the grandmothers and HIV positive women. Emphasis was placed on poster messages, which are not written in the mother tongue of the community members. With regard to PMTCT terminology, Chapters Five and Six suggested that participants understood that the PMTCT programme aims to assist with the prevention of HIV infection of the child. They did not show concern related to the terminology used in the programme. They appeared to assume that the HCPs knew exactly what they were doing, and therefore, did not feel a need to familiarize themselves with the language and terminology of PMTCT. The findings revealed that most participants were not concerned with understanding terms, such as CD4, PCR, viral load and treatment names. They seemed to believe that any problem would be communicated to them in their own language that they understand. Perhaps, a deeper understanding of PMTCT language and terminology would enhance the utilisation of PMTCT cascade processes. Chapter Six of this thesis proposed that the challenge of poor comprehension of PMTCT messages was because grandmothers were not generally found to be learned. Hence, PMTCT communication messages need to address language, literacy and terminology issues, especially for the grandmothers who are highly involved in the practice of childcare.

10.3.1.6 Fear as a facilitator for non-PMTCT adherence

Theme six of this study showed varying factors (individual, community, health system, culture, structural violence) which lead to non-utilisation of PMTCT cascade processes. However, the study interestingly revealed that the underlying cause of these factors seems to stem from 'fear'. The data that emerged from the study highlighted various types of fear which seemed to affect the optimal functioning of the PMTCT programme, at all levels, in this rural context. Table 10.1 below shows the types of fear which affect PMTCT utilisation.

- Fear of HIV testing
- Fear of HIV testing if not pregnant,
- Fear of physical location for HIV testing
- Fear of the healthcare facility

- Fear of HCPs
- Fear of early initiation of antenatal care services
- Fear that HIV consumes blood
- Fear of taking treatment
- Fear of HIV status disclosure (partner, family and in-laws)
- Fear of structural violence factors
- Fear of local perceptions about HIV
- Fear of practicing exclusive feeding
- Fear of not following culture
- Fear of uttering the word HIV
- Fear of giving birth while HIV positive
- Fear and anxiety while waiting for infant HIV PCR test results
- Fear of being discriminated and stigmatised
- Fear of being gossiped about
- Fear of disease burden by grandmothers

Figure 10.1 Types of fear affecting PMTCT utilization in a rural setting

This study suggested that fear is one of the effects of stigma related to maternal and child health (Turan & Nyblade, 2013). Women in this study portrayed behavioural challenges towards health-seeking as being the result of stigma. This study found avoidance of care services, HIV non-disclosure, treatment non-adherence issues and a lack of interest in HCPs as factors which affect the effectiveness of PMTCT. Although fear caused by stigma seems to be the main cause of non-adherence to PMTCT services, the social ecological framework of PMTCT barriers suggests that there are many levels that might influence the decision to use PMTCT services (Busza 2012). The current study found that peer, family, community, cultural and health systems contexts also contributed to poor health-seeking behaviour. Therefore, PMTCT implementation in a rural context should consider these issues. Savage (2010) argued that "how people live their lives and how they experience other people's is determined in part by how they deal with fear: their own and other peoples' responses" (p. 26). This suggests that a possible way to overcome fear is to perform the action that causes it. For instance, the fear caused by the thought of receiving HIV positive results, might be overcome by testing for HIV (Savage, 2010).

10.3.1.7 Enhancing PMTCT programme through health education, community participation, individual and health system change

Theme seven showed data that emerged which relates to factors facilitating PMTCT service utilisation. This data suggested that community mobilisation of societal and cultural factors (Busza et al., 2012; Bajunirwe et al., 2005; Thompson et al (2012), health systems factors (ongoing availability of services, health education provision, adequate data recording, change in HCPs attitudes and enhancing the understanding of PMTCT language) and individual factors (self-love, self-drive) were regarded as vital for PMTCT service improvement. Although Chapter Five suggested that HCPs were feared, the HIV positive women seemed to appreciate the work done by peer counsellors. The data presented in Chapter Five suggested that the inclusion of peer counsellors in the PMTCT programme might facilitate improved participation in PMTCT cascade processes (Kim et al., 2012; Shetty et al., 2008), increased support for HIV positive women (Rotheram-Borus et al., 2011; Futterman et al., 2010) and improved comprehension of PMTCT messages (Agadjanian & Hayford, 2009). This study further identified religion as another method of intervention which might prove useful in reducing the PMTCT barriers that exist beyond the healthcare system. PMTCT communication in a rural context should thus make use of religion to encourage adherence to PMTCT cascade processes.

