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EXPLORING HEALTHCARE USER PERSPECTIVES ON UTILISATION OF PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) SERVICES IN A HIGH-MOBILITY CONTEXT IN JOHANNESBURG , SOUTH AFRICA.

M. Bisnauth

A thesis submitted to the Faculty of Science, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy.

Signed on 13 March 2023 in Johannesburg.



Melanie Bisnauth
(1589334)

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Philosophiae Doctor
In
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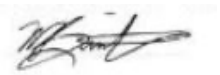
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March 2023

DECLARATION OF ACADEMIC ACHIEVEMENT

I, MELANIE ANN BISNAUTH declare that this Thesis is my own, unaided work. It is being submitted for the Degree of Doctor of Philosophy of Public Health at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



(Signature of candidate)

13th day of March 2023 at University of Witwatersrand, Johannesburg, South Africa.

LIST OF RESEARCH OUTPUTS

Presentations

- Bisnauth, MA. Addressing the Migrant Gap: Maternal Healthcare Perspectives on Utilising Prevention of Mother to Child Transmission (PMTCT) services during the COVID-19 pandemic, South Africa. Oral presentation at: 24th International AIDS Conference (IAS) 2022; July 29-August 2, 2022; Montreal, Canada.

- Bisnauth, MA. Understanding re-engagement in Johannesburg's HIV programme: An analysis of clients re-initiating ART. Oral presentation at: Johannesburg Health District, Translating PHC Research Conference; April 20, 2022; Johannesburg, South Africa. https://profmoosa.com/jhb-phc-conference-2022/

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- Bisnauth, MA. Knowledge, Attitudes, and Practices regarding COVID-19 among Health Care Workers. Oral presentation at: SAAIDS 2021 Conference; June 9-10, 2021; Johannesburg, South Africa.

- Bisnauth, MA. Welcome Back Evaluation and Updates for 2nd 90 Retention. Oral presentation at: USAID and The United States President's Emergency Plan For AIDS Relief (PEPFAR) Continuing Medical Education 2021 for CPD; May 27, 2021; Johannesburg, South Africa.

- Bisnauth, MA. A campaign to encourage re-engagement with antiretroviral therapy in an urban South African district: a qualitative evaluation. Poster presentation at: 23rd International AIDS Conference (IAS) 2020; July 6-10, 2020; San Francisco, California.

- Bisnauth, MA. Evaluation of the Option B+ PMTCT program for HIV at hospital facilities: case study at the Rahima Moosa Mother and Child Hospital, Johannesburg, South Africa. Poster presentation at: 25th Public Health Association of South Africa (PHASA) Conference; September 16-18th, 2019; College of Cape Town, South Africa.

- Bisnauth, MA. Evaluation of the new Option B+ PMTCT programme for HIV at hospital facilities: case study at the Rahima Moosa Mother and Child Hospital. Johannesburg, South Africa. Oral presentation at: South African HIV Clinicians Society (SAHIVCS) Conference, Best Abstracts Session; October 27, 2018; Gallagher Convention Centre, South Africa.

- Bisnauth, MA. Exploring perspectives of HIV: A Journey from Australia to South Africa. Oral presentation at: AIESEC Conference: The 70th Anniversary, AIESEC Empowering Young People for Peace and Fulfilment of Humankind's Potential, Alumni Talks; July 8, 2018; Hurghada, Egypt.

- Bisnauth, MA. Option B+ program for the prevention of vertical transmission of HIV: a case study in Johannesburg, South Africa. Poster presentation at: Public Health for Sustainable Development in Africa, Research Day at School of Public Health; November 27, 2017; University of Witwatersrand, Johannesburg, South Africa.

- Bisnauth, MA. Evaluation of the new Option B+ PMTCT programme for HIV-infected women at hospital facilities & Strengthening the response of the Option B+ PMTCT programme in high-mobility contexts for national and non-national HIV infected women: A cross-sectional analysis at the Rahima Moosa Mother and Child Hospital, Johannesburg, South Africa. Radio interview at: Children's Health Radio; November 13, 2017; Cape Town, South Africa.

- Bisnauth, MA. Evaluation of the new Option B+ PMTCT programme for HIV-infected women at hospital facilities & Strengthening the response of the Option B+ PMTCT programme in high-mobility contexts for national and non-national HIV infected women: A cross-sectional analysis at the Rahima Moosa Mother and Child Hospital, Johannesburg, South Africa. Oral presentation at: AIDS Impact Conference; November 13-15, 2017; Cape Town, South Africa.

Publications

- Bisnauth, MA. The Conversation: Africa, COVID-19, World AIDS Day Special Feature. COVID affected access to HIV treatment: the stories of migrant women in South Africa show how [Internet] 2022, November 30 [cited 27 February 2023] Available from https://theconversation.com/covid-affected-access-to-hiv-treatment-the-stories-of-migrant-women-in-south-africa-show-how-195214

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- Bisnauth MA, Coovadia A, Kawonga M, Vearey J. Providing HIV prevention of mother to child transmission (PMTCT) services to migrants during the COVID-19 pandemic in South Africa: insights of healthcare providers. Health Services Insights. 2022 Jan;15:11786329211073386.

- Bisnauth MA, Coovadia A, Mbuagbaw L, Wilson MG, Birch S. Option B+ program for the prevention of vertical transmission of HIV: a case study in Johannesburg, South Africa. Frontiers in Public Health. 2020 Oct 28;8:533534.

This thesis is dedicated to
the individual stories that will always live on, from both patients and frontline workers during the COVID-19 pandemic & in memory of my mother
Lela Ann Bisnauth
1955- 2022.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
C-section	Caesarean section
CD4	T-lymphocyte cell bearing CD4 receptor
COVID-19	SARS-CoV-2
DoH	Department of Health
DSD	Differentiated service delivery
ESRU	Empilweni Services and Research Unit
FDC	Fixed dose combination
HCT	HIV counselling and testing
HCW	Healthcare workers
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
IOM	International Organisation of Migration
LTFU	Loss to follow-up
MD	Medical doctor
MMD	Multi-month dispensing
MNCH	Maternal, newborn and child health
MTCT	Mother-to-child transmission of HIV
MX	Medical xenophobia
NDoH	National Department of Health
NGOs	Non-governmental organisations
OBGYN	Obstetrics and Gynecology
PCR	Polymerase chain reaction
PI	Principal investigator
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission of HIV
PNC	Postnatal clinic
PNW	Postnatal ward
PPE	Personal protective equipment
RMMCH	Rahima Moosa Mother and Child Hospital
RSA	The Republic of South Africa
SA	South Africa
SADC	Southern African Development Community
SDG	Sustainable development goals
SDI	Same Day Initiation
SMS	Short message service
SSA	Sub-Saharan Africa
STATS SA	Statistics South Africa
STI	Sexually transmitted infections
UNAIDS	Joint United Nations Programme on HIV/AIDS
UPFS	Uniformed Patient Fees Schedule
VL	Viral load
WHO	World Health Organisation
WLWH	Women living with HIV

DEFINITION OF TERMS

Asylum seeker: an asylum-seeker is an individual who has left their country and is seeking protection from persecution and serious human rights violations in another country, but who hasn't yet been legally recognised as a refugee and is waiting to receive a decision on their asylum claim, and is allowed to enter the country.

