

SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF THE WITWATERSRAND

Postnatal experiences, perceptions and practices of the Prevention of Mother to Child Transmission of HIV Programme among women enrolled at a Johannesburg Community Health Centre, South Africa.

A Report Submitted in Partial Fulfilment for the Master of Public Health

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Declaration

I, Benon Ngyende, hereby declare that this research report is my own original work except otherwise stated. It is being submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg in partial fulfilment of the requirement for the degree of Master of Public Health. I declare that to the best of my knowledge, it has not been submitted in part or in full, for any degree or examination at this or any other university.

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Place

Date

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June 2017

Abstract

Introduction: South Africa has made great strides to reduce the national rate of mother to child transmission of HIV (MTCT) since the implementation of Prevention of Mother to Child transmission (PMTCT) programme in 2002. However, the programme still faces a number of challenges including the increasing rate of post-natal MTCT. Although many studies have been done on PMTCT in South Africa, there is a scarcity of information on postnatal PMTCT. In particular, there is a dearth of information regarding postnatal experiences, perceptions and practices among women attending postnatal PMTCT services. Similarly, there is a paucity of data on enablers and barriers to postnatal PMTCT from the users' perspective. The aim of the study was to explore the postnatal PMTCT experiences, perceptions and practices among women enrolled on the programme as well as to identify the key reported enablers and barriers to their attendance of the programme at a Johannesburg community health centre (CHC), during April-May, 2016.

Methodology: Fifteen women enrolled on a PMTCT programme at the CHC participated in the study. A purposive sampling strategy was used to recruit women who have been enrolled on the postnatal PMTCT programme for at least a period of six weeks. A qualitative research design was employed and data were collected through in-depth individual interviews using a standard interview guide. The data was analysed thematically to understand women's experiences, perceptions and practices in the postnatal PMTCT services. Using both deductive and inductive analysis, various themes emerged from the voices of the women themselves. The analysis of results was guided by the conceptual framing of the study, which drew on Ferguson's (2013) literature review of women's experiences in PMTCT services. This literature

review presents PMTCT experiences as comprised health services, individual and societal levels. Health services include counselling, confidentiality and health facility factors, individual level includes attitude and beliefs, perception of need and competing obligations while the societal level comprises stigma, gender and legal and policy environment.

Results: With respect to postnatal PMTCT women's experiences, the study identified confidentiality and health facility factors (availability of drugs and easy access to CHC) as key enablers to the postnatal PMTCT services. However, inadequate postnatal PMTCT counselling, sub-optimal health worker-client interactions (uncaring, rude, judgemental, disrespectful and discriminatory attitudes) and health facility factors (long waiting times, queuing at different departments within the CHC and shortage of the postnatal PMTCT staff) were identified as key barriers to these services. The study identified adequate knowledge on the postnatal PMTCT as enabler, while competing obligations and ART side effects were identified as key barriers to the postnatal PMTCT from individual-level perspective. Furthermore, stigma was identified as the key barrier to the postnatal PMTCT from societal-level perspective.

With regard to postnatal PMTCT women's perceptions, the perceived importance of postnatal PMTCT counselling, the effectiveness of the postnatal PMTCT programme and the convenience as well as cost-effectiveness of exclusive breastfeeding were identified as enablers to postnatal PMTCT. However, negative perceptions of adherence to ART and exclusive breastfeeding were identified as barriers to the postnatal PMTCT from individual-level perspective.

With respect to postnatal PMTCT women's practices, compliance with the follow up clinic visits and adherence to ART were identified as enablers while inadequate practicing of exclusive

breast feeding was identified as a barrier to the postnatal PMTCT from individual-level perspective.

Conclusion: The South African PMTCT programme has made great progress to curb the rate of MTCT since its implementation. However, many challenges still remain including increasing MTCT among HIV exposed infants during the postnatal period. In order to meet the national goal to eliminate the postnatal MTCT, researchers, health policy makers, individual users and community need to be aware of postnatal PMTCT enablers and barriers at different levels: health services, individual and societal levels. Furthermore, it is critical to improve women participation and ensure optimal outcomes for women and their infants by strengthening the programme enablers as well as addressing the bottlenecks.

Key words: Postnatal PMTCT, experiences, perceptions, practices, enablers, barriers

Dedication

To the God of my spiritual father Prophet Shepherd Bushiri Major-1 for revealing God's deep secrets. Major-1 has taught as well as demonstrated to us that everything is possible and nothing is impossible with our God.

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Definitions of Key Terms

Experience

The Oxford dictionary (2005:513) defines experiences as “things that have happened to a person and influenced the way that person thinks and behaves.” Furthermore, experience may be the “knowledge or skill resulting from this” (acquisition of facts or events). Within the context of this study, the term experience refers to things that have happened to, the actual observation or practical personal facts/knowledge the women have acquired on the PMTCT programme.

Perception

The Thesaurus dictionary defines perception as the way in which someone regarded, understood, felt or interpreted something.” In this study, the term perception in the study refers to how the women understood, felt or thought about the programme.

Practice

The Thesaurus dictionary defines practice as the things that are being done to address the situation. Advanced learners dictionary records that practice is “an action or execution as opposed to theory.” In this study, the term practice is used in the study to refer the things or actions that the women are doing/not doing to prevent mother-to-child transmission of HIV.

CHAPTER 1 INTRODUCTION

1.1 Introduction to chapter one

This chapter sets the context of MTCT/PMTCT programme at national and global levels. The gap in the postnatal PMTCT programme is identified and the problem statement is formulated. The study objectives and its justification are presented. Furthermore, a conceptual framework of postnatal PMTCT women's experiences, perceptions and practices is adopted from Ferguson's (2013) literature review.

1.2 Study context

Mother-to-child transmission (MTCT) of human immunodeficiency syndrome (HIV) continues to be a public health challenge worldwide (1). Globally about 1% of expectant women were infected with HIV by 2012 (2). The overwhelming majority (95%) of infected pregnant women was in sub-Saharan Africa (3). At least 150,000 children were newly infected with HIV in 2015, of which 46% (56,000) occurred in East and Southern Africa (4). The rate of postnatal HIV infection in sub-Saharan Africa, including South Africa, remains unacceptably high (5) and about 1000 newborns become infected every day (5).

In South Africa, the HIV/AIDS epidemic represents one of the greatest public health challenges in the country (6). Despite having the world's largest ART programme, South Africa remains the epicentre of the epidemic with the highest number of people living with HIV/AIDS in the world (6). An estimated 160,000 women aged between 15 and 49 years became newly HIV infected in 2014 (7). In the same year, about 92,000 children younger than 14 years old also became newly infected with HIV in South Africa (7).

HIV remains a main cause of infant morbidity and mortality in South Africa, with HIV-associated deaths accounting for at least one third of all deaths in children under five (8). It has been argued that the lack of compliance with the PMTCT guidelines may be the cause of the increasing rate of HIV infection in the postnatal period (9-11). Therefore, exploration of women's experiences, perceptions and practices may provide useful insights to strengthen enablers and address barriers to postnatal PMTCT and consequently improve programme compliance.

1.3 Problem statement

Despite the effectiveness of PMTCT programme in South Africa, the increasing rate of MTCT of HIV during the postnatal period remains a major concern (12). A recent cohort study showed that the rate of MTCT increases after birth with postnatal age in South Africa (12). Studies have shown that there are significant gaps in PMTCT service delivery in the postnatal period (13-15). Several authors have argued that women often fail to comply fully with PMTCT guidelines (9, 10). However, to the best of our knowledge, there is limited research that has been conducted to explore the reasons affecting women's compliance to PMTCT in the postnatal period. The current study attempted to explore the experiences, perceptions and practices of women enrolled on the PMTCT programme at a Johannesburg Community health centre (CHC) in light of the aforementioned problem.

Anecdotally, evidence from clinic-level, suggests a growing concern with the postnatal period in particular (16). For example, one of my supervisors and former facility manager in Johannesburg Health District indicated that the rate of postnatal MTCT of HIV was high and of great concern to programme managers (16). He strongly felt that there was need to conduct a study to inform the programme (16). In addition, the Johannesburg District

Research Committee (DRC) supported our motivation for a study to be conducted at the community health centre to explore the postnatal women's experiences, perceptions and practices of the PMTCT programme.

1.4 Study Question, Aim and Objectives.

1.4.1 Research Question

What are the enablers and barriers to postnatal PMTCT programme among the women enrolled on the programme at a Johannesburg CHC based on their experiences, perceptions and practices during April-May 2016?

1.4.2 Aim of the study

To explore the postnatal PMTCT experiences, perceptions and practices among the women enrolled on the programme as well as to identify the key reported enablers and barriers to the programme at a Johannesburg CHC during April-May 2016.

1.4.3 Specific study objectives

1. To explore postnatal PMTCT experiences among women enrolled on the programme at a Johannesburg CHC, during April-May, 2016.
2. To explore postnatal PMTCT perceptions among women enrolled the programme at a Johannesburg CHC during April-May, 2016.
3. To explore postnatal PMTCT practices among women enrolled on the programme at a Johannesburg CHC during April-May, 2016.
4. To identify key reported enablers and barriers to postnatal PMTCT programme among women enrolled at a Johannesburg CHC, during April-May, 2016.

1.5 Study Justification

This research was carried out in response to an identified gap in the literature and in practice as well as a need for further information identified within the local district where the research took place. For facility managers and staff, as well as policy makers, it is a real concern that the MTCT rate increases with the postnatal age among the exposed infants (12). The findings of this study will, therefore, provide insights for policy makers, programme managers, supervisors and other stakeholders into the postnatal experiences, perceptions and practices of women enrolled on the PMTCT programme.

1.6 Conceptual framework

In 2013, Ferguson conducted a literature review on women's experiences in PMTCT services (17) and categorised women's experiences of PMTCT programme into three broad levels, including health service, individual and societal-levels. Each of the three broad levels encompasses different elements: Health services barriers cover counselling, consent, confidentiality, health worker and client interactions, and health facility factors. Individual-level barriers include attitudes and beliefs, financial barriers, lack of information, competing obligations, perception of needs, partners or spouses and influence of the family members. Societal-level barriers encompass stigma, gender, and the legal as well as policy environment (17). Ferguson's literature review on PMTCT women's experience barriers is summarised in table 1.

Table 1 Ferguson's literature review on PMTCT women's experiences barriers

Health services barriers	Individual–level barriers	Societal-level barriers
<p>Counselling</p> <p>Lack of follow up counselling</p> <p>Feeling unable to ask questions during PMTCT due to power imbalances</p> <p>Consent</p> <p>Perceptions of mandatory testing</p> <p>Confidentiality</p> <p>Breach of confidentiality of health</p> <p>Health worker and client interactions</p> <p>Poor health worker attitudes</p> <p>Lack of trust</p> <p>Health facility factors</p> <p>Long travel time to facility</p> <p>Long waiting times</p> <p>Having to visit multiple clinics</p> <p>Insufficient staff to provide services</p>	<p>Attitudes& beliefs</p> <p>Denial of diagnosis</p> <p>Depression</p> <p>Alternative health beliefs (e.g traditional)</p> <p>Fear of child being diagnosed with HIV</p> <p>Financial barriers</p> <p>Perceived cost of PMTCT services</p> <p>Transport and food costs</p> <p>Lack of information</p> <p>Low knowledge of PMTCT or available services</p> <p>Misconceptions about HIV and PMTCT interventions</p> <p>Competing obligations</p> <p>Work(paid or housework) and children</p> <p>Interrupted personal routine (e.g away from home)</p> <p>Perception of need</p> <p>Lack of perceived benefits of PMTCT</p> <p>Partner/spouse</p> <p>Fear not being able to disclose HIV status to partner, including fear of negative reactions</p> <p>Unsupportive partner</p> <p>Influence of the family members</p> <p>Family pressure</p>	<p>Stigma</p> <p>General fear stigma</p> <p>Fear of being seen at PMTCT services</p> <p>Fear of being obligated not to breastfeed</p> <p>Gender</p> <p>Dependent on husband for income</p> <p>Women’s lack of decision-making power within family</p> <p>Policy and policy environment</p> <p>Absence of a supportive legal and policy environment</p>

Table 2 Current study conceptual framework

	Health Services	Individual-level	Societal level
Experiences	Counselling	Attitudes and beliefs	Stigma
	Confidentiality	Financial barriers	Gender
	Consent	Lack of information	
	Health worker –client interactions	Competing obligations	Legal and policy environment
	health facility factors		
Perception	Perceived importance on PMTCT postnatal Counselling:	Perceived effectiveness of PMTC programme Perceived challenge to adherence to ART and exclusive breastfeeding.	Perceived adequate emotional support from the community
Practices	Follow-up clinic visits and HIV tests	Follow-up clinic visits	Provision of ARVs
	Postnatal counselling	Adhering to HIV treatment and prophylaxis	HIV policies and programmes
			Community intolerance to exclusive breastfeeding

This sections explains the conceptual framework (Table 2) used in this study. The study explores the women’s experiences, perceptions and practices in the postnatal PMTCT programme. Based on the women’s experiences, perceptions and practices, the study identifies the key reported enablers and barriers to the women attending PMTCT programme.