Another important facilitator of adherence to PMTCT processes suggested by this study is HIV disclosure. This study demonstrated that HIV disclosure to family yielded positive spinoffs, which were shown in the form of support and advice related to healthy eating, adherence to treatment, antenatal care attendance and postnatal care attendance. Other studies have also noted HIV disclosure as a factor which promotes adherence to PMTCT cascade processes and reduces stigma (Obermeyer, et al., 2011). The data revealed in the current study suggested that HIV disclosure facilitates support and acceptance from male partners, even though certain male partners did not believe that their partners were HIV positive. This finding suggests that PMTCT messages should also be geared towards male partners. Effective communication strategies to involve men are needed. Although HIV disclosure has been suggested to be a difficult action, it was interesting to note that certain HIV positive women suggested the importance of HIV testing to their partners, without disclosing their own HIV status. Once the women's partners received their own HIV test results, the women would disclose their own status. The disclosure process model suggested by Chandoir et al. (2011) provides an understanding of when and why HIV disclosure is important. In line with Chandoir et al. (2011), this study found that HIV disclosure happened

because of a desire to receive support. Hence in cases where support was not expected, disclosure did not occur. This study, however, raised another issue which is not addressed in the disclosure process model, such that one might suggest the importance of testing with the hope that the other person would also test positive. The study findings suggested that in some cases, disclosure happened when others' HIV status was known. Thus, disclosure was not practised for its benefits, but to share the same HIV status with a partner. This study therefore suggests that sero-concordant HIV disclosure is important in the context of PMTCT, as it might facilitate adherence to PMTCT processes.

10.4 Conclusion

This study revealed six main conclusions which emerged from the findings:

a) The fear of the healthcare facilities and HCPs leads to the non-utilisation of PMTCT services.
b) Societal barriers, including the lack of male involvement in the PMTCT programme, inhibit the utilisation of healthcare.
c) The lack of trust, lack of decision making-power and uncertainty related to infant feeding messages of PMTCT, together with cultural and family factors promote the practice of mixed feeding among HIV positive women and grandmothers. Mixed feeding which is influenced by culture is inappropriate and dangerous to the health of the infant.
d) The lack of understanding (related to language) and lack of complete knowledge of PMTCT promotes poor health-seeking behaviour.
e) Women's vulnerability to structural, cultural and family factors impact negatively on the effective utilisation of PMTCT services.
f) Using a small story analysis framework revealed the context in which the lived experience of participating in the PMTCT programme occurred. It is thus imperative to understand the context in terms of its geographic location (rural or urban), culture and tradition before implementing any PMTCT interventions.

The experiences that I encountered, as a postgraduate student, were life changing. Observing different HIV positive women, young and old, divulge their deepest emotions related to living with HIV sparked my realization of the negative impact of HIV on people's lives,

especially in a rural context. As an outsider, having to listen to the stories of women attending antenatal care late and participating in mixed-feeding practices because of their lack of understanding of PMTCT processes, was devastating. Strong arguments for the promotion of mixed feeding by the grandmothers, allowed the researcher to understand why the HIV positive women engage in this practice in the first place. I understand these women's predicaments which makes me sad because I had a privilege of receiving education and my journey has been very different from theirs. But I now can see what is needed in this country, we need activists and gender specialist to ensure effectiveness of the PMTCT programme. With this knowledge, I am in a position to effect social change. Women in this rural context need education, information and empowerment to make their own decisions on child-caring. This will prevent these problems from happening. Although I only wished and aimed to understand the lived experiences of being in the PMTCT programme, I ended up receiving a surplus of information, which enriched the study in providing additional factors that obstruct the utilisation of the PMTCT programme. The participants' experiences spoke volumes and provided an understanding for the lack of utilisation of the PMTCT programme. Based on the HIV positive women's and HCPs' in-depth-interviews, and the grandmothers' FGDs, conclusions were drawn regarding the non-utilisation of the PMTCT services.

10.5 Implications of the study

There are several implications of this study, which are informed by the findings and conclusions drawn. The implications particularly related to PMTCT HCPs and the Health Ministry.

10.5.1 Implications for PMTCT HCPs

The current study highlights implications for the PMTCT HCPs which might enhance their relationships with HIV positive women in the context of PMTCT.

- **Healthcare worker-client communication and attitude improvement**

As demonstrated in various Chapters of this thesis, the fear of HCPs and the healthcare facility suggests poor communication between HIV positive women and HCPs in the context of this study. Although fear stems from self-stigma and anticipated stigmatisation by others,

it is clear that one of the facilitators of adherence to PMTCT cascade processes relates to the manner in which HCPs interact with the patients. The miscommunication between the HCPs and women could lead to the non-utilisation of the PMTCT services (Kravits et al., 2000; Penn & Watermeyer, 2012; Penn 2007; Feinberg et al., 2002). Data also showed that the HCPs were viewed as agents of stigma by the HIV positive women (Holzemer et al., 2007). This seems to suggest a need to improve the communication between HCPs and patients, in order for the PMTCT programme to achieve its objective of preventing the transmission of HIV from the mother to the child. It is understood that the improvement of communication and the utilisation of PMTCT services could reduce the fear of the healthcare facilities (Bresolin et al., 1990; Gerbert et al., 1991). The data revealed by the current study seemed to suggest that peer counsellors might be instrumental in providing improved communication about PMTCT services. The fact that the peer counsellors are HIV positive might facilitate open communication about issues which women feel are necessary to address.