Displaced individuals: an individual who is forced to leave their home of habitual residence due to conflict but found safety internally in their own country of South Africa.

Highly mobile: an individual located within the peripheral and urban areas of and moving within the City of Johannesburg (CoJ) and contributes to intraregional (defined as individuals who move between the seven regional borders within Johannesburg), interprovincial (defined as individuals who move between the nine provinces of SA), and/or cross-border migration patterns.

Internal migrant: an individual who can migrate internally within their country, across provinces or regions.

Nationals: often used in literature to refer to an individual with South African citizenship.

Non-nationals: refer to an individual without South African citizenship.

Non-national permanent residents: an individuals' place of birth is outside South Africa but resides for five or more years in South Africa.

Migration: is the movement of people from one geographical location to the other, across provinces (**interprovincial**), within regions (**intraregional)** or, across country borders (**cross-border**). The movement can occur regardless of the individual's legal status and whether the movement is voluntary or involuntary.

Persons without documentation: an individual who has no form of identification such as a passport or identification (ID) card in South Africa.

Refugee: a refugee is an individual who has fled their own country because they are at risk of serious human rights violations and persecution there. This individual has been granted asylum status.

Typologies: Typologies are different classifications assigned to the participants are different classifications assigned to the participants based on demographics, clinical characteristics (i.e., length of time on ART), and their overall experiences shared in terms of accessibility dimensions, using PMTCT services and could be based on the individuals' movement patterns, known as, **mobility typologies**.

ABSTRACT

Included in this thesis are four original papers. The first of four papers explored the impact of the Option B+ Prevention of Mother to Child Transmission (PMTCT) of human immunodeficiency virus (HIV) programme on the work of healthcare professionals and, investigated pregnant women living with HIV (WLWH) experiences with antiretroviral therapy (ART) for life, to gain insights in ways to better manage the programme. The first paper (Chapter 6) explored the views of both healthcare providers and user experiences with ART for life at the time the SA's National Department of Health (NDoH) adopted World Health Organisation (WHO) 2013 guidelines on ARVs for HIV treatment and prevention in 2015. This included changes to PMTCT through Option B+ (now known as lifelong treatment). In 2015, little was known about the impact of these guidelines on the work of healthcare workers (HCWs) and no research at the time had focused on how these changes have affected adherence for the patients. Semi-structured interviews were conducted with participants and revealed that work had become difficult to manage for all HCWs because of the need to strengthen indicators for tracking patients to decrease the PMTCT loss to follow-up (LTFU); there was inconsistency in delivery of counselling and support services and a need for communication across clinical departments of the hospital that both offered PMTCT services and had to provide care to the mothers and; a lack of compassion and understanding was existent amongst service providers. The overburdened healthcare environment had affected the overall views and experiences of pregnant WLWH going on ART for life. All patient participants (n=55) responded that they chose the fixed dose combination (FDC) pill for life to protect the health of the baby and felt ART for life could be stopped after giving birth, unaware of the long-term benefits for the mother. Although SA national women were interviewed at the time, RMMCH had provided PMTCT care to many migrants and their experiences needed to be heard. Further research was needed on how to strengthen the programme for long term scalability and sustainability for highly mobile WLWH to better adapt PMTCT programming within the healthcare system. Observations of the population of women accessing PMTCT at RMMCH indicated that many migrant WLWH were utilising the services and called for further investigation and lead into the next two phases of the research study.

In addition, Paper 2 (Chapter 7) and Paper 3 (Chapter 8) data collection occurred during the COVID-19 pandemic.

Paper 2 (Chapter 7) investigated HCWs and their experiences in the provision of PMTCT services to WLWH, specifically migrants that were utilising services during the SARS-CoV-2 (COVID-19) pandemic in SA, to provide further insights on the programme. The COVID-19 pandemic resulted in SA taking preventative and precautionary measures to control the spread of infection, this inevitably

proposed challenges to WLWH, especially migrant women by limiting population mobility with border closures and lockdown restrictions. Semi-structured interviews (n=12) conducted with healthcare providers across city, provincial, and national levels explored how COVID-19 impacted the healthcare system and affected highly mobile patients' adherence and utilisation of PMTCT services. Findings revealed; a need for multi-month dispensing (MMD); fear of contracting COVID-19 leading to the disruption in the continuum of care; added stress to the already existent overburdened clinical environment; mistreatment and xenophobic attitudes towards the migrant HIV population and; three key areas for strengthening PMTCT programme sustainability for migrants.

Paper 3 (Chapter 8) investigated the insights of migrant WLWH. Migrant typologies were not pre-determined *a priori*. This research allowed for the different mobility typologies of migrant women utilising PMTCT services in a high mobility context of Johannesburg to first surface from the data. By analysing these experiences, it explored further into how belonging to a specific typology may have affected the health care received and their overall experience during the COVID-19 pandemic. Interviews with cross-border migrants (n=22) (individuals who move from one country to another) and internal migrants (n=18) (individuals who transcend borders within a country) revealed that women in cross-border migration patterns compared to interprovincial/intraregional mobility; expressed more fear to utilise services due to xenophobic attitudes from HCWs; were unable to receive ART interrupting adherence due to border closures and; relied on short message service (SMS) reminders to adhere to ART during the pandemic. All 40 women struggled to understand the importance of adherence due to the lack of infrastructure to properly educate them following social distancing protocols. COVID-19 amplified existing challenges for cross-border migrant women to utilise PMTCT services. Future pandemic preparedness should be addressed with differentiated service delivery (DSD) including MMD of ARVs, virtual educational care, and language sensitive information, responsive to the needs of mobile women and to assist in alleviating the burden on the healthcare system.

The pandemics' impact on the study timeline, key lessons learnt and, take away messages when conducting research during this unpredictable time are provided in Chapter 4 (Methods) and Chapter 9 (Discussion). It is important to include these reflections because of the impact it had on all participants and the entire PhD process.