In this research report, concepts in Ferguson’s literature review (Table 1) were developed into a framework for categorising women’s postnatal PMTCT experiences, perceptions and practices. Ferguson’s literature review further categorised women’s experiences in PMTCT services into health services, individual and societal levels. The Ferguson’s categorisation of women’s experiences adopted in this report was applied to women’s perceptions and practices in PMTCT services. Furthermore, in Ferguson’s literature, women’s experiences in PMTCT services were articulated as barriers to attending these services. Similarly, based on women’s experiences, perceptions and practices, the study identified key reported enablers

and barriers to attending postnatal PMTCT programme (Table 5 and 6). According to Ferguson's literature, health services women experiences include counselling, consent, confidentiality, health worker-client interactions and health facility factors. On the other hand, individual level women experiences include attitude and beliefs, financial barriers, lack of information and competing obligation. Furthermore, the societal level women experiences include stigma, gender and legal and policy environment. In this report, Ferguson's categorisation of women's experiences in PMTCT services into health services, individual and societal levels used to categorise women's perceptions and practices in PMTCT services. At the health services level, women perceptions include the perceived importance of postnatal counselling. At the individual level, women's perceptions include perceived challenge to adherence to ART, ART side effects and exclusive breastfeeding. Furthermore, at societal level, women's perceptions include perceived inadequate community emotional support.

At the health services level, women's practices in the PMTCT programme include follow up clinic visits and testing and counselling while at the individual level, they include follow up clinic visits and adhering to treatment and prophylaxis. At the societal level, women practices include intolerance to exclusive breastfeeding.

1.7 Chapter one summary

In this chapter, the study context was set, and the problem statement presented. The study question and objectives were stated. Then, the need for the current study as well as the conceptual framework on postnatal PMTC women's experiences, perceptions and practices were justified. The next chapter covers the literature review.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction to chapter two

This chapter highlights key literature relevant to MTCT/PMTCT. A brief overview of South African PMTCT programme and its effectiveness are presented. It covers postnatal PMTCT women's experiences, perceptions and practices. Furthermore, a summary of research gaps and a brief discussion of how this study will close the gaps or contribute to the existing literature is covered.

2.2 Mother-to-Child Transmission of HIV (MTCT)

MTCT is the leading cause of HIV infection in infants worldwide (18). MTCT can occur during pregnancy, childbirth or breastfeeding (19, 20). If no intervention is put in place to mitigate MTCT, the risk of HIV infection would vary from 15 to 25% and from 25 to 35% in developed and developing countries respectively (21). It has been argued that the difference in risk of MTCT is mainly due to longer breastfeeding periods in developing countries (22). In fact about 15-20% infections in infants occur during pregnancy, 10-20% during childbirth and 33% during breastfeeding in developing countries (19, 22). Moreover, the total estimated risk of MTCT is about 15-25% without breastfeeding (9, 23). This risk increases up to 20-35% with breast feeding for 6 months, and 30-45% with breast feeding up to 18-24 months (23).

2.3 Prevention of Mother-to-Child Transmission of HIV (PMTCT)

PMTCT is a combination of interventions including antiretroviral therapy (ART), safe delivery services, and safe infant feeding. The aim of PMTCT is to reduce the risk of new-borns acquiring HIV from their HIV- positive mothers (24).

A well-implemented PMTCT programme is highly effective to improve both maternal and child health status (9, 24) and prevent MTCT by 98% (24). The 2010 World Health Organization report recommends a comprehensive four pronged approach to prevent MTCT (25).

- (i) primary prevention of HIV infection among women of child bearing age;
- (ii) preventing unintended pregnancies among women living with HIV;
- (iii) preventing HIV transmission from a woman living with HIV to her infant; and
- (iv) providing appropriate treatment, care and support to mothers living with HIV and their children as well as their families to prevent the transmission of HIV infection.

2.4 Overview of the South African PMTCT Programme

PMTCT is one of the leading programmes in South Africa to curb transmission of HIV from mothers to new-borns (26, 27). PMTCT has been widely acclaimed as an effective HIV intervention (28). The programme targets women of child bearing age before and during pregnancy, through childbirth and during the postnatal period up to 18 months (29). About 95% of pregnant South African women living with HIV accessed PMTCT services in 2014 (4). From 2010 to 2015, PMTCT services reduced the number of newly HIV infected children by approximately 66% (4). Furthermore, it is estimated that the rate of MTCT fell from 12% in 2008 to 1.5% in 2016 (12, 23).

Following WHO guidelines, South Africa's postnatal PMTCT package comprises a series of interrelated interventions, namely, (i) HIV counselling and testing, (ii) ARV prophylaxis and treatment, (iii) infant feeding counselling, and (iv) postpartum follow-up care. Each

component of the programme is critical and shortcomings in one component will undermine the overall effectiveness (30). The postnatal PMCT components are briefly covered below.

HIV Counselling & Testing (HCT)

HCT represents the first step of PMTCT (31). It provides opportunity for mothers to learn about preventing HIV infections in their offspring. It encourages families and communities to know their HIV status and support mothers attending the postnatal PMTCT services(31). Furthermore, HCT assists to identify and curtail behaviours that escalate risks of HIV transmission (31, 32). It presents an opportunity to provide appropriate patient education on HIV and adherence(31, 32) and is also vital for successful PMTCT and referral pathways linking patients to HIV care (31). For PMTCT programme to be effective, HIV positive mothers must receive appropriate education, counselling and support during the pregnancy and postnatal period (31).

ART Prophylaxis and Treatment

South Africa's 2015 national PMTCT guidelines support the use of ART during breastfeeding to reduce postnatal MTCT (31). The use of ART as a single intervention has the potential to reduce MTCT from 15-45% to less than 5% at 18 months of age (32). The use of ART requires regular engagement between health system personnel and women attending postnatal PMTCT services (31). These services provide the basis for ongoing counselling and support for women seeking postnatal PMTCT services (31). All HIV exposed- infants, regardless of whether they are formula- or breast- fed, should be given Nevirapine(NVP) as antiretroviral prophylaxis from birth to six weeks of age to reduce MTCT (31). At six weeks, infants should be tested by using Polymerase chain reaction (PCR) to ascertain the existence or absence of

HIV infection (31). In cases where the infant is confirmed HIV negative and he/she is on exclusive formula feeding, the NVP prophylaxis is stopped (31). However those who are exclusively breastfed should continue NVP prophylaxis for 6 weeks after cessation of exclusive breastfeeding and the PCR is repeated to verify their HIV status (31). Any positive PCR result at this stage is followed by immediate initiation of life-long ART (31).

Safer infant feeding

The South African PMTCT guidelines state that at every antenatal care (ANC) visit, mothers should be counselled on infant feeding (31). It is recommended that infants born to HIV-positive mothers should be on ART prophylaxis and be exclusively breastfed for six months (31). The South African infant feeding policy is aligned to the WHO 2016 infant feeding guideline update (33).

2.5 Effectiveness of PMTCT programme in South Africa

Since the PMTCT programme was implemented in South Africa in 2002, considerable progress has been achieved (31). Its effectiveness has been widely acknowledged by several studies (1, 12, 23, 24). In fact the current rate of MTCT is 1.5% (12), compared to 12% in 2008 at the 6-8 weeks of age (23). Yet the relative increase in postnatal HIV infections in recent years point to worrying concerns for the health of children (12). The PMTCT programme greatly influences women's lives including their experiences, perceptions and practices (17).

The understanding of women's postnatal PMTCT experiences, perceptions and practices will therefore help service providers and policy makers to provide tailor-made and contextualised services that will improve participation and ensure better outcomes for mothers and their infants (17). Positive experiences may positively influence women's

perceptions and practices which may contribute towards programme effectiveness. Although experiences, perceptions and practices were considered separately in this study, it is worth noting that those three concepts are intertwined (34).

2.6 Postnatal PMTCT women's experiences

The following section reviews the contemporary literature on postnatal PMTCT women's experiences at health services, individual and societal-levels as shown in study conceptual framework (Table 2)

2.6.1 Health Services women's experiences

Ferguson's literature reviews on women's experiences in PMTCT services include counselling, confidentiality, health worker-client interactions and health facility factors (17). The literature review found that in less developed and developing countries little is known about the women's experiences in PMTCT services (17). This study will therefore contribute towards the existing literature on women's experiences in postnatal PMTCT services.

Anderson et al.'s study about the barriers and opportunities for PMTCT programmes in Jamaica found that women had insufficient knowledge about the PMTCT programme due to inadequate counselling offered by the health workers (35). A similar study in Uganda, conducted by Larsson et al. reported inadequate counselling of women attending PMTCT programme (36). Furthermore, in South Africa, Chopra et al.'s study revealed that women in PMTCT services received poor quality counselling (37). Lack of postnatal follow up counselling has generally been identified as a PMTCT programme shortcoming (35) due to impression among health workers that antenatal counselling is sufficient to facilitate long term care, prevention and treatment services(17). To ensure optimal counselling, however, the South African national PMTCT and provincial (Gauteng) policy guidelines, stipulate that the users should be given full and adequate information during the postnatal PMTCT visits

(31).Painter et al.'s study in Abidjan, Cote d'Ivoire reported that a substantial number of women in PMTCT services complained about breach of confidentiality (38). In Nyanza, Kenya, Moth et al.'s study found that women on PMTCT programme could know one another's HIV results (39). Furthermore, Hardon et al.'s study reported that the women on PMTCT programme were given their HIV test results in the presence of other people including strangers (40). A study in a resource-poor setting in Eastern cape, South Africa, reported that the health service users fear a lack of confidentiality among counsellors(41) Ferguson contends that in the context of high levels of HIV-related stigma, any action that may result in the disclosure of one's HIV-status could be a barrier for future uptake of PMTCT services (17).The national PMTCT policy guidelines, however, state that health workers and health facilities should provide services that adhere to principles of medical ethics including keeping clients' information confidential (31).

The sub-optimal interactions between health workers and clients, including uncaring and rudeness, judgemental, disrespect and discrimination is well documented (17, 40,43). For instance, Hardon et al.'s study in four African countries revealed that there were inappropriate health worker-client interactions in PMTCT services (40). Another study in Lilongwe, Malawi by O'Gorman and colleagues made similar findings (44). Kebaabetswe in Ferguson's literature review described the interactions between health workers and clients as sub-optimal and a barrier to use of the PMTCT services (17). In South Africa, Varga and Brookes reported that sub-optimal interactions between health workers and clients were common in PMTCT services (42).To address this situation, the South Africa White Paper on transforming public service delivery stipulates that health providers should comply with the

Batho Pele principles which include consultation, service standards, access, courtesy, information, openness and transparency, redress and value for money (45).

In terms of uncaring attitude, a study in South Africa conducted by Varga and Brookes reported the “gruff and uncaring attitude of health workers to mothers attending postnatal PMTCT programme (42). However, the South African National Core Standards for health establishments state that health workers should treat patients with care, respect and consideration (46).

A study by Solomon in South Africa, reported that the HIV-positive women who fell pregnant again inspite of knowing their status were likely to be negatively judged by PMTCT health workers (47). A similar study in Pietermaritzburg, South Africa reported that mothers who for whatever reason, decided to not to breastfeed in the contexts where exclusive breastfeeding was recommended such as PMTCT services run a risk of being judged by health workers providing information and advice (48). Pule’s study found that women infected with HIV may be deterred from coming to health facilities by the health workers’ judgemental attitudes (1). However, the Patients’ Right Charter states that health providers should show courtesy, human dignity and empathy to their patients (49).

In Malawi, O’Gorman et al.’s study found that health workers were described as harsh, threatening and lacking respect towards women attending the PMTCT programme (43). To ameliorate this challenge, the South African National Core Standards for health establishments state that health workers should treat patients with care, respect and consideration (46).