- **On-going HIV education and community mobilisation related to PMTCT cascade messages**

Although the data that emerged from the current study demonstrated that the PMTCT programme has been acknowledged for its important role of preventing children from being infected with HIV (Hardon et al., 2012; Etiebet, 2004), it also revealed negativities related to the utilization of PMTCT services. The discussions in Chapter Five suggested that these negativities are based on societal constructions and perceptions of health issues. The data revealed that the provision of health education that addresses early antenatal care attendance and postnatal care attendance could change some of the current perceptions including those which cause stigmatisation. The participants' narratives also suggested that there are misconceptions (for example, that pregnancy medication enlarges one's stomach), ignorance and inflexibility towards health messages at the community level. The data showed that these misconceptions, ignoring of health messages and inflexibility manifest themselves in various beliefs. Some of these beliefs included that HIV only affects certain people; people with HIV are bewitched or cursed and that an HIV positive person always looks very sick etc. The findings seem to suggest that such misconceptions and inflexibilities require a strong and massive community mobilisation towards accepting the importance of adhering to PMTCT services. It also calls for a need to conduct HIV testing and self-love campaigns on an on-

going basis. In this way, such mobilisation and campaigns might reduce the fear associated with the use of healthcare facilities and HCPs.

Community mobilisation might also attempt to facilitate parental unity, which may encourage young men and women to participate in the PMTCT programme. PMTCT programmes need to examine the messages and beliefs of specific cultures. It is for this reason that PMTCT interventions cannot take a one-size-fits-all approach. In the context of this study, PMTCT messages could involve raising awareness about infant feeding, care and treatment of the child's umbilicus, and could also involve traditional healers, to convey medically appropriate messages about child's fontanels.

The findings of this study also indicated that cultural beliefs coupled with human experiences adversely affect the utilisation of PMTCT services. This suggests that education in PMTCT should address some of the cultural beliefs and social network barriers (Thorsen et al., 2008; Kebaabetswe, 2007) that could impact negatively on the PMTCT programme. Furthermore, the findings showed that trust in the abilities of the PMTCT programme continues to form an issue (Thorsen et al., 2008; Kebaabetswe, 2007). This requires urgent intervention to review the current methodologies in which PMTCT messages are transmitted to patients. There is a need to address individual, community and economic factors that hinder PMTCT utilisation. This seems to suggest that community barriers should also be addressed during health education. It is important to develop 'TRUST' interventions, to facilitate peoples' trust in HCPs. Messages in such interventions could address HIV testing by conveying that "to test is not to infect"; ARV prophylaxis by voicing that "ARV prophylaxis really prevents the child from being infected with HIV and keep the mother healthy" and infant feeding by expressing that "exclusive breastfeeding will protect the child from being infected with HIV" and that "any child requires exclusive breastfeeding for them to be healthy". Moreover, education within the healthcare facility should also address misconceptions related to traditional and religious beliefs which inhibit adherence to treatment. Such messages could be phrased as "tea from church will not cure HIV, only treatment will and applying mouses' excretions will not heal the child's umbilicus, it will make it septic".

- **Ongoing infant feeding education**

The narrative intersections in Chapter Eight revealed that mixed feeding is a common practice in the study setting (Ukpe et al., 2009). It also revealed that family involvement, such as that of grandmothers, seems to pressurise mothers into practicing mixed feeding (Doherty et al., 2006; Thairu, 2005). The data suggested that infant feeding education for the mother alone is not enough, because often the entire family is involved in infant feeding issues. Hence, there is a need to employ infant feeding intervention strategies that should address the dangers of mixed feeding by HIV positive women. In providing such interventions, it would be best to train the grandmothers, who in turn could train other grandmothers on appropriate infant feeding practices. Since grandmothers are often fully involved in infant feeding decisions (Penn et al., 2010; Barrat & Penn, 2009; Falnes et al., 2011), they need to be informed (educated) of the recommended procedures to follow. Infant feeding interventions could address issues such as the timing of solid food introduction, water introduction, and medication from traditional healers or churches. The infant feeding campaigns should also address the social stigma related to infant feeding choice and inform community members of policy changes related to infant feeding. PMTCT messages should also take literacy issues into consideration by providing simplified PMTCT education especially for the grandmothers.