Paper 4 will be a future policy piece, drawn from Chapter 9, addressing the need for responsiveness from the SA government and NDoH. Chapter 9 brought together collectively the previous papers 1,2, and 3 and drew overall conclusions, recommendations, and a way forward for both policy and programme implementation. This chapter provided the principal findings of the overall thesis and in relation to other studies in the field, as well as implication for policy practice and research. Chapter 9 concludes with the recommendations for future research on WLWH, mobility typologies, service

provision of PMTCT and future pandemic preparedness, and the vision for the South African PMTCT programme.

CHAPTER ONE: INTRODUCTION

1.1 General Introduction

Migration is a recognised social determinant of health which has specifically impacted urban areas worldwide.[1,2] Migration is the movement of people from one geographical location to the other. [1,2] The movement can occur regardless of the individual's legal status and whether the movement is voluntary or involuntary.[1,2] Migration can occur across different demarcations of provinces (referred to as *interprovincial migration*), and/or within regions also known as the municipalities across the City of Johannesburg in South Africa (SA) (referred to as *intraregional migration* in this study) or, across international country borders, including neighbouring countries of the South African Development Community (SADC) and SA (referred to as *cross-border migration*).[1,2]

This thesis research embarked on a journey to unravel preconceived notions about migration and the healthcare system in the inner City of Johannesburg (CoJ), SA. Although migration is recognised as a social determinant of health, healthcare systems have struggled to address service provision gaps and, alleviate the burden of human immunodeficiency virus (HIV) for vulnerable populations, such as highly mobile migrant women living with HIV (WLWH).[1,2] For the purpose of this research, *highly mobile* is defined as an individual located within the peripheral and urban areas of, and moving within the CoJ and contributes to intraregional (defined as individuals who move between the seven regional borders within Johannesburg), interprovincial (defined as individuals who move between the nine provinces of SA), and/or cross-border migration patterns.[3-5]

This thesis utilised the Prevention of Mother to Child Transmission (PMTCT) of HIV lifelong treatment programme (formerly known as Option B+) as a lens to explore the health of migrants in urban areas, within a high mobility context of a state (public) hospital in Johannesburg, Rahima Moosa Mother and Child Hospital (RMMCH). RMMCH is located in Gauteng province and provided a space to explore the challenges that highly mobile WLWH may encounter, when utilising PMTCT healthcare services.

Although, SA has the world's largest ART programme, it has undergone many challenges historically to establish a national PMTCT programme.[7,8] A major challenge included government

decision to delay PMTCT and treatment support programmes for mother-infant pairs, resulting in severe consequences of HIV infections for the nation.[7,8]

Women involved and enrolled in the PMTCT lifelong treatment programme are sources of valuable information that can help incorporate the perspective of patients in policy implementation.[9] The utilisation experiences of these WLWH are key indicators in informing whether the PMTCT programme is being adapted into state hospitals effectively. Research studies have often focused solely on the dichotomy of citizenship versus nationality and disregard the importance of the depth that an individual story may have.[1,2,4,5] This highlights potential opportunities that can help address gaps in the provision of PMTCT services through further exploration of the experiences of highly mobile WLWH.

The focus of this thesis takes literature one step further by breaking apart the reproduction and rhetoric used in literature, that often focuses on the dichotomy of citizenship versus nationality.[2,5] It employed methods using typologies to gain a better understanding of the challenges WLWH who are highly mobile undergo when utilising PMTCT care.[2,5]

Typologies are different classifications assigned to the participants based on demographics, clinical characteristics and could be based on the individuals' movement patterns, known as, *mobility typologies*.[2-5]

This research dove into the similarities and differences of these women when comparing their movement patterns, allowing for different mobility typologies to surface from the data collected.[2-5] Mobility typologies included (but not limited to) WLWH who moved between countries, provinces, regions, and those with or without identifying documentation (ID) (i.e., asylum seeker papers). Typologies were also formed by different classifications assigned to the participants based on the participants overall experiences shared in terms of utilising PMTCT services.[2-5]

After the semi-structured interviews with both service providers and users, transcripts were analysed with the collected data on 1) migrant status (i.e. nationality, document status, refugee, asylum seeker) 2) geography (i.e. intraregional, rural to urban), 3) temporality (i.e. length of time spent in location(s)), 4) motivations/casual classifications (i.e. job seeking, family reunification) 5) socio-demographics (i.e. age of patient, household income, employment, and education); and 6) users clinical characteristics (i.e. year of HIV diagnosis, attendance rate/number of healthcare facility visits, duration on PMTCT lifelong

treatment, date of delivery, and outcome of baby (HIV status)) to help guide and form the different typologies and stories that arose from the data.[2-5]

This research emphasizes the importance of the depths that an individual story can hold. It highlights the potential opportunity that could help address gaps in the provision of PMTCT services,[2,5-7] through further exploration of the experiences of WLWH. This study worked towards providing these WLWH, the opportunity and platform to share their stories. Their individual stories are enriched with information that can better improve healthcare system gaps for PMTCT to highly mobile women.[2,5-7]

It is important to point out that this research does not conclude that all migrants are necessarily highly mobile women.[2,5,6] For example, an individual has a different country origin than SA, this does not solely mean that this person travels more frequently in comparison to other WLWH residing within the inner CoJ.[8]

Furthermore, the COVID-19 pandemic had taken SA by storm, especially since its inception back in March 2020, when the first positive case was announced.[9] The COVID-19 pandemic has impacted healthcare systems worldwide, and more specifically its impact on HIV services which majority of SA's population (made up of over 40% of internal migrants) relies on.[11] The impact of migration on healthcare systems during COVID-19 is little understood but cross-border migration remains both highly a health and, a political issue for recipient countries, like SA.[10] The pandemic caused SA government to implement strict measures to limit population mobility through a serious lockdown and action regional, provincial, and cross-border closures.[10]These COVID-19 measures influenced healthcare service provision, including PMTCT across the country and impacted utilisation for WLWH, specifically these women who are highly mobile.[10]

COVID-19 had ultimately impacted the provision of PMTCT care, highlighting existing challenges to PMTCT programme delivery and was undertaken as data collection continued throughout the first and second waves of the pandemic. The COVID-19 pandemic intersected with the fieldwork of this thesis and to provide true reflections of the PMTCT user experiences of these women, COVID-19, and its impact on the utilisation of services was then stipulated in the research.