A global survey of people infected with HIV recorded that the clients did not trust health workers due to their discriminatory tendencies (35). In Viet Nam, a study by Hardon et al. revealed that overwhelming majority of women in PMTCT services complained about the health workers' impolite and discriminatory behaviour (40). In 2015, South Africa experienced various xenophobic hostility flare ups in a number of provinces including Kwazu-Natal, Limpopo and Gauteng that impacted on health services delivery including PMTCT programme (50). Furthermore, a study in South Africa, about how health system weakness constrain access to PMTCT and maternal HIV services reported that health workers refused to attend to women due to their HIV status (51). However, the Patients' Right Charter, maintains that everyone has a right to access health care services regardless of nationality, especially children under five and pregnant women (49)

Ferguson literature review on women's experiences in PMTCT services, recorded that health facility factors include long waiting times, queuing at multiple departments, shortage of staff, availability of drugs and access to the health facility (17). This review further noted that the health facility factors could deter women from attending the services (17).

A study conducted at Nyanza hospital, Kenya reported that women attending PMTCT programme experienced long waiting time to access health services (39). A similar study in South Africa by Sprague and colleagues found that long waiting time was one of the constraints to women in PMTCT services (51). To address long wait times, the South African National Core Standards for health establishments, stipulate that waiting times should be well managed to improve patients' satisfaction (46).

Chinkonde et al.'s in Lilongwe, Malawi noted that women attending postnatal PMTCT services had to visit and queue at multiple departments in the health facility to be served (52). A study in South Africa on health system weaknesses conducted by Sprague and colleagues reported similar findings (51). However, the South African National Core Standards for health establishments, state that waiting time in health facilities should be well managed to improve patients' experience in (46).

In relation to human resources, a study reported shortage of human resources for health as a major challenge in the rapidly expanding HIV prevention, treatment and support services. The study further noted that worldwide there were 61 countries with critical shortage of health care professionals and 41 were found in Africa (51). A study in Lilongwe, Malawi found that there was a shortage of health workers in the postnatal PMTCT services (52). Other studies, one in Uganda (54) and another in South Africa (49) reported similar findings. However, the South African National Core Standards for health establishments stipulate that health facilities should be optimally staffed (46).

With reference to availability of HIV drugs, various studies have documented shortage of these drugs in health facilities as one of the barriers to accessing PMTCT services. For instance, two studies in South Africa found that health facilities offering PMTCT services occasionally experienced shortage of ARVs (30, 51). The South African government, nevertheless, took a bold step to provide HIV treatment in all health facilities (52)

Inability to access health services is a barrier to the use of the postnatal PMTCT services (17). Two studies, one in Lilongwe, Malawi (52) and another in Abidjan, Cote d'Ivoire (38),

found that access to the PMTCT services for mothers and their infants was difficult due long distance to the health facilities. On the other hand, a study by Medical Research Council in 2010 reported that PMTCT services in South Africa were available in at least 95% of public health facilities (8). Nevertheless, the Department of Health, is committed to uphold, promote and protect the right to access of health care services as enshrined in the constitution of Republic of South Africa (54).

2.6.2 Individual-level women's experiences

Ferguson's literature review on women's individual-level experiences in PMTCT services includes competing obligations (such as work, childcare, interrupted personal routine) and ART side effects (17).

A study in Lilongwe, Malawi, found that women attending postnatal PMTCT services experienced difficulty to get time to take infants for follow-up visits (52). However, Bucyibaruta noted that women need the spouse and family support to better access and use maternal health services including PMTCT services (56).

Regarding ART use, a study at Nyanza hospital in Kenya found that women on PMTCT programme developed ART side effects (39). Another study in Nairobi, Kenya made similar finding. The study noted that women experiencing ART side effects are likely not to continue attending postnatal PMTCT programme (57). However, the South African PMTCT policy guidelines state that women experiencing ART side effects should report to the health facility for proper management (31).

2.6.3 Societal-level women experiences

In South Africa, Peltzer and Shikwane's study found that women attending PMTCT services experienced negative financial support from their spouses, families and community (58). On the other hand, a study in Nyanza, Kenya (39) and another in Lilongwe, Malawi (52) reported stigma-related issues amongst women attending postnatal PMTCT services. They were concerned that the services were offered in designated sections of health facility perceived by the community to cater for women living with HIV only. However, a study in South Africa by Bucyibaruta recorded that sustainable effort to decrease the HIV-related stigma in the community is important (56).

2.7 Postnatal PMTCT women's perceptions

Similar to women's experiences in 2.6 above, the literature on the PMTCT women's perceptions was reviewed at health services, individual and societal-levels as shown in study conceptual framework (Table 2).

2.7.1 Health services women's perceptions

In Tanzania, a study found that women perceived the postnatal PMTCT services including counselling as important (59). Similarly, the South African PMTCT policy guidelines view the programme as key to the elimination of vertical transmission of HIV (31).

The South African PMTCT policy guidelines stipulate that postnatal counselling is a critical aspect of the PMTCT programme as it curtails behaviours that escalate risks of mother-to-child transmission of HIV (31). Furthermore, the PMTCT policy guidelines regard counselling a prerequisite for effective postnatal PMTCT programme (31).

2.7.2 Individual-level women's perceptions

Research findings have documented individual-level women's perceptions including use of ART and exclusive breastfeeding. For instance, studies have found that women in PMTCT

services perceived adherence to ART as challenging (60, 61). A related study in Tanzania by Ngarina and colleagues revealed that women became sickly, dizzy and stressed at the beginning of the PMTCT programme (60). Another study in South Africa reported similar findings (62). The South African PMTCT policy guidelines, nevertheless stipulates that ART side effects should be managed accordingly (31).

Regarding breastfeeding, a study conducted in the four provinces in South Africa revealed that women perceived exclusive breastfeeding as insufficient for infant's health and normal growth (63). The South Africa PMTCT policy guidelines contend that exclusive breastfeeding is sufficient for the infant during the first six months of life (31).

In terms of effectiveness, postnatal PMTCT programme is widely considered effective to mitigate mother-to-child transmission of HIV (32). One UNAIDS report refers to PMTCT programme as a proven intervention and substantial donor investment (64). In South Africa, Barron et al.'s study underlines PMTCT programme's potential to virtually eliminate mother-to-child transmission (23). Equally, the South African PMTCT policy guidelines regard the PMTCT programme to be effective (31).

2.7.3 Societal-level women's perceptions

Perez et al.' study reported that if support from the community is perceived to be inadequate will have a negative impact on the use of PMTCT services and adherence (65). A study by Peltzer and Shikwane in South Africa recorded that women living with HIV received a negative emotional support from the partners and families during the postnatal period (58). Bucyibaruta, underlined the need for the spouses and families to support mothers including those who are HIV positive to better access maternal and postnatal PMTCT services (56).

2.8 Postnatal PMTCT women's practices

Like the women's perceptions, literature on postnatal PMTCT women's practices was reviewed at health services, individual and societal-levels as shown in study conceptual framework (Table 2)

2.8.1 Health services women's practices

The South Africa PMTCT policy guidelines provide the schedule for follow-up clinic visits and HIV testing. The policy maintains that these programme practices should be strictly adhered to (31).

2.8.2 Individual-level women's practices

Exclusive exclusively breastfeeding during the first months remain far below optimal (66). Worldwide, about 38% of infants aged 0 to 6 months are exclusively breastfed (66). Siziba et al.'s study found that there were low rates of exclusive breastfeeding in the four provinces of South Africa (63). On the hand, however, South Africa PMTCT policy guidelines recommend that all women living with HIV exclusively breastfeed their infants for the first six months except if the basic conditions are met for formula feeding (31).

2.8.3 Societal-level women's practices

A study in resource-poor-settings described the importance of community support in adhering to ART and practising exclusive breastfeeding among women attending the postnatal PMTCT programme (62). A research, for instance reported that the support for breastfeeding at community-level is critical. Furthermore, it records that successful scale up efforts for exclusive breastfeeding will not be possible if community-based support is not given enough emphasis (67). The South African PMTCT policy guidelines, however, highlight the need to mobilise the communities to support women attending maternal services including postnatal PMTCT programme (31).

2.9 Chapter three summary

This chapter provided a synthesis of contemporary local and international literature on postnatal women's experiences, perceptions and practices in PMTCT services. It summarised the research gaps and briefly discussed how this study could contribute to closing the gaps or existing literature. The next chapter covers the research methods.

CHAPTER 3 RESEARCH METHODS

3.1 Introduction to chapter three

This chapter presents the methods used in the study. It outlines the study design, setting, population, sampling method and sample size. It also describes data collection, management and analysis. Furthermore, it covers research dissemination, limitations and ethical considerations.

3.2 Study Design

This was a qualitative study to explore the experiences, perceptions and practices of women enrolled on the postnatal programme at a Johannesburg CHC, during April-May 2016. A qualitative study design is valuable for soliciting in-depth responses from the participants' perspectives about a sensitive topic (68). Furthermore, it has considerable ability to generate answers "what" and "how" questions (68).

3.3 Study Setting

The study was conducted at a community health centre (CHC) in one of the oldest townships of the Johannesburg Metropolitan City. The health centre is located in one of the most impoverished areas of the city (69). According to census Statistics South Africa, the township had a population of 117,074 people in 2011 (37). The CHC Annual Report recorded that the health centre was serving many undocumented foreign nationals who lived in the area (70).

3.4 Study Population

The study population consisted of all women, enrolled on the postnatal PMTCT programme, at a Johannesburg CHC during April-May 2016.

3.4.1 Inclusion criteria

All the women aged 18 years and above who were enrolled on the postnatal PMTCT programme at a Johannesburg CHC for a period of at least 6 weeks during April-May 2016 and signed consent forms to participate in the study.

3.4.2 Exclusion criteria

Women younger than 18 years or in the postnatal PMTCT programme less than 6 weeks or those who did not sign the consent for participation and /or audio-recording were excluded in the study.

3.4.3 Study Sample Size

A sample refers to a subset of the bigger population that meets the inclusion criteria and has been selected to participate in a study (71). For the current study, 15 women attending the postnatal PMTCT programme at a Johannesburg CHC were purposively selected to participate.

Joubert and Ehrlich argue that great emphasis is put on purposive sampling where the researcher deliberately chooses participants to ensure that the sample covers a range of characteristics of interest in qualitative methods (72). Purposive sampling “attempts to ensure that the data (main themes) emerging from the research represent shared and divergent views of the population under study” p. 125 (72).

3.5 Data Collection

A female research assistant with considerable experience in data collection was hired to collect the data. An interview guide with open-ended questions (Appendix 1) was used to conduct the interviews in the four common languages spoken in the district (Isizulu, Xhosa,

Sesotho and English). The foreign nationals were Ndebele speaking; a language similar to isizulu. They were also able to communicate in English. Every participant was interviewed in the language in which she was most proficient and comfortable. The interview guide consisted of key questions to serve as a check list to ensure that no essential questions were omitted during the interviews (71) and to enable the interviewer to guide the interview process without leading the participant. Those interviews were also audio- recorded. Each interview lasted for about an hour.

3.6 Data Management

After data collection, all the recordings were transferred to a password protected computer file and anonymised by the research assistant. The audio-visual files were also stored on a password-secured computer and were saved as numbers (e.g. P001, 24 years old) which were delinked from names of the participants. The researcher and research assistant separately coded the first three transcripts and their codes were reviewed by the supervisors, then compared and discussed to establish inter-coding agreement. After that the researcher coded the remaining transcripts, engaging closely with the supervisors.

3.7 Data analysis

The data from the interviews were translated and transcribed verbatim into Microsoft Word and transferred into MAXQDA Version 11 software. The verbatim transcripts were coded using deductive and inductive methods. Deductive analysis begins with a preconceived idea or framework and then uses the data to approve or dismiss the ideas while inductive method uses the data to generate ideas (73). In this study, Ferguson's literature review of women's experiences in PMTCT services was adopted to develop a conceptual framework which guided the analysis. Deductive themes emerge from the participants' narratives following preconceived idea or theoretical framework while inductive themes emerge from

the narratives of the participants. They may be unexpected or different from literature. However, the inductive themes are useful as they represent the issues that were most important to the participants (74).

Codes were developed into sub-themes and themes (72). This enabled the researcher to make sure that the data analysis provided rich and meaningful results that are linked to the research objectives and grounded in the experiences, perceptions and practices of the participants (72). The data were systematically coded until no more new information emerged – this is called saturation (72). These codes therefore represented a wide range of information about postnatal PMTCT women's experiences, perceptions and practices (75).

3.8 Truthfulness

In the context of the current qualitative and exploratory study, "truth" is used to refer to the researcher's confidence that the findings are a true representation of the participants' postnatal PMTCT experiences, perceptions and practices. In the current study, truth was achieved by ensuring that all the interviews were audio-recorded to obtain the verbatim narratives of the participants. Furthermore, through the inter-coding agreement, the researcher's analysis of transcribed data was compared with that of the research assistant and differences addressed.