- **On-going HIV counselling post HIV diagnosis**

Data that emerged in the current study seemed to suggest that there are underlying challenges for the women, which include internalised stigma that causes poor adherence to PMTCT cascade processes. These challenges suggest a need for the on-going provision of counselling post HIV diagnosis for pregnant women and mothers who are HIV positive. The current data seemed to suggest that such counselling should include the following content areas: assisting the mother to accept her diagnosis, infant feeding guidance, treatment adherence counselling, counselling on HIV PCR testing of the child, on-going counselling of mothers waiting for the infant HIV PCR test results, counselling of mothers receiving HIV PCR test results, second and third childs' HIV testing until the baby is five years, counselling on partner dynamics and family dynamic counselling. This implies that the counsellors would need to be trained in specific issues that affect PMTCT utilisation, such as psychosocial factor 'fear'.

- **On-going male involvement intervention**

Based on the HCPs' lived experiences in Chapter Seven, men seem to show disinterest in health education that is provided on a daily basis at healthcare facilities. This was portrayed by their behaviour of moving away from groups of people who were participating in health talks. This finding suggested that there should be male-specific interventions to address their knowledge and understanding of HIV and PMTCT. It might be useful if male peer supporters could be recruited to train and counsel these men. Men should not be seen as obstacles to the PMTCT programme, but rather as vehicles for change. It is thus crucial that the traditional beliefs related to male participation in health programmes be addressed at a policy level. Male-specific interventions could take place at different venues where men in rural setting convene, such as taverns, shebeens, taxi ranks, door-to-door campaigns or boys' schools (Dwadwa-Henda et al., 2010).

- **Religious intervention for PMTCT**

A different recommendation provided by the grandmothers in Chapter Six was related to prayer. The grandmothers suggested that prayer could eliminate unruly, risky behaviour and the non-adherence to PMTCT services. This implies that religion might be an important channel through which PMTCT could be encouraged in a rural context such as the current study setting. Incorporating religion into PMTCT activities could include the following activities: attending women's prayer sessions, attending health days at church which informs community members about PMTCT and attending church youth days.

- **Other PMTCT interventions which require well-defined communication and messages**

    - Healthcare provider confidentiality interventions. This means that HCPs need to further be trained on confidentiality issues tailored for the PMTCT programme. Such training should provide guidelines on how to handle different types of HIV positive patients in different contexts.

- HIV stigma interventions, addressing issues such early antenatal care attendance, non-preference of HBCs and non-preference of HCPs and the healthcare facility.
- This study shows that social construction of health-seeking encourages the behaviour of late utilisation of healthcare services. Therefore, campaigns to change societal views about health-seeking and avoidance of the practice of HIV testing only when pregnant are vital.
- It is imperative to have HIV disclosure interventions that will address womens' fear of disclosing their HIV status because of not wanting to hurt their family members. Community members need to be taught that HIV disclosure benefits outweigh the consequences of non-disclosure especially in the context of PMTCT.
- Having campaigns that focuses on the effects of following peers in health-seeking is also important. This involves changing individual perceptions on health-seeking behaviour.
- Traditional PMTCT messages focused attention on the child. Therefore, the current study revealed a need to have campaigns that will emphasise that HIV testing is done to protect both the mother and child. If the mother is not healthy, chances of the child becoming healthy are poor.
- This study found that fear affects utilisation of PMTCT services. Therefore, it is imperative to have campaigns that address fear related to utilising PMTCT services.
- Although a lot of campaigns have been done on HIV testing through media and community mobilisation, none of those campaigns outlines through the use of laymen's language how the processes of HIV testing occurs. In the current study context, men seem to believe to be infected with HIV during HIV testing process. Therefore, in a rural context such as the area of study, there is a need to have campaigns that address the HIV testing process (step by step guide to HIV testing process) in lay mens' language.
- The current study shows communication challenges which relate to avoidance of calling the word HIV. Thus it is important to have campaigns related to the demystification of HIV communication. Such campaigns could define terminologies used in PMTCT programme and understanding its meaning.

- Structural factors have been identified as factors that affect utilisation of PMTCT services. Having campaigns that will address barriers beyond healthcare system, such as crime, pregnancy, transactional sexual relationships etc. is important in a rural context. Such campaigns could emphasise the importance of a healthy life vs. wealthy life.
- This study also revealed a high adherence on traditional and cultural treatments. Having campaigns related to traditional and cultural treatment adherence could facilitate better adherence to health services in this setting.

10.5.2 Implications for the Health Ministry

Data of the current study also suggests implications for the Ministry of Health in ensuring the effectiveness of the PMTCT programme.