In Chapter 7 and 8 (Papers 2 and 3) data collection occurred during the COVID-19 pandemic, and COVID-19 inevitably had an impact on the PMTCT programme provision and its service utilisation by

WLWH. This research advanced the knowledge in particular for migration and migrant WLWH by also qualitatively exploring the differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

This research contributes to the field of migration and health, on how to address gaps in the healthcare system, policy, and programming space for different typologies of migrants and Republic of South Africa (RSA) national women. It is an exploratory assessment that is novel, as it sought to understand the high mobility context and challenges the commonly held notions of healthcare users being viewed as homogeneous groups of national versus non-national.[5,9]

Overall, this thesis brought together three different aspects which included the; 1) migration of WLWH and their utilisation experiences of PMTCT in a high mobility context; 2) experiences of PMTCT healthcare service provision by healthcare workers (HCWs) and; 3) the impact of SARS-CoV-2 (COVID-19) pandemic in SA on PMTCT.

1.2 Outline of Thesis

In Chapter 1, the thesis is outlined as the following:

1.2.1 Overall Aim

The aim of the research was to qualitatively investigate women's utilisation experiences of the PMTCT programme at Rahima Moosa Mother and Child Hospital (RMMCH) as healthcare users, and HCWs perceptions as service providers of PMTCT, and perceptions of key stakeholders in policy and programming at city, provincial and national levels, regarding PMTCT utilisation in a high mobility context. The study further aimed to identify and explore the differences and similarities between different mobility typologies for both accessibility and adherence as concepts of utilisation of the programme during the COVID-19 pandemic.

1.2.2 Objectives

The objectives of this study were the following:

1) To explore women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH;
2) To investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic;
3) To identify the various mobility typologies of women utilising the PMTCT services at RMMCH and;
4) To qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme at RMMCH during the COVID-19 pandemic.

1.2.3 Procedures (methods)

The thesis research employed a qualitative approach which included semi-structured interviews. Healthcare providers across the city, provincial and national levels and were involved at the PMTCT programming across different units at RMMCH were asked to participate. The inclusion criteria for Stage 1a (healthcare staff and key stakeholders for PMTCT policy, guidelines, and programming) included: currently had contact or involvement with patients on PMTCT at the time of data collection; had contact with patients on the programme since its initiation in 2015 and/or who currently had contact or involvement with developing or implementing PMTCT policy, programme, or guidelines since its initiation in 2015, and worked in the public healthcare sector at district, provincial, or national level. Participants were only excluded if they were newly employed with no previous interaction with patients on PMTCT.

WLWH that were utilising PMTCT services at RMMCH were also invited to partake in a semi-structured interview. The inclusion criteria included HIV-infected women whom were either pregnant, newly delivered or those in post-natal follow-up, between the ages of 18 and older (identified reproductive age group according to WHO guidelines for the Option B+ policy in PMTCT programming), enrolled on the PMTCT programme and on the lifelong treatment for at least 1 month at RMMCH. Purposive sampling was used to recruit women on the PMTCT programme at RMMCH. Participants were not excluded based on race or language.

The nurse identified all users attending the antenatal clinic or PNW on the data collection days that are HIV-positive and specifically on the PMTCT lifelong treatment programme (as first point of contact is with frontline nurses in waiting rooms). The nurse would first ask the patient if they were interested in this study and if the patient agreed, they would queue with others to be introduced individually to the principal investigator (PI) in a separate room.

Qualitative interviews were used to explore perceptions and understand the impact on adherence and utilisation and its different components of accessibility: availability, affordability, acceptability, and adaptability that may impact the provision and utilisation of PMTCT services for different mobility typologies of WLWH during the COVID-19 pandemic.

After the interviews with both service providers and users, transcripts were analysed with the collected data on 1) migrant status (i.e. nationality, document status, refugee, asylum seeker) 2) geography (i.e. intraregional, rural to urban), 3) temporality (i.e. length of time spent in location(s)), 4) motivations/casual classifications (i.e. job seeking, family reunification) 5) socio-demographics (i.e. age of patient, household income, employment, and education); and 6) users clinical characteristics (i.e. year of HIV diagnosis, attendance rate/number of healthcare facility visits, duration on PMTCT lifelong treatment, date of delivery, and outcome of baby (HIV status)) to help guide and categorised the different typologies and stories that arose from the data. Typologies are different classifications assigned to the participants based on the six abovementioned categorical areas and the participants overall experiences shared in terms of accessibility and using PMTCT services. Typologies also looked specifically at their movement patterns, referred to as *mobility typologies*. Typologies then were compared to draw similarities and differences with challenges of adherence to the PMTCT programme and utilisation between different mobility typologies. Movement patterns of WLWH were compared to further investigate how PMTCT programme and policy gaps that existed and possible ways to address this for certain mobility typologies of women (i.e., cross-border migrant women) and their use of PMTCT healthcare services during the COVID-19 pandemic.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

2.1.1 Topic of Research

Access of maternal public healthcare services in SA is a challenge for highly mobile women WLWH, especially when it comes to PMTCT services in the inner city of Johannesburg.[11,12] The term access can often be a notion conflated with utilisation. In this research, PMTCT utilisation experiences of highly mobile women are explored. It is important to acknowledge by exploring user experiences and using 'utilisation of care as a proxy for access', this means the individual essentially had a form of access to the programme.

HIV prevalence has increased in the concentrated urban areas of Johannesburg, as the healthcare system struggles to integrate this vulnerable population, to supply services and programming to meet their needs and the demand for HIV and PMTCT care.[12,14]

The COVID-19 pandemic has caused SA to take strict measures, limiting population mobility by placing restrictions of movement from the Department of Home Affairs (DHA).[15] These restrictions were regulated by the Department of Cooperative Governance and Traditional Affairs, the custodian of the Disaster Management Act.[15] Nationally, this resulted in a serious lockdown and border closures for anyone travelling between provinces, countries and regionally within the CoJ.[15] Policing of people occurred during the first wave where road blocks were put in place and all individuals had to have documentation indicating a reason for travelling, especially outside of curfew hours.[15] These COVID-19 measures influenced healthcare provision across the country and impacted access and utilisation, specifically for vulnerable groups, such as WLWH who are highly mobile.[15,16]

Regarding the updated PMTCT protocol and guidelines by World Health Organisation (WHO) as part of the NdoH HIV and Acquired Immune Deficiency Syndrome (AIDS) and Sexually Transmitted Infections (STI) National Strategic Plan, it does not address the complexities of mobility and health care access in high mobility contexts.[6,15] Therefore, better understanding and engagement with vulnerable

and highly mobile migrant WLWH could potentially alleviate challenges to help prevent risk of the mother to child transmission (MTCT) and reduce its rate to less than 5%.[15,16]

RMMCH provides PMTCT healthcare services to an increasingly large non-national (defined as non-SA citizens) and mobile population since it was first offered by the public health sector.[17,18] 'Non-national' women are seen as a homogeneous and politically weak group because of the inability of political institution and policy makers to drive equitable healthcare practices for these individuals. These 'non-national women' that have not gained visibility on SA's health policy agenda, are at an elevated risk of facing inequalities and unfair treatment by HCWs when utilising PMTCT healthcare services across Johannesburg. [9,19] A research gap is existent due to a lack of understanding about how migration and mobility affect women's experiences of utilising PMTCT services, and their experiences of the PMTCT lifelong treatment programme at RMMCH.