3.9 Researcher reflexivity

It has been observed that the researchers have expectations and may impose their own beliefs and orientation on participants during the research process (76). It is therefore essential that researchers bear this in mind and "acknowledge and describe their own beliefs and biases as a way to establish trustworthiness or validity through the research process" (77). It was considered necessary to recruit a South African adult female as a

research assistant in order to win the confidence of the female participants. The research assistant had considerable experience in qualitative research and ran her own private research consultancy. The researcher constantly challenged his own thoughts to acknowledge possible personal biases. After the interviews, the principal investigator went through the data many times to make sense of it and to seek clarity on any unclear issues that arose from the data through daily debriefing sessions with the research assistant and regular discussions with the supervisors.

3.10 Ethical considerations

Ethical clearance (appendix 2 Protocol Ref No.M151174) was granted by the University of Witwatersrand Ethics Committee. Permission (appendix 3 Reference No.2015-16/037) to conduct research at a Johannesburg community health centre was granted by City of Johannesburg District Research and Ethics Committee (DRC). Co-operation to access the facility was obtained from the CHC management. Two days were used for orientation and preparation at the facility. The researcher and the assistant met with the facility manager, PMTCT programme manager and briefed them on the content of the study, including rationale, objectives, methods and ethical considerations of the study. The PMTCT programme manager introduced the researcher and assistant to the PMTCT programme nurses. The researcher, researcher assistant and the PMTCT programme nurse discussed the appropriate venue for conducting interviews. A room within the clinic was provided (depending on availability) to ensure the necessary privacy and confidentiality.

The participants were briefed on the purpose of the study (appendix 4 Information sheet). Ethical principles of voluntary consent, rights to withdraw, confidentiality and anonymity

were also explained. The participants were asked to sign consent forms. There were two forms of written consent; one for participating in the study (appendix 5) and another one for audio-recording (appendix 6). Only the researcher assistant, principal investigator and supervisors have access to the data. The de-identified data were stored safely in the researcher's computer protected with password, and data were only shared with supervisors. The soft copy of the transcripts was securely stored in the researcher's laptop protected with a password. The hard copy of the transcripts was kept in locked cabinets. The tape records were stored in locked cabinets. The transcripts including soft and hard copies as well as the tape records will be destroyed two years after publication of the findings or six years if the findings have not been published.

3.11 Chapter three summary

This chapter presented the methodology used in the study. The study design and setting, study population and sample size were outlined. Moreover, data collection, management and analysis were described. Furthermore, study limitations and ethical considerations were covered. The next chapter presents the study findings.

CHAPTER 4 STUDY FINDINGS

4.1 Introduction to chapter four

This chapter presents the main demographic and clinical characteristics of the study participants. It also presents the findings of the participants' postnatal experiences, perceptions and practices. Furthermore, it presents the identified enablers and barriers to postnatal PMTCT programme at a Johannesburg CHC.

4.2 Demographic and clinical characteristics of the study participants

Fifteen women participated in this study. Two-thirds (n=10) of the participants were South African citizens. The majority (n=14) of the women were not married. Ten out of 15 women were employed. The participants were aged between 20 and 39 years. All the participants had education levels above primary school; the minimum education level was grade nine (high school) and the highest education level was third year of university. Other demographic characteristics are presented in appendix 7.

The voluntary HIV counselling and testing uptake among the participants was poor prior pregnancy period. In fact only one woman was voluntary tested for HIV prior to her first pregnancy. The rest of the women (n=14) were tested for HIV during ANC either at first (6), second (6) and third pregnancy (2). Besides one mother who was attending the postnatal PMTCT programme for the third time, the rest of the mothers (n=14) were attending the programme for the second time. All the participants had been currently enrolled on the programme for more than six weeks. All the participants had been compliant with the postnatal PMTCT programme with respect to follow up clinic visits.

4.3 Postnatal PMTCT programme women's experiences

4.3.1 Health service experiences

Data analysis of the women's narratives revealed women's experiences across four key areas, namely; postnatal PMTCT counselling, confidentiality, health worker-client interactions and facility-based factors.

With respect to postnatal PMTCT counselling, all the women reported that they received inadequate postnatal PMTCT counselling at the CHC:

"... I have not received counselling at this clinic since I delivered." (P007; 29 years old)

Furthermore, three participants said that the postnatal PMTCT staff provided them with inadequate information regarding the choice of infant feeding options. All the participants indicated that the PMTCT staff told them to choose between exclusive breastfeeding and formula feeding. However, they said that they were not provided with adequate information about the specific conditions for formula feeding. In fact, one of the participants said:

"...they [the PMTCT staff] told me, it is up to me whether I breastfeed or give him formula for 6 months, and then start giving him solids" (P0013; 30 years old).

Of the 14 women who responded to the question about the infant follow-up and testing dates, four reported that the postnatal PMTCT staff did not give them information about infant testing dates:

"They [PMTCT staff] did not tell me anything. I just thought it would make sense to test her when she turns 1." (P002; 24 years old)

Regarding confidentiality, the majority (n=13) of the participants said that the postnatal PMTCT staff kept their health information confidential:

“...I do not have a problem with confidentiality at this clinic. The nurses keep our information secret...” (P001; 33 years old)

With regard to health worker-client interactions, the majority of participants (n=10) reported that some healthcare workers had poor attitudes towards them. They said that some of the PMTCT staff was sometimes uncaring, rude, judgemental and discriminatory:

“...that old woman [PMTCT staff] that works here at room 2 has a bad attitude. She can't talk to people...She said my blood is rotten. ”(P005; 29 years old)

"...Some clinic staff can be cheeky- shouting at patients..." (P007; 29 years old)

“...You women don't understand! How many times you need to be told not to be pregnant again because you have the disease [HIV]? ...” (P001; 33 years old)

In addition, five women experienced discrimination:

“...You, Kwerekwere [foreigners] You left your home [country], you were hungry and you come here[South Africa] and now you are eating that is why you have so many babies...”(P005; 29 years old)

With regard to health facility factors, women's experiences included long waiting times, queuing at multiple departments within the facility, and shortages of the PMTCT staff.

Considering long waiting time, most of the women (n=13) reported that they waited for a long time in order to be served. Those women felt that they waited unnecessarily long at the CHC:

“... We do wait too much because I came at 6.00 AM in the morning and I am still not sure when I am going to leave. I waited there until 10.00 AM. Now I am waiting here. I don't know when I will leave.”(P007; 29 years old)

"Waiting time is very bad because you wake up in the morning telling yourself that you will finish by 9 or 10 but you sit here until late afternoon.”(P002; 24 years old)

Considering queuing at the multiple departments within the facility, all participants said that they indeed queued at multiple departments within the facility. Those departments include maternity room, PMTCT room and Pharmacy. One woman said:

“...here we make many long queues...when I came, I started with queuing there at maternity room, now I am queuing at PMTCT room, and after here I will go to queue for medicine...”(P007;29 years old)

Considering postnatal PMTCT staff at the CHC, the majority of the women (N=10) said that there was shortage of postnatal PMTCT staff to provide services in a timely fashion:

“...I have brought her [infant] at one week, she had flu. They [the PMTCT staff] told us that we have to wait for a long time because there was only one doctor (P003; 27 years old)

“...We [the PMTCT participants] are too many. Just like right now, the sister is helping here, she came from that side...” (P009; 39 years old)

4.3.2 Individual –level experiences

The analysis of the data revealed women's two individual-level experiences at the health CHC, namely: women's competing obligations and ART side effects.

With reference to women's competing obligations, nearly half of the women (n=7) said that work (paid or house chores) and the childcare made difficult to get time to take the infants to the CHC:

"...This can be a challenge because when I visit the clinic, I must take a day off, and if they [her work managers] decline, I must take unpaid leave for the day. I cannot take a half a day and later go to work. It can't happen because of finishing late at the clinic. And it may be difficult to ask for another day in the same week."(P007; 29 years old)

"... I ask to take the baby to clinic. They [managers] agree, but when I get here they [PMTCT staff] turn me back...saying please come back tomorrow. To ask time off in the same week is not easy..."(P001; 27 years old)

Considering ART side effects, five participants said that they developed side effects especially at the start of ART programme:

"...I became sickly and felt dizzy during the first 2-3 weeks. From then nothing has happened."(P011; 24 years old)

4.3.3 Societal-level experiences

From the women's narratives, two societal-level experiences emerged: financial support and HIV-related stigma. All women (n=15) said that they received financial support from their family and community members to attend the postnatal PMTCT services.

“...I am receiving enough support from my family and community. They always give me money for transport and food when I come to the clinic...” (P003;27 years old).

In contrast, HIV-related stigma emerged as a negative aspect of the women’s societal-level experiences. Three women reported that they were uncomfortable and fearful to be seen at the PMTCT services. Those women said that they were concerned that the PMTCT services were offered in a particular section of the facility which the community perceived to cater for HIV women infected women:

“They [people who come to the CHC] say those who are sitting that side are sick [HIV-positive]. Because this is where they [PMTCT staff] tell us to come.”(P002; 24 years old)

4.4 Postnatal PMTCT women’s perceptions

4.4.1 Health service perceptions

From the women’s narratives, it was revealed that health services, including postnatal PMTCT counselling were perceived as important components of the PMTCT programme at the CHC.

“...I feel that health services are needed. For example counselling helps us to accept our situation [HIV-positive status] and informs us what to do to ensure that our babies are not infected...” (P005;29 years old).

4.4.2 Individual-level perceptions

The analysis of data revealed women’s two perceptions on postnatal PMTCT at CHC. These perceptions included challenging adherence to ART and exclusive breastfeeding.

Considering perception on adherence to ART, all the participants generally perceived adherence as challenging, especially at the beginning of the programme:

"...At the beginning...in the first year, it was really difficult but on the second year and following years, it becomes normal. I think now it is close to 10 years."(P0013; 30 years old)

"...At the beginning, I didn't feel okay...I even lost weight, stressed, thinking about that thing [prophylaxis and ARVs], I ended up setting an alarm to make sure I don't forget."(P0011; 24 years old)

With reference to exclusive breastfeeding, twelve women considered exclusive breastfeeding as difficult and emotionally challenging:

"...No, that [exclusive breastfeeding] is not alright. You find that sometimes she (infant) cries because she's not quite full. And she just continues crying. So you just don't have a choice. She cries all the time, she just cries. You can see that she is not quite full. And there is nothing you can do because they [PMTCT staff] said she must not eat anything." (P004; 33 years old)

"...It is difficult to only [exclusively] breastfeed the baby for 6 months because sometimes he [infant] looks like he hasn't had enough but for the sake of his health it is important that you do it. I do not want to lie. I saw him crying every day, crying during the day, crying during the evening when he turned 4 months, I realised that it is not working. I ended up buying him purity, I gave him, and then he ate and stopped crying."(P0011;24 years old).

4.4.3 Societal-level perceptions

From the women's narratives, there were mixed-feelings about women's emotional support from their partners and families. Nine women said that they got adequate emotional support from their families.

"... I can't complain. I feel they [family members] are always there for me. They really support me when I'm feeling down..." (P001; 27 years old).

However, the remaining six women said that they were not receiving enough emotional support from their families.

"...I feel I do not receive enough support. When, for example, I ask them [spouse or family members] to give me transport [money] to bring the baby to the clinic. They tell me to walk... They say they have no money even when they have..." (P003; 27 years old).

4.5 Postnatal PMTCT women's practices

4.5.1 Health services practices

From women's narratives, it was revealed that health services practices; including follow-up clinic visits and testing were necessary and influenced the postnatal PMTCT programme at the CHC.

"...I have to bring my baby to the clinic all the time for check-up and tests to ensure that she is ok [healthy]..." (P009,39 years old).

4.5.2 Individual -level practices

The analysis of the data revealed women's three key individual-level practices at the CHC, namely: adherence to ART, compliance with follow up clinic visits and testing and inadequate practice of exclusive breast feeding.

With regard to adherence to ART, despite the reported ART side effects, the women said that they had no choice but to adhere to the ART for the sake of their babies' health:

"...at the beginning, the drugs made me sickly, dizzy and sometimes got headache.

But for the sake of baby I had no choice but to continue taking..." (P0012, 28years old)

With regard to compliance with the follow up clinic visits and testing all the women said that they complied with follow up and testing schedule despite other competing obligations:

"...I brought her here for check-up and testing on the first follow up visit [six week], brought her here again at the next visit [ten weeks] and today [14 weeks], I am here again..." (P007,29 years old)

Only seven women reported that they practised exclusive breastfeeding. The other seven women said that they were formula feeding and only one woman confirmed that she was mixed feeding her infant.

4.5.3 Societal -level practices

The analysis of data revealed that family members and community elders interfere with women's societal-level practices including exclusive breastfeeding, making it challenging to sustain.