Health systems improvement

- Chapter Six highlighted some of the observations made by grandmothers regarding the staffing component at the healthcare facilities. These observations imply that the government needs to develop staff recruitment and staff retention strategies, in order for PMTCT services to be up-scaled. For the PMTCT services to be effective, the current data suggested a need for the improvement of infrastructure (WHO & UNICEF, 2007). The data revealed that the non-utilisation of PMTCT services might be due to the physical location the PMTCT services. Chapter Five demonstrated that because of limited space, HIV testing rooms are labelled as rooms for HIV positive people. The data also suggested a need to address drug shortages at a facility level. The challenges could discourage people from participating in the PMTCT programme.
- Chapter Seven also highlighted challenges related to the recording system for HIV data, which affects the provision of reliable statistics on HIV positive women in the rural context. As part of the health systems improvement plan, the findings of the study suggest that there should be an integrated central PMTCT data recording system that would enable service provision to all the PMTCT clients, regardless of their point of PMTCT initiation. Presumably, an Integrated Central Data Recording System

(ICDRS) would track the movement of women between facilities. This might resolve the duplicated counting of women involved in the programme.

- Although the work of peer counsellors has been acknowledged as beneficial for the PMTCT programme, by both the HIV positive women and the HCPs, Chapter Seven revealed that peer counsellors are currently working on a contract basis. In order for the peer counsellors to continue providing excellent service within the PMTCT programme, the data suggested that the counsellors need to be offered long term contracts or permanent positions, as they were reported as instrumental in HIV counselling and testing services. Offering counsellors long term contracts or permanent positions, would encourage uninterrupted utilisation of PMTCT services.
- Chapter Seven of this thesis highlighted infant follow-up challenges, which affect PMTCT programme utilisation, and thus respond to this challenge. The provision of a clear infant follow-up plan by all the PMTCT healthcare facilities in Mpumalanga would assist in retaining most PMTCT clients. The findings showed that PMTCT clients do not always know about their follow-up dates and what the dates mean.
- Furthermore, intersecting narratives were found among the three groups of participants related to challenges with PMTCT language, especially for the older generation. This finding suggested that PMTCT messages should be simplified so that they may be fully comprehended by the community, including older members of the community, as older women are often involved in the programme. Native language should be used on posters and in any other form of PMTCT communication. HCPs should further simplify PMTCT language when conversing with patients.
- The data revealed by the study suggested that the family involvement of grandmothers and male partners is important for the success of the PMTCT programme. The HCPs proposed an important amendment of policy related to family involvement in PMTCT. This calls for policy amendment that allows grandmothers to initiate children's treatment, as they are often already the primary caregivers of the children. Male involvement strategies in a rural context need to be explored.

10.6 Areas for further research and dissemination of the findings

a. Exploration of the impact of PMTCT communication training programmes at the community and healthcare facility level.

b. Further research is needed to understand the community perceptions and views on pregnancy issues, in order to successfully implement interventions that would assist with PMTCT utilisation. Addressing societal fears of health needs to form part of PMTCT education.
c. Further research needs to be conducted on the reasons for women's preference of traditional and cultural practices over medical solutions that are been provided to achieve baby wellness, particularly in the context of PMTCT.
d. A review of what rural patients understand about the PMTCT programme is needed.
e. Further research to explore the differences between rural and urban PMTCT education is required, in order to identify factors (such as language use) that have the potential to negatively affect PMTCT in a rural context.
f. Further research is needed to understand the male perceptions of PMTCT and their views on participation in the PMTCT programme in a rural context.
g. Exploration of the impact of grandmothers' and males' involvement in the PMTCT programme is required.
h. Exploration of how structural violence factors affect PMTCT effectiveness is needed.
i. Exploration of how the effects of gender vulnerability affect PMTCT effectiveness is required.
j. Exploration of collective parenting as a way of improving PMTCT utilisation in a rural setting is required.

The results for the current study will be disseminated to the Mpumalanga Department of Health which granted permission for the current study to be conducted. These results might assist the PMTCT staff at the healthcare facilities to better understand the reasons for non-timeous utilisation of PMTCT services at their respective facilities. The results might also assist policy and decision makers in introducing the necessary interventions to improve PMTCT services. The results will also be published in peer reviewed journals.