Research is needed for a better understanding and more nuanced characterisations of migrant women that goes beyond the narrow conceptualisations often used in the literature and based on nationality versus citizenship.[12,13] This research emphasises the importance of heterogeneity of migrants and the diversity of these individuals as a valuable source of information. By identifying the wide range of typologies, which are different classifications assigned to the participants based on demographics, clinical characteristics (i.e. length of time on ART), and their overall experiences shared in terms of utilisation of PMTCT services, it moves away from these narrow concepts of migrants and who they are. Typologies are also used to specifically analyse different migrant WLWH and their movement patterns, and is referred to as *mobility typologies* in this study.[16] Mobility typologies included different WLWH who moved between countries, provinces, and rural and urban regions of CoJ.

It was not well understood whether there are similarities and differences in PMTCT service utilisation between groups of women according to typologies of mobility. When comparing mobility typologies, similarities, and differences with challenges of adherence to the PMTCT programme and utilisation between different migrant WLWH, it highlighted service provision and policy gaps that existed. However, more work is needed than just the highlighting stories of these 'non-nationals', this calls for action to address the wider implications of the healthcare system and its failure to include migrant women of all different mobility journeys.

This research suggests ways to help address these gaps by targeting interventions for certain mobility typologies of women (i.e., cross-border migrant women) and their use of PMTCT healthcare services during the COVID-19 pandemic.[15,17] There needs to be tailored strategies to reduce the risk of HIV to all migrant mother and infant pairs.[15] This understanding is important in the context of Johannesburg where mobile populations are not only non-nationals.

2.2 Migration, Mobility and Social Determinants of Health

Globally, the Sub-Saharan Africa (SSA) region experiences high levels of urbanisation, a trend of movement from rural to urban areas for migrants.[11] Urban areas in particular are associated with high disease burden.[11] This is exemplified with approximately 1.7 times higher HIV prevalence in SSA urban areas compared to rural areas.[11,13]

SA experiences increased human mobility occurring across the country's borders (cross-border migration) as well as within the country (internal migration). The nation is home to diverse historical and contemporary population movements, predominantly associated with livelihood seeking.[11,13] In particular, SA is the greatest recipient of migrants from SADC.[13,20]

The impact of migration on healthcare systems during COVID-19 is little understood but cross-border migration remains a highly political issue for SA as a recipient country.[13,22,23] Although the SA Constitution indicates the right to access health care for all who live in SA, and the National Health Act provides for free primary healthcare access for all in the country, with no mention of nationality and legal status, interpretation of the legislation is less inclusive in practice.[9,13,20] There is a notion that cross-border migrants are burdening the healthcare system.[9,13] This notion has been challenged by evidence that suggests a 'healthy migrant effect' is occurring in SA, where healthy individuals are moving to seek improved livelihood opportunities in both urban and peripheral urban areas.[9,11,13] In addition, the largest population of migrants are SA nationals who move within the country, often between provinces and within cities (internal migrants), and are largely located in the peripheral and urban areas of the city. [15,16] Internal migrants constitute 44% of SA's population and only 8% are cross-border migrants.[16] These statistics challenge the popular notion that SA is overwhelmed by cross-border migrants immigrating from other countries.[9]

There is a need to improve understanding that 'migration is a continuous, repeated process rather than a single event'.[11,13] Social determinants of health change overtime and space and therefore, the timing of migration in relation to past migration events is meaningful. [11,13] The first time an individual migrates, for example leaving a family home, is very different than subsequent migrations and may be linked to different HIV risk exposure.[11,13,20] Research shows that both non-SA and SA internal migrants face challenges in access and utilisation of healthcare services.[15] The public healthcare system, on which majority of the population relies has struggled to consider mobility or migration, despite this data and existing evidence on the diverse population movements within SA.[9,11,13,15,16,20] These diverse movements include (but are not limited to) the following;

- refugees (an individual who has been forced to leave their country in order to escape war, persecution, or natural disaster);
- asylum seekers (a person who left their home country as a political refugee and is seeking asylum in SA, who may have refugee status and is allowed to work in SA);
- displaced individuals (an individual who is forced to leave their home of habitual residence due to conflict but found safety internally in their own country of SA);
- RSA nationals (an individual who holds a South African passport) and;
- non-national permanent residents (defined as an individuals' place of birth is outside SA but reside 5 or more years within SA).[9,12,13,15,16]

Furthermore, the province of Gauteng has the largest proportion (27%) of the SA population and holds the greatest number of internal migrants.[12,16] According to StatsSA, approximately 1, 444, 000 account for the largest inflow of migrants into Gauteng compared to Western Cape at 460,000 (12%) during the COVID-19 pandemic.[11,16] More specifically, internal migrants are concentrated in Johannesburg, a city full of urban migration patterns, where mobility is often overlooked. reflecting missed opportunity to facilitate the integration of migrants into the healthcare system.[11,16]

2.3 Migrant Women Living with HIV and Healthcare Utilisation

Research has indicated that women in SA undergo major challenges and may face healthcare inequalities, as patients when accessing and utilising healthcare services in the public healthcare system.[11,13,16-24] Some barriers to accessing healthcare services for patients include long waiting times and negative service provider attitudes, often leading to treatment interruption, lack of retention in care, and become loss to follow-up (LTFU).[16,21-24]

More specifically, women whom access HIV services may often face further difficulties regarding sexual and reproductive health care.[20,21,24] Studies suggest that a lack of information regarding HIV and pregnancy, poor psychosocial support, contraceptive use, negative attitudes towards childbearing and problem in accessing safe legal abortions remain problematic within the provision of care provided by the public healthcare system.[11,13,16,20,21,24] Although research claims many national women in SA may undergo some of these barriers, it is important to recognise those barriers are non-specific to national women and contribute to the pre-existent challenges faced by 'non-nationals'.[16,20,25-27]

An increased HIV disease burden is occurring across the country and its relationship to migrants is complex and contested, especially with women aged 15-24 years that account for 25% of new infections annually– four times to the male counterpart.[13,22] A significant number of women with poor healthcare outcomes surface in the inner CoJ.[13,16,,21,23] StatsSA suggests that approximately 60% of the migrant population reside within urban areas in SA, 32% of which are women (both internal and cross-border) that are highly mobile.[13,20]