"...I am trying to follow the advice of the nurse to feed [to exclusively breastfeed] my baby but the elders in my family and community insist that I am starving the baby and should give solid as well..." (P004;33 years old).

4.6 Postnatal PMTCT women enablers and barriers

The analysis of the women's experiences, perceptions and practices identified enablers as well as barriers to the postnatal PMTCT at three levels, namely health services, individual and societal levels. The key reported enablers and barriers are presented in the tables 3 & 4.

Table 3 Identified key enablers to the postnatal PMTCT programme

Enablers	Health services	Individual-level	Societal-level
Experiences	Confidentiality	Adequate knowledge on	Financial support
	Maintaining health information confidential (n=13)	PMTCT (n=15)	from family and community (n=15)
	Health facility factors		
Perceptions	Availability of drugs and supplies (n=12)		
	Easy access to health facility (n=14)		
	Perceived importance of health services (n=13)	Perceive effectiveness of PMTCT programme (n=15)	Perceived adequate emotional support from their partners: (n=9)
Practices		Perception of exclusive breast feeding as convenient & cost-effective (n=3)	
	Clinic follow-up visits and testing (n=15)	Women did follow-up to clinic visits(n=15)	There was no practice enablers identified at societal level
		Women do attempt to adhere to treatment and prophylaxis (n=13)	

Table 4 Identified key barriers to the postnatal PMTCT programme

Barriers	Health Services	Individual-level	Societal-level
Experiences	Counseling Inadequate experiences of counseling (n=15):	Competing obligations (n=7)	Stigma Fear of being seen at PMTCT services: (n=3)
	Health worker-client interactions Poor HCW attitudes, judgmental and unresponsiveness (n=10) Discrimination (n=5)	ART side effects (n=5)	
	Health facility factors Long waiting times (n=13) Queuing at different departments (n=15) Shortage of the PMTCT staff (n=10)		
Perceptions	Perceived inadequate counselling (n=15)	Perceived challenging adherence to ART (n=15) Difficult and emotionally challenging exclusive breast feeding (n=13)	Perceived family/community emotional support (n=6)
Practices	Inadequate practice of postnatal PMTCT counselling (n=15)	Inadequate practicing of exclusive breastfeeding (n=7)	Community intolerance to exclusive breastfeeding (n=7)

4.7 Chapter four summary

This chapter presented the main demographic and clinical characteristics of the study participants. It also explored the postnatal PMTCT women's experiences, perceptions and practices. Furthermore, it identified the key reported enablers and barriers to the postnatal PMTCT at a Johannesburg CHC as summarised in tables 3 & 4. The next chapter discusses the study findings.

CHAPTER 5 DISCUSSION OF FINDINGS

5.1 Introduction to chapter five

This exploratory study provides useful insights into women's experiences, perceptions and practices of the postnatal PMTC programme at a Johannesburg CHC. To realise this goal, the study pursued the following objectives: (i) to explore postnatal PMTCT experiences among women enrolled on the programme at a Johannesburg CHC during April-May 2016; (ii) to explore postnatal PMTCT perceptions of those women during the same period; (iii) to explore postnatal PMTCT perceptions practices of those women. The discussion of the study findings is presented below.

5.2 Postnatal PMTCT women's experiences

With respect to the first objective, the discussion of key results is provided in the following section.

5.2.1 Health service experiences

This study explored women's experiences that affect postnatal PMTCT programme. These experiences include postnatal PMTCT counselling, confidentiality, health worker-client interactions and health facility factors.

With respect to postnatal PMTCT counselling, the study found that postnatal PMTCT counselling was generally inadequate at the CHC. The participants said that the counselling was mainly provided during pregnancy when women were attending the ANC visits. The findings of this study are consistent with the results from other studies conducted in developing countries (35,36) including South Africa (37). For example, Anderson et al.'s findings reported existence of postnatal counselling gaps in Jamaica (35). In Uganda, Larsson et al.'s study found inadequate postnatal PMTCT counselling (36). Similarly, Chopra et al.'s

study mentioned the poor quality of the postnatal PMTCT counselling in South Africa (37) It is noteworthy mentioning that the findings of the current study are not in agreement with the South African National and Provincial (Gauteng) PMTCT policy guidelines which promote the provision of full and adequate information during the postnatal PMTCT counselling period (31).

With regard to confidentiality, the study found that for the participants, PMTCT staff at the CHC was generally felt to maintain the confidentiality of their health information. However, some studies on confidentiality among women enrolled on postnatal PMTCT reported different findings. For example, Painter et al. reported that the women were complaining about the breach of confidentiality in postnatal PMTCT in Abidjan, Côte d'Ivoire (38). Moth et al. also found that the women on postnatal PMTCT programme could know each other's' HIV results in Kenya (39). Furthermore, Hardon et al. reported that women on postnatal PMTCT programme were given HIV test results in the presence of other people, even strangers in Viet Nam (40). A related study conducted in the rural setting in Eastern Cape, South Africa reported similar concerns (41). Ferguson contends that in the context of high levels of HIV-related stigma, any actions that may result in the disclosure of one's HIV status may deter users from future uptake of PMTCT services (17). It is noteworthy highlighting that the results of the current study are consistent not with the National PMTCT policy guidelines which states that health providers and facilities should provide services in line with principles of medical ethics including keeping personal information confidential (31). However, it may be important for the facility to re-look at its use of space, given that some of the women perceived that they were receiving services in an HIV positive section. While it is laudable that individual providers are conducting their care ethically, these efforts will be

minimised if the facility itself is not conducive to care provision in a destigmatised space, and could even become a barrier to access.

With respect to sub-optimal health worker-client interactions, this study found that the health workers had inappropriate attitudes. They were uncaring, rude and judgemental. Some of the health workers were disrespectful and discriminatory. These results are in agreement with other studies (17,40,43). It is noteworthy mentioning that the results of the current study are inconsistent Batho Pele Principles, which are consultation, service standards, access, courtesy, information, openness and transparency, redress as well as value for money (45).

Most of the participants experienced uncaring and rude attitude from the postnatal PMTCT staff. These results are in agreement with a study conducted in South Africa by Varga and Brookes which reported the “gruff and uncaring” attitude of health workers towards the teen mothers attending postnatal PMTCT services (42). It is important to note that the results of the current study are not consistent with National Core Standards for health establishments in South Africa which state that the staff should treat patients with care and respect and consideration (46).

Most of the participants experienced being judged by the postnatal PMTCT staff. This study finding is consistent with two studies done in South Africa namely; Solomon’s study which reported that the HIV-positive women who fell pregnant knowing their HIV status are likely to be judged by the PMTCT health workers (47) and Seidel’s study which recorded that women judged for not complying with the recommended infant feeding practices in the PMTCT services(48). It is noteworthy mentioning that the results of the current study are not

in agreement with Patients' Rights Charter which states that health care workers should show courtesy, human dignity and empathy to patients (49).

Some participants experienced disrespect from the postnatal PMTC health workers. These findings are consistent with O'Gorman et al.'s findings that reported that the health workers were described as harsh, threatening and lacking respect towards women attending the postnatal PMTCT (43). It is important to highlight that the results of the current study are inconsistent with National Core Standards for health establishments in South Africa in consideration with respectful health worker attitude toward the patients (46).

Some participants reported that they had experienced discrimination from some health workers at the CHC. Like in many other resource poor settings in South Africa, the health service delivery at this health facility is constrained by limited resources (50). As a result, some South African nationals, including health workers are contend these foreigners are there to compete for the limited resources meant for nationals (50). The impression from the interviews was that the discrimination occurred during the period when there were xenophobic flare ups in the country. These xenophobic hostility flare ups took place in a number of provinces including Gauteng where the current study was conducted (50). These findings are in agreement with other studies which reported that women attending the PMTCT services experience discrimination based on their nationality in the developing countries (40) including South Africa (51). The results of this study are not consistent with the Patients 'Rights charter which stipulates that everyone has a right to access health care services especially children under five and pregnant women regardless their nationalities (49).

With regard to health facility factors, this study found that the long waiting time, queuing at multiple departments within the facility, shortage of the postnatal PMTCT staff, availability of drugs and access to the facility were the main issues experienced by the participants at the CHC.

Considering long waiting time specifically, this study found that all the participants waited for a long time at the CHC to be served. These results were in agreement with other studies that reported the long waiting time among women attending the postnatal PMTCT services (39). It is noteworthy mentioning that the results of the current study are not consistent with the National Core Standards for Health Establishments which stipulated that waiting times should be managed to improve patients' satisfaction (46).

Referring to queuing at multiple departments within the facility, the study found that all the participants queued at multiple departments. This finding is in agreement with Chinkonde et al.'s study findings which reported that women attending the postnatal PMTCT services had to visit and queue at multiple clinics within the same facility (52). It is noteworthy mentioning that the results of the current study are not consistent with National Core Standards for Health Establishments in respect to waiting time management (46).

Regarding shortage of staff, the study found that there was the shortage of postnatal PMTCT staff at the CHC. These results are in agreement with other studies that have recorded shortage of health workers in the postnatal PMTCT. A study reported that the shortage of human resources for health is a challenge in delivery of the rapidly expanding of HIV prevention, treatment and support services globally(51). For instance, Chinkonde et al.'s study in Lilongwe, Malawi found that there was the shortage of staff in the postnatal PMTCT services (52). Duff et al. reported shortage of postnatal PMTCT staff in Uganda (54).

In a related study, Sprague et al. reported shortage of staff in the PMTCT programmes in South Africa (51). It is important to note that the results of the current study are not consistent with the National Core Standard for Health Establishments about staffing in public institutions (46).

Referring to availability of drugs, the study found that the majority of the participants were provided with the drugs every time they visited the CHC. On the contrary, other studies on the availability of ART reported the shortage of resource, including ART in health facilities offering PMTCT services (30,51). However, it is important to note that the results of this study are consistent with the South African government position on its commitment about ART availability in the country (54).

Considering access to the facility, the study found that the participants had generally easy access to the health centre. This finding is consistent with the Medical Research Report (MRC) which reported that PMTCT services are available in at least 95% of public health facilities countrywide (8). However, these finding are not in agreement with other studies which found that access to PMTCT treatment for mothers and their infants was difficult due to long distance to the health facilities (38, 51). It is noteworthy mentioning that the results of the current study are in line with the Department of Health's commitment to uphold, promote and protect the right of access to health care services as guaranteed by the constitution of South Africa,1996 (Act No.109 of 1996)55.

5.2.2 Individual-level women's experiences

The study explored women's individual-level experiences that may affect the postnatal PMTCT at the CHC. The experiences explored were competing obligations and ART side effects. With respect to competing obligations, the study revealed that some participants

experienced difficulty to get the time to take their infants to the health centre because of other competing obligations including work and house chores. These findings are in keeping with Chinkonde et al.'s study which found that the women experienced difficulty to get time to take infants for follow-up visits (52). It is, however, important to note that, from the health systems perspective, the women need support from the spouse and family for better access and use of maternal health services as recommended by Bucyibaruta's MPH research report on analysis of acceptability of health services (56).

With regard to ART side effects, the current study found that some participants developed ART side effects. The participants reported that they felt sickly and dizzy especially at the beginning of the programme. These findings are in agreement with other studies (39,57). It has been noted that the women experiencing ART side effects are likely not to continue attending postnatal PMTCT programme (57). Thus from health policy perspective, women experiencing ART side effects should be encouraged to report to the facility in accordance to ART management guidelines (31).

5.2.3 Societal-level women's experiences

Financial support from family and community members and HIV-related stigma were found from some women's narratives to influence the postnatal PMTCT services at the CHC. With regard to financial support, women said that they received financial support from their families and community. These findings are not in agreement with Peltzer and Shikwane's study which reported a negative financial support from spouses and families for women attending PMTCT services (58). In terms of HIV-related stigma, some women reported that they were uncomfortable and fearful to be seen at the postnatal PMTCT services. These women said that they were concerned that the postnatal PMTCT services were offered in a

particular section of the health centre which the community perceived to cater for women living with HIV. These findings are consistent with other studies (39, 52). Using the health systems lens, the current study findings are calling for a sustainable effort to decrease the HIV-related stigma in the community despite the decline in HIV stigma as it has been reported by Bucyibaruta (56).

5.3 Postnatal PMTCT perceptions

With regard to the second objective, the discussion of results is provided in the section below.

5.3.1 Health service women's perceptions

The current study found that health services including counselling were perceived as important aspects of the postnatal PMTCT programme at the CHC. The findings of the current study are keeping with, Mrisho et al.'s study in Tanzania which reported that the postnatal PMTCT services were perceived by women to be important (59). Thus, it is noteworthy to continue providing postnatal PMTCT services routinely to all mothers and their infants who need them according to the South Africa PMTCT guidelines (31).