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APPENDICES

Appendix A: Published Articles by the researcher

1. Peltzer K & **Mlambo G** (2013). Sexual HIV risk behaviour and associated factors among pregnant women in Mpumalanga South Africa. BMC Pregnancy and Childbirth, 13:57
2. Matseke, G, Peltzer, K and **Mlambo, G.** (2012) Partner violence and associated factors among pregnant women in Nkangala District Mpumalanga. South African Journal of Obstetrics and gynaecology, 18(3).
3. **Mlambo MG** and Peltzer K (2011). HIV Sero-status disclosure and sexual behaviour among HIV positive patients who are on antiretroviral treatment (ART) in Mpumalanga, South Africa. *Journal of Human Ecology*, 35 (1): 29-41.
4. Nancy Phaswana-Mafuya, Karl Peltzer, Rendani Ladzani, **Gladys Mlambo**, Adlai Davids, Khanyisa Phaweni, Pelisa Dana & Mandisa Ndabula (2011): Pre- and post-intervention assessment of a PMTCT-programme strengthening initiative in a rural area of the Eastern Cape, South Africa, African Journal of AIDS Research, 10:1, 83-93
5. Peltzer, K; **Mlambo M**; Phaswana-Mafuya N & Ladzani R (2010) Determinants of adherence to single-dose Nevirapine regimen for the prevention of mother-to-child HIV transmission in Gert Sibande District in South Africa. *Acta Paediatrica*. 99:699-704.
6. Peltzer K & **Mlambo G**. (2010) Factors determining HIV viral testing of infants in the context of mother-to-child transmission. *Acta Paediatrica*. 99:590-596.
7. Peltzer K; **Mlambo G** & K Phaweni (2010) Factors determining prenatal HIV testing for the prevention of mother-to-child transmission of HIV in Mpumalanga, South Africa. AIDS Behaviour, 14(5) 1115-23
8. Phaweni K; Peltzer K; **Mlambo G** & Phaswana-Mafuya N (2010) Factors influencing pregnancy desires among HIV positive women in Gert Sibande District in Mpumalanga, South Africa. *Gender & Behaviour*, 2: 2960-2975.
9. Ladzani R; Peltzer K; **Mlambo MG**; Phaweni K (2010) Infant-feeding practices and associated factors of HIV-positive mothers at Gert Sibande, South Africa. *Acta Paediatrica, 100 (4): 538-542.*

Appendix B: University of the Witwatersrand Ethics approval letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Motlatso Gladys Mlambo

CLEARANCE CERTIFICATE	**M110666**
PROJECT	HIV Positive Women's Experience of Participating in the Prevention of Mother-to-Child Transmission of HIV Programme in Nkangala District, Mpumalanga
Province	
INVESTIGATORS	Ms Motlatso Gladys Mlambo.
DEPARTMENT	Speech Pathology & Audiology
DATE CONSIDERED	24/06/2011
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 20/07/2011 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Claire Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix C: Ethics approval letter Mpumalanga Department of Health

MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
No. 7 Government Boulevard
Riverside Park Extension 2
Nelspruit
1200
Republic of South Africa

Private Bag X 11285
Nelspruit, 1200
Tel: 013 766 3429
int: +27 13 766 3429
Fax: 013 766 3458
int: +27 13 766 3458

Department of Health

Litiko Letemphilo | Umnyango WezaMaphilo | Departement van Gesondheid

Enquiries: Themba Mulungo (013) 766 3511

11 March 2013

Ms. Gladys Mlambo
134 Pretorius Street
PRETORIA
0002

Dear Ms. Gladys Mlambo

APPLICATION FOR RESEARCH & ETHICS APPROVAL: HIV POSITIVE WOMEN'S EXPERIENCES OF PARTICIPATING IN THE PMTCT PROGRAMME IN NKANGALA DISTRICT, MPUMALANGA PROVINCE.

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent.

Kindly ensure that you provide us with the soft and hard copies of the report once your research project has been completed.

Kind regards

Machaba

Mr. Molefe Machaba
Research and Epidemiology

11/03/2013
Date

We care. Do you?
Siyanakekela

MPUMALANGA
A Pioneering Spirit

Appendix D: Sample letter to study sites

Healthcare Manager

To Whom It May Concern,

My name is Motlatso Mlambo and I am doing PhD in Speech Pathology and Audiology & Linguistics at the University of Witwatersrand. I am conducting a study titled: "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context." The sample for the study would be twenty-five (25) HIV positive women recently diagnosed with HIV; four (4) focus group discussions with grandmothers in the area of study and five (5) healthcare professional interviews. The women will be recruited at the following proposed sites: Phake CHC, Nokaneng CHC and Mmametlhake hospital.

Women will be recruited during the antenatal care and postnatal care services at the clinic. At the hospital, women will be recruited after delivery. In order to elicit information on how these women understand and make decisions about participation in PMTCT, in-depth narrative interviews would be conducted with the five categories of women who are at different stages and/ or at different points within the PMTCT programme. Firstly, the interview would be conducted with five (5) pregnant women who are coming for the second ANC visit and have been diagnosed HIV positive in their first antenatal care visit. The second interview session would be with five (5) women who have just received AZT at 14 weeks together with infant feeding counselling. The third interview session would be with five (5) women who have just given birth. The fourth interview session would be with five (5) women who have come for the 6 weeks visit coinciding with PCR testing of the infant at six weeks of age. The last interview session would be with five (5) women who came to receive their infants' PCR test results.

Furthermore, four focus groups (2 in each area of study) will be conducted with grandmothers in order to elicit narratives on community's general understanding of PMTCT. In order to avoid stigma for HIV positive women, grandmothers will be randomly chosen at the healthcare facility to participate in the focus group discussions. In-depth interviews will also be conducted with five (5) health care professionals in the three (3) facilities (two (2) interviews per CHC and 1 interview at the hospital). The interviews will be conducted with the staff that is offering PMTCT services.