Structural discrimination has largely influenced health-seeking behaviours resulting in social exclusion of both internal and cross-border migrant women within healthcare facilities.[19-21,23,26] Often, many cross-border migrant women do not access healthcare for fear of being asked for official documentation and deportation.[16,20,21,23,26] Many of these cross-border migrant women face barriers (i.e. denied treatment from healthcare facilities due to lack of identification) that disrupt their ability to adhere to medication and treatment for chronic diseases such as HIV, which requires long-term discipline and a responsive healthcare system.[16,,20,21,23,26]

In addition, healthcare service cutbacks for provision of counselling and support to help assist both internal and cross-border migrant WLWH have resulted in adherence challenges and often LTFU.[20,21,26] Mobile women attending different facilities remain difficult to trace by an identification number because of the lack of syncronised healthcare information systems available to identify when multiple patient identification numbers are assigned to an individual who is moving across clinics in the region, province or country.[20,25]

Furthermore, research suggests ill treatment by HCWs can impact access to care for foreign nationals, such as the phenomenon of medical xenophobia (MX) in the contemporary SA public health system.[21,26,27] MX refers to "the negative attitudes and practices of HCWs towards migrants and refugees

based purely on their identity as a non-South African which impacts the services that are provided for and accessed by patients".[21,26,27,33] Studies point out some examples of MX including, declining non-nationals entrance into a healthcare facility and, health professionals placing non-nationals in a longer queue.[36,39] For this study, it is important that we acknowledge not all ill treatment can be attributed to MX attitudes but acknowledge that there are larger systems at play that impact healthcare institutions (i.e. hospitals).[21,23,,26,27,34] Discrimination can become embedded in practices of 'street level bureaucrats', also known as the frontline HCWs.[21,23,,26,29,32] HCWs become roped into a cyclical process overwhelmed by healthcare system challenges, battling burnout from the patient demand, lack of human and clinical resources, and support needed-especially psychosocial support to care for others.[21,23,26,27,29,32] All users of the SA public healthcare system face challenges including; long queues; medication stock-outs; stigma; barriers of gatekeepers such as security and administrative clerks. [21,23,26,27,32,34] Support staff at health facilities may turn away patients even before they are able to access any healthcare service at the facility. [21,23,26,27,32,34] These challenges especially due to embedded practices from HCWs and support staff, homogenise all migrants, and 'other' these individuals, refusing them of their basic rights to healthcare.[21,22,,29,32] MX attitudes may effect healthcare user experiences, specifically different typologies of migrant woman due to the stigma, mistreatment, and service delivery received.[21,28,29] This care is often not the best care available due to the presumptions that there is an increased burden on the SA public healthcare system due to migrants.[21,29,32]

Research shows that HIV-positive women are more susceptible than their male counterparts to discrimination and encounter challenges in relation to their status, particularly with maternal and reproductive health care, in both urban formal and informal settings where HIV prevalence remains high.[30] Studies suggest that some migrant women experience a healthy migrant effect, when health inequity increases when the individual arrives to the city and then returns 'home' to seek healthcare and care from their families.[1,16] It is important that we acknowledge this complexity and the multiple layers of vulnerability when looking at risk factors of acquiring HIV, both as a migrant and as a woman, understanding this process does not allude to one story but many different processes and experiences for the individual.[27,29-32]

2.4 Migrant Typologies and Why Consider the Perspectives of the Woman Living with HIV: The Danger of a Single Story (Inspired by Chimamanda Ngozi Adichie)

Studies on migration and health have focused mostly on defining migrants in the dichotomy of non-

nationals or nationals, where methodologies have used nationality and the ownership of citizenship and documentation to predetermine categories of migrants.[9,15,31,32] This reproduction seen in research is "methodological nationalism" which focuses solely on nationality when exploring population movements and when categorising and measuring migration and mobility.[9,31,32] Research shows that human behaviour commonly groups people into categories with the aim to make sense of the environment we live in. [9,31,32,35,36] However, the risk is that these 'groups', the categories become "single stories" that give incomplete and simplistic understandings of the identities of others.[9,31,32,35,36]

Instead, research to understand the influence of population movement on healthcare systems 'needs to consider the complexities of migration'.[15,32,36] Migrant typologies have been used "to assist in understanding the association between these two of areas of migration and health to discover ways to better engage with the complex, dynamic, and intersections of migrant typologies".[32,36]

Research suggests that reductionist categories to simply compare internal versus cross-border migrants is not enough and runs the risk of the single story. [32,36] It is important to acknowledge that mobile populations may be categorised into more nuanced typologies with different compositional, contextual, and collective characteristics that may contribute to their healthcare experiences.[35,36] For example, typologies may include nationals who are internal migrants, non-national permanent residents, displaced individuals, migrants with or without documentation.[15,36]

However, by defining typologies a priori it limits the ability to understand how the complexity of migration affects healthcare user experiences and prohibits comparison of RSA nationals and foreign migrant experiences. [9,35,36] Therefore, research has suggested that there is "a need in the way in categorising different migrant groups and to develop a set of nuanced yet flexible typologies that are able to capture the contextually relevant factors affecting migrant experiences", at both individual and population levels "when exploring epidemiological profiles and associated burdens of disease", such as HIV.[36] Previous research has "carefully taken into consideration the multiple factors to improve our understandings of the ways in which diverse migrant groups are associated, or not, with various health and wellbeing outcomes" including; migrant status (nationality); documentation status; tourists; business travellers; job-seeker; refugees; irregular migrants; asylum seekers; internally displaced persons; migrant workers; geography (rural to urban migrants; intra-urban migration; inter-regional migration; internal migration; transnational migration; return migration); temporality (weekly/monthly commuting; seasonal migration; labour related contractual migration; short-term or protracted migration; time in transit); socio-demographic status (age; gender; family structure; economic status; education level; level of

professional and occupational skills) and; motivations/casual classifications (job seeking; family reunification; asylum seeking; refugee resettlement; labour migration; student migration).[33,35,36]

Furthermore, research has placed emphasis that different typologies "will face different levels of health vulnerabilities and resiliencies based on their migration trajectory", providing the example of a "refugee entering a country with an offer of permanent resettlement" versus "an asylum seeker without documents or a clear pathway to needed healthcare and protection".[32]

In the policy and programming spaces, research raises "an awareness that the complexities which underlies the need to document multiple migrant voices and experiences along the diverse trajectories when exploring" the nexus "of migration and health".[35,36] The established limitations and challenges include sampling biases, practical barriers of language and culture and reaching people that are highly marginalised and often unable to access healthcare.[35,36]