5.3.2 Individual-level women's perceptions

The study explored individual-level women's perceptions that may affect the postnatal PMTCT at the health centre. These included perceptions on adherence to ART, exclusive breastfeeding, PMTCT effectiveness and postnatal PMTCT counselling

Considering adherence to ART, adherence to ART was perceived as challenge as some women reported that they became sickly, dizzy and stressed at the beginning of the programme. These findings are in agreement with other studies conducted in different countries (60, 62) including South Africa (62). From the health policy perspective, it is

noteworthy mentioning that the results of the current study highlights the importance of ART effects and their management according to the ART management guidelines (31).

With respect to exclusive breastfeeding, this study found that most of the women perceived exclusive breastfeeding as difficult and emotionally challenging. The participants reported that the challenge was due to persistent crying of the infants after exclusive breastfeeding and the mothers' perception that the breast milk as insufficient. These results are in keeping with Siziba et al.'s study which reported that the mothers perceived exclusive breastfeeding as insufficient (63). From the findings of the current study, it is noteworthy mentioning that postnatal PMTCT counselling should put more emphasis on the sufficiency of exclusive breastfeeding during the first six months even though the infants may continue to cry. The mothers need to understand that whenever infants cry, it does not necessarily mean that they are hungry.

Referring to postnatal PMTCT effectiveness, the current study revealed that all women that participated in the interviews perceived postnatal PMTCT programme as effective, even though they experienced inadequate counselling. This finding supports WHO reports which recorded that PMTCT programme is highly effective (32). In South Africa, Barron and colleagues also contend that the PMTCT programme may lead to virtual elimination of vertical transmission of HIV in South Africa (23)

The current study found that all the participants considered postnatal PMTCT counselling as an essential component of the programme. It is noteworthy mentioning that the results of the current study are consistent with the national PMTCT guidelines which state that users should be provided with adequate information about the programme (31).

5.3.3 Societal-level women's perceptions

The current study showed that emotional support from families and community was generally regarded as inadequate and influenced the postnatal PMTCT programme at the CHC. The findings are consistent with Peltzer and Shikwane's study which noted a negative emotional support from the partner and or family perceived by HIV positive mothers in postnatal period (58). Thus, from health policy perspective, mothers including those who are HIV positive, should be supported by partner and or family for better use and acceptance of maternal health services such as postnatal PMTCT programme (56).

5.4 Postnatal PMTCT practices

With respect to the third objective, the discussion of the key results is given in the following lines.

5.4.1 Health service women's practices

The current study found that women's health service practices such as follow-up clinic visits and testing were essential aspects of the postnatal PMTCT programme at the CHC as infant HIV-testing enables women ascertain the HIV-status of their infants. This finding is consistent with the national PMTCT guidelines (31).

5.4.2 Individual-level women's practices

Inadequate practising of breastfeeding was the only individual-level women's practices that may influence the postnatal PMTCT programme at the CHC.

Referring to inadequate exclusive breastfeeding, the current study found that most of the women were not practising exclusive breastfeeding. These findings are consistent with WHO/UNICEF report which documented that exclusive breastfeeding during the first months remains far below optimal. In fact, it states that about 38% of infants aged 0 to 6 months are exclusively breastfed (64). Siziba et al.'s study which found that there were low

rates of exclusive breastfeeding in four provinces of South Africa (63) However, it is noteworthy stating that the PMTCT guidelines recommend that all mothers infected with HIV should exclusive breastfeed their infants for the first six months (31). Moreover, formula feeding may be used if the basic conditions are met (31).

5.4.3 Societal-level women's practices

The current study revealed that spouses, family members and community elders interfered with exclusive breastfeeding making it challenging to sustain. The finding of the current study is highlighted by Horta and Victoria (67) and Busza et al.'s (63) study findings which described the importance of the community support in adhering to ART and practicing exclusive breastfeeding among women attending the postnatal PMTCT services.. Thus, from health policy perspective, effort should be made to mobilize the community support for women to attend available maternal health services including postnatal PMTCT programme (31).

5.5 Study Limitations

The researcher used a research assistant to conduct, translate and transcribe all the interviews. This could have introduced possible errors in the study. This source of error was, however, minimised given that the research assistant had considerable experience in the qualitative interviewing process and had a debriefing with the researcher after every interview.

The study was conducted in one community health centre, rendering the study findings and conclusions not transferable, but emphasis was on exploring postnatal PMTCT women's experiences, perceptions and practices at a given CHC. The recall bias was considered one of possible sources of error given that some of the participants might not have been able to

remember all the information regarding the postnatal PMTCT programme. However, this was minimised by probing and asking open ended questions.

Social desirability [(which means that the participants tend to provide the responses that are perceived as impressive) (78)] among respondents could have been another possible source of errors. This source of error was minimised by the research assistant asking open-ended questions and probing.

5.6 Chapter five summary

This chapter discussed the results of the current study in line with existing literature on the postnatal PMTCT women's experiences, perceptions and practices. The similarities as well as differences were acknowledged. The implications of health systems and policies were considered in views of women's experiences, perceptions and practices of the postnatal PMTCT programme. Limitations of the study are also highlighted in this chapter. The next chapter covers conclusion and recommendations.

CHAPTER 6 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Although it is well documented that the postnatal HIV infection among exposed infants increases with postnatal age, there is limited research that has been conducted to explore the enablers and barriers to postnatal PMTCT programme from the women's experiences, perceptions and practices. The current study attempted to identify key reported enablers (Table 5) and barriers (Table 6) to postnatal PMTCT programme from the women's narratives.

With respect to the enablers, the study identified health services and individual-level women's experiences. It also identified individual-level women's perceptions and practices as enablers to the postnatal PMTCT programme. To improve women's participation and ensure optimal outcomes for women and their infants, programme managers, staff and policy-makers need to address bottlenecks as well as strengthen enablers to the postnatal PMTCT programme in the context of South Africa.

Tables 5 and 6 present the enablers and barriers to the postnatal PMTCT programme respectively.

Table 5 Identified key enablers to women enrolled on postnatal PMTCT at Johannesburg CHC.

	Health Services	Individual-level	Societal level
Experiences	Maintaining clients' information confidential	Adequate knowledge of postnatal PMTCT programme	Financial support from family and community
	Availability of drugs including ARVs		
	Easy access to health centre		
Perception	Perceived importance of PMTCT programme including postnatal counselling	Perceived effectiveness of PMTCT Programme	Perceived adequate emotional support from Family and community
		Perceived and cost-effectiveness Of exclusive breastfeeding	
Practices	Clinic follow-up visits and HIV testing	Women do follow-up clinic visits	
		Women adhere to ART treatment and prophylaxis	

Table 6 Identified key barriers to women enrolled on postnatal PMTCT at Johannesburg CHC.

	Health Services	Individual-level	Societal level
Experiences	Inadequate postnatal counselling	Competing obligations	HIV-related stigma
	Sub-optimal health worker-Client interactions	ART side effects	
	Long waiting times, queuing at multiple departments and shortage of postnatal PMTCT staff		
Perception	Perceived inadequate postnatal counselling	Perceived challenging to ART adherence	Perceived inadequate emotional support from family and community
		Perceived difficult exclusive breastfeeding	
Practices	Inadequate practising of postnatal counselling	Inadequate practising of exclusive breastfeeding	Community intolerance to exclusive breastfeeding

6.2 Recommendations

This study explored women's postnatal PMTCT experiences, perceptions and practices. Furthermore, it identified the key reported postnatal PMTCT enablers and barriers at different levels which are critical to derive maximum benefit from the programme and to address the programme bottlenecks. The following recommendations are proposed.

6.2.1 Researchers

More research on postnatal PMTCT programme, including qualitative, quantitative and mixed methods, are recommended to explore and fully understand the reasons of increasing postnatal infection rate with postnatal age among exposed infants. Furthermore, research needs to be conducted to explore postnatal PMTCT experiences, perceptions and practices from the provider's perspective, a topic which has not been covered by this study.

6.2.2 Health policy makers

While the confidentiality was found to be in line with the existing postnatal PMTCT guidelines, and thus recommended to be maintained, some interactions between postnatal PMTCT health workers and their clients were found to be sub-optimal. It is therefore recommended to the health policy makers to formulate the policies and guidelines to improve the interactions between health workers and clients, as well as monitoring and evaluating the implementation of those policies and guidelines.

6.2.3 Health systems management

The availability of drugs and easy access to the facility were identified as enablers to postnatal PMTCT programme. Thus, it is recommended to the health services managers to maintain the existing drug availability standards and maintain easy access to the facility.

However, postnatal PMTCT counselling was generally inadequate. In addition, the women waited for long time to be served, queued at different departments within the facility, and there was generally a shortage of PMTCT staff. It is noteworthy commenting that significant progress has been made in improving the PMTCT service delivery in the face of recognised limitations such as infrastructures, financing and human resources. However, it is recommended that health services managers revise the implementation of postnatal PMTCT counselling to be aligned with existing national and provincial PMTCT guidelines. Emphasis should be put on postnatal PMTCT counselling to ensure that the participants get adequate and clear information including infant feeding methods. Furthermore, plans to reduce the long waiting time and multiple queues within the facility should be put in place and monitored. In addition, adequate number of postnatal PMTCT staff should be recruited and trained to satisfy service delivery.

6.2.4 Health workers

From the women narrative, the study found that some PMTCT staff displayed inappropriate attitude towards the participants. Therefore it is recommended that health workers are encouraged to change their attitude that undermine service delivery and align the practice to the Patients' Rights Charter.

6.2.5 Individual users

The study identified a number of enablers to postnatal PMTCT programme that are recommended to be strengthened. It also identified a number of barriers to postnatal PMTCT programme that are recommended to be addressed. The participants showed adequate knowledge of PMTCT programme and compliance with the follow up clinic visits

and testing schedule and adherence to the ART. It is recommended that users maintain or even improve the aforementioned experience and practices considered as enablers to postnatal PMTCT programme. However, the majority of the women perceived exclusive breastfeeding as difficult and insufficient. Therefore, it is recommended that women should understand that exclusive breastfeeding is sufficient for the first six months and therefore they should practice it. In addition, the women perceived adhering to ART as challenging especially at the start of the programme due side effects. It is recommended that women communicate any ART side effects immediately to health workers to be advised. Furthermore, the women reported experiencing competing obligations which made difficult to bring their infants to the CHC. It is recommended that women seek support from their spouses and families so that they get time to attend the postnatal PMTCT programme.

2.2.6 Society

Despite the decline of the HIV-related stigma in communities, the current study identified stigma as one of the barriers experienced by women attending PMTCT programme at CHC. It is hence recommended to the community to provide support with household chores and childcare while the women are attending the PMTCT services. Furthermore, communities should be mobilised to create an enabling environment for the women attending postnatal PMTCT programme.

REFERENCES

1. Pule M. Exploring Perceptions and Attitudes of Users and Providers on Interventions towards Prevention of Mother to Child Transmission of HIV in Soweto, South Africa. Johannesburg: Witwatersrand; 2014.
2. Hampanda K. Vertical Transmission of HIV in Sub-Saharan Africa: Applying Theoretical Frameworks to Understand Social Barriers to PMTCT. *ISRN Infectious Diseases*. 2013;2013:5.
3. Stringer EM, Chi BH, Chintu N, Creek TL, Ekouevi DK, Coetzee D, et al. Monitoring effectiveness of programmes to prevent mother-to-child HIV transmission in lower-income countries. *Bulletin of the World Health Organization*. 2008;86(1):57-62.
4. Joint United Nations Programme on HIV/AIDS. Fact Sheet November 2016: Global HIV Statistics 2016. [20/06/2016]. Available from: <http://www.unaids.org/en/resources/fact-sheet>.
5. Besser M. Preventing Mother-to-Child HIV Transmission in Africa Using New Paradigms in Health Care Delivery 2010. [13/05/2016]. Available from: <http://www.slideshare.net/mothers2mothers/preventing-mtct-in-africa-using-new-paradigms-a-dr-besser-presentation>.
6. Navario P, Blecher M, Darkoh E, Hecht R, McIntyre J, et al. Special Report on the State of HIV/AIDS in South Africa. *Global Health Magazine*. 2012:1-8.
7. Joint United Nations Programme. Progress report on the global plan towards the elimination of new HIV infections among children and keeping their mothers alive 2015. [30/05/2016]. Available from: http://www.unaids.org/en/resources/documents/2015/JC2774_2015ProgressReport_GlobalPlan.