Ethics approval has been granted by both the Witwatersrand Research Ethics committee and Mpumalanga Department of Health, Ethics.

If you have any queries, kindly contact Ms Mlambo on 072 123 0778.
Sincerely

Ms Motlatso Mlambo
University of Witwatersrand

Appendix E: Information sheet for patient individual interviews

Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

Good Day,

My name is **Motlatso Mlambo** from Witwatersrand University. I am conducting a study on "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context". I would like to invite you to participate in this study which involves asking you some questions about the PMTCT services which you have received. I would also like to ask you a few questions about your health and how you feel. I will record the interview on the tape. The information that you will provide will help the PMTCT staff to improve the services in this Province.

The interview will last about 60 minutes. When it comes to answering questions there are no right and wrong answers. Everything that you say when answering the questions will be treated as private and confidential. This means that apart from the person who asks you the questions, no one will know how you answered. Your name will not be revealed in any written data or report resulting from the study. I want to stress that it is completely voluntary to participate in this study. If you choose not to take part in answering these questions, you will not be affected in any way whatsoever. If some of the questions make you feel uncomfortable, you do not have to answer them. If you feel you need further counselling, I will refer you to the counsellors in this healthcare facility.

There are potential risks to participating in this study. There is the potential for breaches of confidentiality of someone's sero-status. Procedures have been put in place to ensure that this will not occur. To avoid possible breaches of confidentiality, our staff has been trained to carefully follow detailed procedures designed to assure that no information about any persons will be released to anyone outside the research team. Any information on the tape recorders will be held in private and kept in the strictest confidence. It will not be provided to other persons. The only place where names will appear is on the informed consent form, indicating agreement to take part in this study. These forms will be kept in a locked filing cabinet, which will be kept separate from the interview. Codes will be used to protect identity.

Once we have started the interview, you still have the right to withdraw your consent or discontinue your participation at any time without any penalties. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact Ms Motlatso Mlambo by phoning 012-302-2608 or Professor Claire Penn and Professor Tommaso Milani at 011 717 4577. If you have any ethical concerns about the study you may also call the Witwatersrand University Medical Ethics Committee on 011-717 1234. Please note that this information sheet is for you to keep. Thank you

Appendix F: Information sheet for grandmothers Focus Group Discussions (FGDs)

Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

Good day,

My name is Motlatso Mlambo from Witwatersrand University. I am conducting a study on "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context". I would like to invite you (grandmothers) to participate in this study which will involve asking you some questions about the PMTCT services that women (your daughters and daughters in law) in this community receive from clinics and hospitals. I would like to get your views regarding your understanding of the programme and what impact would it have if grandmothers are involved. I will record the interview on the tape. The information that you will provide will help the PMTCT staff to improve the services.

The focus group interview will last about 120 minutes. When it comes to answering questions there are no right and wrong answers. Everything that you say when answering the questions will be treated as private and confidential. This means that apart from the person who asks you the questions, no one will know how you answered. Your names will not be revealed in any written data or report resulting from the study. I want to stress that it is completely voluntary to participate in this study. If you choose to not take part in answering these questions, you will not be affected in any way whatsoever. If some of the questions make you feel uncomfortable, I will refer you to the counsellors in this facility.

There are potential risks to participating in this study. There is the potential for breaches of confidentiality of someone's sero-status. Procedures have been put in place to ensure that this will not occur. To avoid possible breaches of confidentiality, our staff has been trained to carefully follow detailed procedures designed to assure that no information about any persons will be released to anyone outside the research team. Any information on the tape recorders will be held in private and kept in the strictest confidence. It will not be provided to other persons. The only place where names will appear is on the informed consent form, indicating agreement to take part in this study. These forms will be kept in a locked filing cabinet, which will be kept separate from the interview. Codes will be used to protect identity.

Once we have started the interview, you still have the right to withdraw your consent or discontinue your participation at any time without any penalties. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact Ms Motlatso Mlambo by phoning 012-302-2608 or Professor Claire Penn and Professor Tommaso Milani at 011 717 4577. If you have any ethical concerns about the study you may also call the Witwatersrand University Medical Ethics Committee on 011-717 1234. Please note that this information sheet is for you to keep. Thank you

Appendix G: Information sheet for Healthcare Provider interviews



Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

Good day,
My name is Motlatso Mlambo I am a PhD student at Witwatersrand University. I am conducting a study entitled: "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context." This study aims to explore and understand HIV positive women's lived experiences of participating in the PMTCT programme, understand grandmothers views of PMTCT and explore HCPs lived experiences of PMTCT service provision. I therefore would like to get your views on PMTCT programme implementation. Your input will complement responses given by HIV positive mothers on their experiences of participating on the PMTCT programme and that of grandmothers. Information provided will assist us in making recommendations for improved utilization of PMTCT services to the Nkangala District.