A key challenge remains "when comparing migration data internationally, differences in the definition of who is an international migrant, non-national, or internal migrant; inconsistent data sources; and limited data coverage".[36] For example, measures of adherence to ART are skewed if cross-border migrants return to their countries of origin without informing healthcare service providers at the clinic, documented as LTFU in the tracking system.[36] "Poor quality reporting or "non-comparable population data that fails to measure and/or report migration can give rise to misleading conclusions and limits the validity of data interpretation."[36] However, as research suggests, "migration is an ever-changing" and "dynamic process" and the ability to gather migration data and incorporate better data systems into an "enabling environment" that considers the complexities of migration, could improve healthcare information systems and inform national disease control programmes for HIV.[36]

Studies that allow for typologies of migrants to surface using a qualitative approach are needed. Gordon et al. argues that due to existent qualitative research literature, this raises thought provoking questions as to '*why has more quantitative attitudinal research on foreign immigrant attitudes not been undertaken?*' This highlights the need for qualitative research to further investigate different typologies of migrants by allowing them to surface firsthand from the data. Quantitative data have relied on pre-categorisation of migrants to compare perspectives including attitudes of migrants.[31,36,37] By predetermining typologies, this often limits understandings of ones' experience with healthcare access and does not allow us to draw possible correlations between different variables with individuals

experiences. [9,33,35,36] Qualitative approaches could help avoid the pitfall of the single story and the reproducing this dichotomy of citizenship vs. migrant. [9,35-37]

Furthermore, research reported that with *'equally good PMTCT coverage, there was no difference in prevalence of maternal HIV infection and also no difference in reported difficulties by immigrants in terms of access to healthcare'*.[37] Although this research suggested there were larger differences reported in educational levels, and socioeconomic factors, it concluded it did not significantly affect ANC attendance, delivery outcomes, immunisation coverage, or PMTCT coverage for the immigrant group compared to South Africans.[37] A knowledge gap exists, as this was a cross-sectional study executed from children being admitted to paediatric and neonatal wards and did not explore further into internal migrants or even compare different migrant typologies to cross-border migrants. Instead, this research has grouped all migrants as 'immigrants'. [31,38] This is not to say that this is not relevant research that is still needed, but more importantly we need to recognise *"cross-border migration has continually increased in South Africa, resulting in increased attention of health-related issues pertaining to immigrants from governmental organisations, the media, and communities themselves"*.[38]

Although all women face challenges, different groups of women may face different barriers in using PMTCT healthcare services from a system that needs improved responses for patient-centered care.[19] Women involved in the lifelong treatment programme are sources of valuable information that can help incorporate the perspective of patients in policy implementation. Utilisation experiences are key in strengthening healthcare service delivery in Gauteng public healthcare facilities and in informing whether the lifelong treatment PMTCT programme is being adapted into state hospitals effectively.[35-36,39,42]

2.5 The HIV Epidemic in South Africa

Research reveals a large burden of HIV has continued in SA and is driven by the interplay of contextual and socio-behavioural factors.[21,26] The prevalence of HIV infections is higher amongst females (14%) when compared to the male (10%) counterpart.[21] Female adults between the reproductive ages of 25-49 are most affected, and remain the most vulnerable group.[21] The Human Sciences Research Council (HSRC) has conducted national surveys since 2002, and its longitudinal data has revealed evidence of prevalence, incidence and risk behaviours that contribute to the country's HIV prevalence and overall understanding of SAs HIV epidemic.[21,26] HSRC data have suggested that there are underlying structural

factors including, the increasing levels of migration that the country is experiencing.[26,,40] The survey alludes to these vast migration patterns that SA experiences may contribute to risk of HIV transmission.[21,40] Migrants are painted with one brush and are often blamed and argued to be at higher risk of spreading HIV for reasons including their vulnerability, exposure to risky behaviour, sexual partners, and job insecurity.[21,40] It is important to understand that although migrants may 'appear' to be at higher risk, migrants are not 'the cause' for the HIV epidemic in SA.[21,40]

We need to look at the individual level and factors that contribute to the HIV epidemic to better understand the support needed within the healthcare system as a whole. Mathematical modelling of the impact of migration on the HIV epidemic in SA and regional data have indicated that the impact of migration depends upon the stage of the epidemic.[41] Demonstrated early in the epidemic, frequent urban migration caused influx to the inner-city from both informal and formal populations with different HIV prevalence rates and accelerated HIV transmission and its spread.[44] Research states that HIV prevalence is impacted by the frequent return of migrants to urban areas, an important risk factor when coupled with increased sexual behaviour.[38,40] Research studies suggest that migrant males were 2.4 times more likely to be HIV infected compared to non-migrant males, increasing HIV transmission risk for their female counterpart.[38,40] For instance, some migrant workers in SA do not have frequent contact with their partners, which lowered the probability of HIV transmission between some couples compared to returning migrants.[38,40] However, it is important to understand that different risk factors coupled with migration would increase amongst HIV prevalence amongst females, and does not depend solely on grouping individuals as migrants alone.[38,40]

Furthermore, research has indicated SA's HIV prevalence was relatively stable only between 2002 and 2008, and HIV incidence declined in the younger than 25 years population.[21,26] A decline in the rate of HIV transmission of mother-to-child infections at six weeks, suggested the effectiveness of policy changes from actors such as the Joint United Nations Programme on HIV/AIDS (UNAIDS), and WHO to improve implementation of the PMTCT programme with focus on HIV prevention,, treatment, care and support in mother-infant pairs, suggesting scaling up of these services would benefit the HIV population overall.[26,,37]

2.5.1 UNAIDS 90-90-90 Targets

Retention of women that are highly mobile, such as migrant WLWH remains a critical barrier to

reaching the UNAIDS 90-90-90 targets in SA. These targets consist of; the first 90, 90% of all people living with HIV are screened and know their status; the second 90, 90% of all PLHIV with a diagnosed HIV infection will receive 'sustained' ART and; the third 90, 90% of all PLHIV receiving ART will be virally suppressed by 2020.[40,42,43]

UNAIDS reported in 2019 that "there were 7 500,000 people living with HIV in SA, of which 92% (6 900,000) had been diagnosed with HIV, 70% (5 200,000) were on ART and 92% (4 800,000) were virally suppressed".[41-44] In 2020, in Gauteng province, 87% of PLHIV have been diagnosed with HIV, but only 61% remain on ART and of those, 88% are virally suppressed.[41]