8. Shisana TR, Simbayi LC, Zuma K, Jooste S, Zungu N, Labadarios D, et al. South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town, South Africa: HSRC Press; 2014.
9. Laher F, Cescon A, Lazarus E, Kaida A, Makongoza M, Hogg RS, et al. Conversations with mothers: exploring reasons for prevention of mother-to-child transmission (PMTCT) failures in the era of programmatic scale-up in Soweto, South Africa. *AIDS and behavior*. 2012;16(1):91-8.
10. World Health Organisation. Progress report 2011: Global HIV/AIDS response 2011. [02/09/2016]. Available from: http://www.who.int/hiv/pub/progress_report2011/en/.
11. Chetty T, Knight S, Giddy J, Crankshaw TL, Butler LM and Newell ML. A retrospective study of Human Immunodeficiency Virus transmission, mortality and loss to follow-up among infants in the first 18 months of life in a prevention of mother-to-child transmission programme in an urban hospital in KwaZulu-Natal, South Africa. *BMC pediatrics*. 2012;12:146.
12. Goga DJ, Lombard C, Ramokolo V, Ngandu N, Sherman G, et al. Highest risk of mother to child transmission of HIV or death in the first 6 months postpartum: results from 18 month follow-up of an HIV-exposed national cohort, South Africa. 21st International AIDS Conference; Durban 2016.
13. Chi BH, Bolton-Moore C and Holmes CB. Prevention of mother-to-child HIV transmission within the continuum of maternal, newborn, and child health services. *Current opinion in HIV and AIDS*. 2013;8(5):498-503.

14. Barker PM and Mate K. Eliminating mother-to-child HIV transmission will require major improvements in maternal and child health services. *Health affairs (Project Hope)*. 2012;31(7):1489-97.
15. Wettstein C, Mugglin C, Egger M, Blaser N, Vizcaya LS, Estill J, et al. Missed opportunities to prevent mother-to-child-transmission: systematic review and meta-analysis. *AIDS (London, England)*. 2012;26(18):2361-73.
16. Nhemachena D. The rate of postnatal MTCT of HIV is a great concern to programme managers within Johannesburg Health District 2014.
17. Ferguson L. Women's experiences in services for preventing the mother-to-child transmission of HIV: a literature review 2013. [10/11/2005]. Available from: http://apps.who.int/iris/bitstream/10665/90780/1/WHO_HIV_2013.47_eng.pdf.
18. DeLemos LM, Lippi J, Rutherford GW, Duarte GS, Martins NG, Santos VS, et al. Maternal risk factors for HIV infection in infants in northeastern Brazil. *International journal of infectious diseases : IJID : official publication of the International Society for Infectious Diseases*. 2013;17(10):e913-8.
19. De Cock KM, Fowler MG, Mercier E, de Vincenzi I, Saba J, Hoff E, et al. Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice. *Jama*. 2000;283(9):1175-82.
20. Núñez IG and Jaja M. Cuban program for Prevention of Mother-to-Child Transmission. 4th International Conference on HIV/AIDS in Cuba, Central America and the Caribbean; Havana, Cuba2000.
21. World Health Organisation. Prevention of HIV transmission from mother to child: Strategic options 1999. [10/11/2016]. Available from: http://www.unaids.org/sites/default/files/media_asset/prevention_en_0.pdf.

22. World Health Organisation. HIV transmission through breastfeeding: A review of available evidence 2007. [05/12/2016]. Available from:
http://www.who.int/maternal_child_adolescent/documents/9789241596596/en/.
23. Barron P, Pillay Y, Doherty T, Sherman G, Jackson D, Bhardwaj S, et al. Eliminating mother-to-child HIV transmission in South Africa. Bulletin of the World Health Organization. 2013;91(1):70-4.
24. Bhardwaj S, Barron P, Pillay Y, Treger-Slavin L, Robinson P, Goga A, et al. Elimination of mother-to-child transmission of HIV in South Africa: rapid scale-up using quality improvement. S Afr Med J. 2014;104(3 Suppl 1):239-43.
25. World Health Organisation. New guidance on prevention of mother-to-child transmission of HIV and infant feeding in the context of HIV 2010. [05/01/2017]. Available from: <http://www.who.int/hiv/pub/mtct/PMTCTfactsheet/en/>.
26. National Department of Health. The 2012 National Antenatal Sentinel HIV & Herpes Simplex Type-2 Prevalence Survey in South Africa 2013. [10/12/2016]. Available from: https://www.health-e.org.za/wp-content/uploads/2014/05/ASHIVHerp_Report2014_22May2014.pdf.
27. National Department of Health SANAC. Clinical guidelines: PMTCT (Prevention of Mother-toChild Transmission) 2010. [08/11/2016]. Available from:
http://www.fidssa.co.za/Content/Documents/PMTCT_Guidelines.pdf.
28. United Nations Children's Fund. A Call to Action: Children the missing face of AIDS 2005. [15/07/2016]. Available from:
https://www.unicef.org/publications/index_29157.html.
29. Government of Western Cape. Prevention of Mother to Child Transmission (PMTCT) 2015. [20/07/2016]. Available from:

<https://www.westerncape.gov.za/service/prevention-mother-child-transmission-pmtct>.

30. Nkonki LL, Doherty TM, Hill Z, Chopra M, Schaay N and Kendall C. Missed opportunities for participation in prevention of mother to child transmission programmes: simplicity of nevirapine does not necessarily lead to optimal uptake, a qualitative study. *AIDS Research and Therapy*. 2007;4:27.
31. National Department of Health SA. National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults 2015. [25/05/2015]. Available from: <http://www.kznhealth.gov.za/family/HIV-Guidelines-Jan2015.pdf>.
32. World Health Organisation. PMTCT strategic vision 2010-2015. 2010. [18/04/2016]. Available from: http://www.who.int/hiv/pub/mtct/strategic_vision/en/.
33. World Health Organisation. HIV and infant feeding guidelines 2016. [20/09/2016]. Available from: http://www.who.int/maternal_child_adolescent/topics/newborn/nutrition/hivif/en/
34. Ellway BPW and Dean AM. The reciprocal intertwining of practice and experience in value creation. *Marketing Theory*. 2016;16(3):299-324.
35. Anderson G, Caswell G, Edwards O, Hsieh A, Hull B, Mallouris C, et al. Community voices: barriers and opportunities for programmes to successfully prevent vertical transmission of HIV identified through consultations among people living with HIV. *Journal of the International AIDS Society*. 2012;15 Suppl 2:17991.
36. Larsson EC, Thorson A, Pariyo G, Conrad P, Arinaitwe M, Kemigisa M, et al. Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda. *Health policy and planning*. 2012;27(1):69-75.

37. Chopra M, Doherty T, Jackson D and Ashworth A. Preventing HIV transmission to children: quality of counselling of mothers in South Africa. *Acta paediatrica* (Oslo, Norway : 1992). 2005;94(3):357-63.
38. Painter TM, Diaby KL, Matia DM, Lin LS, Sibailly TS, Kouassi MK, et al. Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study. *BMJ (Clinical research ed)*. 2004;329(7465):543.
39. Moth IA, Ayayo AB and Kaseje DO. Assessment of utilisation of PMTCT services at Nyanza Provincial Hospital, Kenya. *SAHARA J : journal of Social Aspects of HIV/AIDS Research Alliance*. 2005;2(2):244-50.
40. Hardon A, Vernooij E, Bongololo-Mbera G, Cherutich P, Desclaux A, Kyaddondo D, et al. Women's views on consent, counseling and confidentiality in PMTCT: a mixed-methods study in four African countries. *BMC Public Health*. 2012;12:26.
41. Peltzer K, Mosola T, Shisana O, Nqueko and Mngqundanis O. Barriers to prevention of HIV transmission from mother to child (PMTCT) in a resource poor setting in the Eastern Cape, South Africa. *Ajournal of Reproductive Health*. 2007;57-66.
42. Varga C and Brookes H. Factors influencing teen mothers' enrollment and participation in prevention of mother-to-child HIV transmission services in Limpopo Province, South Africa. *Qualitative Health Research*. 2008;18(6):786-802.
43. O'Gorman DA, Nyirenda LJ and Theobald SJ. Prevention of mother-to-child transmission of HIV infection: Views and perceptions about swallowing nevirapine in rural Lilongwe, Malawi. *BMC Public Health*. 2010;10:354.

44. Mahiti GR, Mkoka DA, Kiwara AD, Mbekenga CK, Hurtig AK and Goicolea I. Women's perceptions of antenatal, delivery, and postpartum services in rural Tanzania. *Global health action*. 2015;8:28567.

45. National Department of Public Administration. Batho Pele - "People First": White paper on transforming public service delivery 1997. [02/01/2017]. Available from: <http://www.dpsa.gov.za/dpsa2g/documents/acts®ulations/frameworks/white-papers/transform.pdf>.

46. National Department of Health . National Core Standards for Health Establishments in South Africa 2011. [04/01/2017]. Available from: <http://www.rhap.org.za/wp-content/uploads/2014/05/National-Core-Standards-2011-1.pdf>.

47. Solomon KF. Strengthening PMTCT through communication: A review of the literature 2009. [30/11/2016]. Available from: https://www.unicef.org/southafrica/SAFresources_pmtctcommunication.pdf.

48. Seidel G. Reconceptualising issues around HIV and breastfeeding advise: findings from KZN , South Africa. *Review of African polical economy*. 2000. 27(86),501-518

49. Health Professional Council of South Africa. National Patients' Rights Charter: Guidelines for good practice in the health care professions. 2008.

50. South African History Online. Xenophobic violence in democratic South Africa: Timeline. 2015.

51. Sprague C, Chersich MF and Black V. Health system weaknesses constrain access to PMTCT and maternal HIV services in South Africa: a qualitative enquiry. *AIDS Research and Therapy*. 2011;8:10.

52. Chinkonde JR, Sundby J and Martinson F. The prevention of mother-to-child HIV transmission programme in Lilongwe, Malawi: why do so many women drop out. *Reprod Health Matters*. 2009;17(33):143-51.
53. Assefa Y, K iflie A, Tekle B, Mariam DH, Langa M and Van Damme W. Effectiveness and acceptability of antiretroviral treatment in health centres by health officers and nurses in Ethiopia. *Journal of health services research and policy*. 2012;17(1):24-29.
54. Duff P, Rubaale Tand Kipp W. Married men's perceptions of barriers for HIV-positive pregnant women accessing highly active antiretroviral therapy in rural Uganda. *International Journal of Women's Health*. 2012;4:227-33.
55. Parliament of South Africa. South Africa takes bold step to provide HIV treatment for all [press release]. 10 May 2016.
56. National Department of Justice and Constitutional Affairs. Constitution of the Republic of South Africa, 1996 (Act No. 108 of 1996). [06/01/2016]. Available from: <http://www.justice.gov.za/legislation/constitution/saconstitution-web-eng.pdf>.
57. Bucyibaruta J. Analysis of acceptability of HIV, TB, and maternal health services: A case study of a Johannesburg sub-district, South Africa. Johannesburg: Witwatersrand; 2016.
58. Otieno PA, Kohler PK, Bosire RK, Brown ER, Macharia SW and John-Stewart GC. Determinants of failure to access care in mothers referred to HIV treatment programs in Nairobi, Kenya. *AIDS care*. 2010;22(6):729-36.
59. Peltzer K and Shikwane ME. Prevalence of postnatal depression and associated factors among HIV-positive women in primary care in Nkangala district, South Africa 2011.