I would therefore like to invite you to participate in this study which will involve asking you some questions about the PMTCT services implementation. I will record the interview on the tape. The interview will last about 60 minutes. When it comes to answering questions there are no right and wrong answers. Everything that you say when answering the questions will be treated as private and confidential. This means that apart from the person who asks you the questions, no one will know how you answered. Your names will not be revealed in any written data or report resulting from the study. I want to stress that it is completely voluntary to participate in this study. If you choose to not take part in answering these questions, you will not be affected in any way whatsoever. If some of the questions make you feel uncomfortable, I will refer you to the counsellors in this facility.

There are potential risks to participating in this study. There is the potential for breaches of confidentiality of someone's sero-status. Procedures have been put in place to ensure that this will not occur. To avoid possible breaches of confidentiality, we have been trained to carefully follow detailed procedures designed to assure that no information about any persons will be released to anyone outside the research team. Any information on the tape recorders will be held in private and kept in the strictest confidence. It will not be provided to other persons. The only place where names will appear is on the informed consent form, indicating agreement to take part in this study. These forms will be kept in a locked filing cabinet, which will be kept separate from the interview. Codes will be used to protect identity.

Once we have started the interview, you still have the right to withdraw your consent or discontinue your participation at any time without any penalties. If you have any questions about your rights as a study participant, or questions or concerns about any aspect of the study, you may contact Ms Motlatso Mlambo by phoning 012-302-2608 or Professor Claire Penn and Professor Tommaso Milani at 011 717 4577. If you have any ethical concerns about the study you may also call the Witwatersrand University Medical Ethics Committee on 011-717 1234. Please note that this information sheet is for you to keep. Thank you

Appendix H: Consent form for patient individual interveiws

Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

I……..*(full names)*, hereby willingly volunteer to participate in the WITS-led study entitled: "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context."

I have read and understood the provided information sheet and understand that any information that I may give will not be linked to my personal identity.

I, therefore, consent to be interviewed, to enable the WITS research team to collect information during the study.

_____ _____

Participant Name (printed) Date of Birth

_____ _____

Signature of Participant Date

_____ _____

Interviewer Signature Date

If verbal consent is provided, the interviewer must sign below in the presence of the participant and a witness.

_____ _____

(Signature of interviewer certifying that informed consent has been given verbally by respondent) Date

_____ _____

(Signature of witness certifying that informed consent has been given verbally by respondent) Date

_____

I……..(full names), hereby willingly give consent for the interview to be **tape recorded and transcribed and** to be used by the WITS for the purpose of data analysis and report writing.

_____

Participant Name (printed)

_____ _____

Signature of Participant Date

Appendix I: Consent form for Focus Group Discussions

Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

I……..*(full names),* hereby willingly volunteer to participate in the WITS-led study entitled: "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context."

I have read and understood the provided information sheet and understand that any information that I may give will not be linked to my personal identity.

I, therefore, consent to be interviewed, to enable the WITS research team to collect information during the study.

_____ _____

Participant Name (printed) Date of Birth

_____ _____

Signature of Participant Date

_____ _____

Interviewer Signature Date

If verbal consent is provided, the interviewer must sign below in the presence of the participant and a witness.

_____ _____

(Signature of interviewer certifying that informed consent has been given verbally by respondent) Date

_____ _____

(Signature of witness certifying that informed consent has been given verbally by respondent) Date

_____

I……..(full names), hereby willingly give consent for the interview to be **tape recorded and transcribed and** to be used by the WITS for the purpose of data analysis and report writing.

_____

Participant Name (printed)

_____ _____

Signature of Participant Date

Appendix J: Consent form for Healthcare Providers

Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context

I……..*(full names),* hereby willingly volunteer to participate in the WITS-led study entitled: "Intersecting narratives of PMTCT: the lived experiences of HIV positive women, grandmothers and HCPs in a rural South African context."

I have read and understood the provided information sheet and understand that any information that I may give will not be linked to my personal identity.

I, therefore, consent to be interviewed, to enable the WITS research team to collect information during the study.

_____ _____

Participant Name (printed) Date of Birth

_____ _____

Signature of Participant Date

_____ _____

Interviewer Signature Date

If verbal consent is provided, the interviewer must sign below in the presence of the participant and a witness.

_____ _____

(Signature of interviewer certifying that informed consent has been given verbally by respondent) Date

_____ _____

(Signature of witness certifying that informed consent has been given verbally by respondent) Date

_____

I……..(full names), hereby willingly give consent for the interview to be **tape recorded and transcribed and** to be used by the WITS for the purpose of data analysis and report writing.

_____

Participant Name (printed)

_____ _____

Signature of Participant Date