- 60\ Mrisho M, Obrist B, Schellenberg JA, Haws RA, Mushi AK, Mshinda H, et al. The use of antenatal and postnatal care: perspectives and experiences of women and health care providers in rural southern Tanzania. *BMC pregnancy and childbirth*. 2009;9:10.
61. Ngarina M, Popenoe R, Kilewo C, Biberfeld G and Ekstrom AM. Reasons for poor adherence to antiretroviral therapy postnatally in HIV-1 infected women treated for their own health: experiences from the Mitra Plus study in Tanzania. *BMC Public Health*. 2013;13(1):450.
62. Hodgson I, Plummer ML, Konopka SN, Colvin CJ, Jonas E, Albertini J, et al. A Systematic Review of Individual and Contextual Factors Affecting ART Initiation, Adherence, and Retention for HIV-Infected Pregnant and Postpartum Women. *PloS one*. 2014;9(11).
63. Nachega JB, Uthman OA, Anderson J, Peltzer K, Wampold S, Cotton MF, et al. Adherence to antiretroviral therapy during and after pregnancy in low-income, middle-income, and high-income countries: a systematic review and meta-analysis. *AIDS (London, England)*. 2012;26(16):2039-52.
64. Siziba LP, SM. Hanekom SM and Wentzel-Viljoen E. Low rates of exclusive breastfeeding are still evident in four South African provinces. *S Afr J Clin Nutr*. 2015;28(4):170-9.
65. 2006 Report on the global AIDS epidemic;UNAIDS,2006. Available on http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp. Accessed on 15/06/2017.
66. Busza J, Walker D, Hairston A, Gable A, Pitter C, Lee S, et al. Community-based approaches for prevention of mother to child transmission in resource-poor settings:

- a social ecological review. Journal of the International AIDS Society. 2012;15(Suppl 2).
67. Horta BL and Victoria CG. Long term effects of breastfeeding: a systematic review. Geneva: World Health Organisation, 2013.
 68. M. Saunders m, Lewis P and Thornhill A. Research Methods for Business Students. 5th ed. England: Pearson Education Limited; 2000.
 69. Alexandra Health Center and University Clinic Annual Report 2012. 2012.
 70. Statistics South Africa. 2011 Census. 2012. [15/05/2016]. Available from: http://www.statssa.gov.za/census/census_2011/census_products/Census_2011_Census_in_brief.pdf.
 71. De Vos HT, Strydom H, Fouche CB and Delport CSL. Research at Grass Roots: For the social sciences and human service professions. 4th ed. Pretoria: Van Schaik; 2011.
 72. Ehrlich R and Joubert G. Epidemiology: A research manual for South Africa: OUP Southern Africa; 2008.
 73. Holloway I. Basic concepts of qualitative research. Oxford: Blackwell science; 1997.
 74. M. Hennink M, Hutter I, Bailey A. Qualitative Research Methods: Sage; 2010.
 75. Trinidad HS. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. Qualitative Health Research. 2007;17:1372-80.
 76. John W and Dana L. Determining validity in qualitative inquiry. Theory Into Practice. 2000;39:124-30.
 77. Li Y. Learning to do qualitative analysis: An observation study of doctoral work. Qualitative Health Research. 2007;17:1442-52.
 78. Fischer JR. Social Desirability Bias and the Validity of Indirect Questioning. Journal of Consumer Research. 1993;20(2P):303-15.

APPENDICES

Appendix 1 Interview guide

Section 1: Personal Information and background

Before we commence our interview, I would like to know more about you:

- 1.1 Home language (Isizulu/Isixhosa/seSotho/English/other)
- 1.2 Age.....
- 1.3 Education/last grade.....
- 1.4 Employment status: employed/unemployed
- 1.5 Marital status: married/not married
- 1.6 Citizenship: South Africa/Non South Africa(please specify)
- 1.7 Number of previous pregnancies
- 1.8 Number of follow up visits since you delivered this baby...

Section 2:

Question 1: Please tell me about your experiences at this clinic since you have had your baby.

Question 2: Since you gave birth, tell me about the information the clinic staff/counsellors have shared with you.

Probe:

- 2.1 How about the infant feeding options?
- 2.2 How about the ART prophylaxis and treatment?
- 2.3 How about follow up visits and testing?
- 2.4 How about the importance of adherence?

Question 3: Please tell me about how you feel about the postnatal PMTCT programme at this community health centre.

Probes:

- 3.1 How about counselling and testing?
- 3.2 How about follow up visits and infant testing?
- 3.3 How about the effectiveness of ART prophylaxis and treatment?

3.4 How about adherence to ART prophylaxis and treatment?

3.5 How about recommended infant feeding practices?

Question 4: Since you gave birth, please tell me what you are doing to ensure the health of your baby?

Probes:

4.1 How about attending postnatal PMTCT counselling?

4.2 How about adherence to ART prophylaxis and treatment?

4.3 How about follow up visits and infant testing?

4.3 How about safe infant feeding practice?

Question 5(a): In your opinion, what would discourage women like you from continuing to attend this programme at this clinic?

Probes:

5.1 How about counselling and testing?

5.2 How about confidentiality of health information?

5.3 How about provider-client interactions?

5.4 How about long waiting time?

5.5 How about shortage of PMTC staff?

5.6 How about personal circumstances?

5.6 How about family/community issues?

Question 5 (b): In your opinion, what would encourage women like you to continue to attend this programme at this clinic?

Probes:

5.1 How about counselling and testing?

5.2 How about confidentiality of health information?

5.3 How about provider-client interactions?

5.4 How about long waiting time?

5.5 How about shortage of PMTC staff?

5.6 How about personal circumstances?

5.6 How about family/community issues?

Thank you for your participation.

Appendix 2 Ethical Clearance Number: M151174



R14/49 Mr Benon Ngyende

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M151174

NAME: Mr Benon Ngyende
(Principal Investigator)

DEPARTMENT: School of Public Health
Alexandra Community Health Clinic

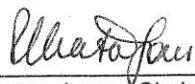
PROJECT TITLE: Postnatal Experiences, Perceptions and Practices
of the Prevention of Mother to Child Transmission
of HIV Programme Among Women Enrolled at Alexandra
Community Health Clinic, Johannesburg

DATE CONSIDERED: 27/11/2015

DECISION: Approved unconditionally

CONDITIONS: Title Change (23/03/2016)

SUPERVISOR: Prof John Eyles, Ms Bronwyn Harris and Dr Daniel Nhemachena

APPROVED BY: 
Professor P. Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 14/03/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA



a world class African city

JOHANNESBURG HEALTH DISTRICT

Enquiries:
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03/02/2016

Benon Ngyende
University of the Witwatersrand
E-mail: benngyende@gmail.com

Reference no: 2015-16/037

Dear Benon Ngyende,

Re: Study protocol: *Postnatal experiences, perceptions and practices of the Prevention of mother to child prevention of HIV programme among women enrolled at Hillbrow CHC, Johannesburg.*

Your application the above approval project refers. The District Research Committee has reviewed your application. This letter serves as an in-principle approval to access the Districts Health facilities (mentioned below) for the above project, subject to following conditions:

- The facility to be visited: Sub-district/ Region E (Alexandra Health Centre CHC).
- This facility will be visited from 15 February 2016 to 31 March 2017.
- Please contact the Sub-district Manager (Region E) prior to visiting the health facilities:

Sub-district Manager	Contact no	Cell phone
Mr Peter Mathole	011-4401259	082772-0582

- You will report to the Facility managers of the Clinic before initiating the study.
- Participants' rights and confidentiality will be maintained all the time.
- No resources (Financial, material and human resources) from the above facilities will be used for the study. Neither the District nor the facility will incur any additional cost for this study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit a six-monthly progress report (see attached) to the District Research Committee. Your supervisor and University of the Witwatersrand will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.

Appendix 4 Participant information sheet

Study title: Postnatal Experiences, Perceptions and Practices of the Prevention of Mother to Child Transmission of HIV Programme among Women enrolled at Alexandra Community Health Clinic, Johannesburg

Greeting: Good day.

Introduction

We, Benon Ngyende and Rose Nkabinde, are from the School of Public Health, Wits University. We are doing research on Prevention of Mother to Child Transmission of HIV Women enrolled at Alexandra Community Health Clinic, Johannesburg. Research is just the process to learn about the answer(s) to a problem. In this study we want to learn about the Postnatal Experiences, Perceptions and Practices of the Prevention of Mother to Child Transmission of HIV Programme among Women enrolled at Alexandra Community Health Clinic. We also want to learn the key postnatal barriers to the programme. Women's experiences of the programme influence perceptions and practices and hence its effectiveness. The findings from this study will therefore help the policy-makers, managers and women to identify gaps and weaknesses to improve effectiveness of the programme.

Invitation to participate: We are inviting you to take part in the research study.

What is involved in the study?

We (researchers) will before the interviews/data collection explain the purpose of the study, the research procedure, risks, benefits, voluntary participation, reimbursement and confidentiality and request 15 eligible participants for a signed consent form(s) to participate in the study. The participants will be women enrolled on at Alexandra CHC during the period March –April, 2016.

Women (15) enrolled on the programme will be asked to take part in about an hour long individual in-depth interviews using a standard interview guide covering the postnatal PMTCT experiences, perceptions, practices and programme barriers. The interviews will be conducted by the principle research investigator together with an experienced mature female research assistant in a quiet and convenient venue within the proximity of the clinic. The interviews will be the four dominant languages (Isizulu, Xhosa, Setsetho and English) and will be video-taped to ensure that your information is correctly captured.

Risks of being involved in the study

The study has no obvious risk to participants. However, during the interviews, participants will be asked to describe their previous postnatal programme experiences, perceptions and practices. Some of these may be adverse and cause psychological stress. In addition, identifying the programme barriers may raise need for psycho-social support which is beyond the direct scope of the study interviews. In the event that the participant is stressed, the interviews will be terminated and referred to counseling services. Furthermore, the participants will be informed not to answer any questions that make them feel uncomfortable.

Benefits of being in the study

There is no immediate benefit accruing to the participants directly. However, it is hoped that the study findings will be taken into consideration by policy-makers, managers and supervisors to strengthen the programme which may have future benefits to Alexandra CHC and women enrolled on the programme.

Voluntary Participation

Participation is voluntary, and refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled and the participant may discontinue participation at any time without penalty loss of benefits to which the participant is otherwise entitled.

Reimbursements

No remuneration will be provided to the participants

Confidentiality

Efforts will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee.

Persons who will have access to raw data are the principal researcher, research assistant and supervisors.

Study results will be reported in form of a research report, publications and conference presentations. If results are published, the data will not contain the names of the participants and pseudo names will be assigned so that no individual or cohort of individual may identified.

Data will be de-identified. The de-identified data will be stored safely in the researcher's laptop protected with a password. The tape records will be securely stored by researcher and be destroyed two years after publishing the results or six year in the event that results are not published.

Contact details for researcher(s)

For further information/reporting of study related study, please feel free to contact researcher on 011-717-2237(Office), Cell.0724077996

E-mail:benngyende@gmail.com or the supervisor Prof. John Eyles on 011-717 2200

Contact details for REC Administrator and Chair

Should you require to direct any queries, concerns or complaints regarding the ethical activities surrounding the study, please contact the Human Research Ethics Committee administrator and Chair on 011-717-2301,email: peter.cleaton-jones1@wits.ac.za or Administrative officer Ms Zanele Ndlovu 011 717 27000/1234/1252, Email:zanele.ndlovu@wits.ac.za

Thank you for your time to read this information sheet

Appendix 5 Consent to participate in the study

I hereby confirm that I have been informed by the interviewer,.....,about the procedures, nature, benefits and risks of the study.

I have also received, read and understood the written information (Participants information Leaflet and Informed Consent) regarding the study

I am aware that the findings of the study, including personal details regarding my sex, age, date of birth, initials and profession will be anonymously processed into a study report

I view of the requirements of research; I agree that the data collected during this study can be processed in computerised system by the researcher.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask any questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

.....

Printed Name

Signature/Mark or Thumbprint

Date and Time

I,hereby confirm that the above participant has been fully informed about the nature ,conduct and precautions of the above study.

INTERVIEWER:

.....

Printed Name

Signature

Date and Time

Appendix 6 Informed Consent for Voice Recording

I hereby confirm that I have been informed by the interviewer,.....,that the information I provide during the interview will be voice-recorded.

I am also aware that the voice-recording will be done using a small silence digital voice –recording machine. I have also been informed that the information recorded will be stored electronically and confidentially.

I am aware that the recording is done for research purposes only, and that the recording will not be made available to anyone else besides the research team (researcher, assistant and supervisors) and not for any other purpose besides research.

In view of the research requirements, I agree that the information recorded be stored electronically using a computerised system

I may, at any stage, without prejudice, withdraw my consent to recording of the interview. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepare to have the interview recorded.

PARTICIPANT:

.....

Printed Name

Signature

Date and Time

I,, hereby confirm that the above participant has been fully informed about the nature of the voice-recording for the study.

INTERVIEWER:

Printed.....Signature.....Date and Time.....

Appendix 7 Demographic characteristics of the study participants

Age	
20-24	2 (13.3%)
25-29	5 (33.3%)
30-34	6 (40%)
35-39	2 (13.3%)
Education status	
Primary	0 (0%)
Secondary	14 (93%)
Tertiary	1 (7%)
Marital status	
Married	1 (6.7%)
Not married	14 (93.3%)
Employment status	
Employed	10 (67%)
Unemployed	5 (33%)
Citizenship	
South Africans	10 (70%)
Non-South African	5 (30%)
No of postnatal PMTCT clinic visits	
2	6 (40%)
3	6 (40%)
4	2 (13%)
6	1 (7%)
Time of HIV diagnosis	
Voluntary testing	1 (7%)
ANC (Pregnancy)	14 (93%)
TOTAL N=15	