The first 90 target has been achieved across the country, 87% of PLHIV have been HIV diagnosed in the province and the SA's ART programme has rapidly expanded over recent years. "*There has been a strong focus on achieving high initiation rates,*" however, SA has lost focus on the second target, 90% of all people with diagnosed HIV infection will receive sustained ART.[9,40-42] Research has further suggested that only 63% of PLHIV who initiated ART remained in care after four years, indicating that the second 90 target has now been increased to the 95-95-95 for 2030, and remains a challenge of retaining patients in care for provincial healthcare systems.[9,38, 40-43]

Monitoring retention for patients that are highly mobile remains a challenge in SA.[9,41,42] Healthcare systems need to incorporate strategies to help strengthen tracing of migrants to combat any risk of treatment interruption, and the loss to follow-up (LTFU), especially amongst pregnant HIV-positive migrant mothers.[9,40-42] There remains a crucial need to strengthen the healthcare system especially in the Gauteng province, full of vast mobility patterns to tackle barriers with retention, including PMTCT care.[17,42] Greater efforts are needed to provide services that target the needs of highly mobile, migrant WLWH (many of which are internal migrants) utilising healthcare, especially in the urban areas and the inner CoJ.[39,42]

The development of effective interventions are well-needed to re-engage highly mobile WLWH who have interrupted treatment due to difficult life circumstances through no fault of their own.[42,44] The healthcare systems should aim to alleviate any burden caused for highly mobile individuals and remove barriers to long-term care for HIV.[42] Healthcare systems need to engage with the movement patterns of highly mobile WLWH to provide the best possible care before the third target can even be achieved for viral suppression.[38,40-42]

2.6 The COVID-19 Pandemic in South Africa

Globally, the COVID-19 pandemic has become a significant public health concern. As of March 2023, over 4 million positive cases and over 106,000 deaths have been recorded in SA alone.[14,17,42,46] This has impacted the clinical work environment across the largest province of Gauteng, that experienced an increased burden of COVID-19 infections during the second wave.[42,45,46] The pandemic has led to burnout for HCWs that have experienced emotional exhaustion, depersonalisation and reduced personal accomplishment in their workplace.[42,43,45,46] Burnout can result in extreme consequences for HCWs working in already overburdened clinical environments, having their resources stretched thin.[39,42,45] It is important to recognise different service providers' perspectives, experiences, and practices and how these may be influenced in different work environments.[45,46]

Studies worldwide have shown that burnout of healthcare providers during the pandemic contribute to HCWs psychological problems, '*especially in those having experienced a COVID-related traumatic event and in those having experienced interpersonal avoidance in the workplace and personal life*'.[42,45,46] HCWs who are suffering from burnout syndrome have been shown to feel less involved in their relationship with patients, showing signs of disengagement, were more inclined to make medical mistakes, and even to compromise the clinical outcomes of patients.[44-47,50]

In SA, where the healthcare system continues to face challenges with providing services to WLWH (yet alone migrant mothers that are highly mobile). The COVID-19 pandemic added another layer of challenges in constrained settings, including both human and infrastructural/structural resources, within the clinical environments.[45-46] Specifically in Gauteng province, the imposed restrictions to reduce the risk of COVID-19 transmission were impractical for most of the population.[27,32] Madhi suggests that there should not be domestic or international travel bans because *"the virus will disseminate irrespective of this"*.[48,49]

Ensuring "healthcare facilities are prepared, not only on paper- but actually resourced with staff, personal protective equipment (PPE)" and "allocating over 2000 qualified HCWs, still waiting for placement confirmations, to health facilities that need them".[48,49,51] It is suggested that higher levels of restrictions need to be tailored accordingly for when health facilities anticipate high-burden rates of infection and hospitalisation by a few weeks to relieve pressure, making it more manageable for frontline HCWs and the overall healthcare system in SA.[48,49,51]

The pandemic now in its third year should trigger key stakeholders such as government, the NDoH and policy makers, to think of ways on how to both action research to consistently strengthen PMTCT healthcare services for highly mobile women and, adapt and learn to live with the COVID-19 virus while resuming provision and utilisation of healthcare services. [48,49,51]

A large area of uncertainty remains with COVID-19 and its impact on the HIV population in SA.[23,24] This calls for a more holistic view on the direct and indirect impact of the pandemic on livelihoods, especially for vulnerable populations, that are cross-border migrants, which include asylum seekers, refugees and undocumented migrants.[50,52-54] Greater efforts are needed to provide services that target the needs of highly mobile women utilising healthcare in CoJ.[53,56]

2.7 South Africa's National Health Act

SA's National Health Act needs to recognise the impact of COVID-19 on HIV and migration.[48-51,54] Repeated border closures led to; irregular migration; lack of access and utilisation of care and humanitarian support and; an increased risk of violence and exploitation of migrants, often stuck in border towns awaiting documentation, many simply to access healthcare services in SA.[48,49] Section 27 of the Refugee Act states that refugees and undocumented migrants (who are citizens of any SADC country) are entitled to the same access to treatment and 'basic health care services' as SA national citizens in Johannesburg public health facilities.[9,32,48,49] This has become 'blurred' in neglected public healthcare systems at large.[28,32,48-49,52,54] As stated by the SA's National Health Act, primary healthcare facilities including state hospitals, "clinics and community health centres, must provide free care to everyone, except for individuals that are covered by medical aid or receiving payment from the workers Compensation Fund- for individuals that are injured, contract a disease or die while working, losing their source of income." [9,48-52] However, many WLWH and on the move may be unemployed, alone in the country and, rely on their partner(s) or family as a source of income.[25,38-39]

Research has suggested that the migrant population should be seen as a high-risk group and be advocated for when it comes to promoting the basic public health rights of these individuals for equal healthcare access.[38] After the establishment of the Border Management Act, the 2017 White Paper on International Migration had a vision that 'South Africans must embrace internal migration for development, while guarding sovereignty, peace and security'.'[32,50] However, the constitutional right to basic needs and health care is often ignored when in policy is put into practice.[32,50,52] In 2018, the SA

Human Rights Commission reported on public hospitals in Gauteng province denying migrants healthcare services linked to their nationality and/or legalstatus.[32,38,52] There is a failure to ensure access to preventative and treatment interventions for all in SA, which undermines any single nation's sovereign response to both HIV and now COVID-19 care.[53] A call to action in SA is needed for the inclusion of migrants and mobile populations to help strengthen the healthcare response nationally and form 'regional harmonisation and operate inclusive healthcare systems' going forward, especially for vulnerable populations such as many migrant WLWH.[53,55]

2.8 PMTCT Policy and Programming in Resource-Constrained Settings

PMTCT is a clear example of a maternal and child health programme that was offered across SA since 2001.[21,56] The PMTCT cascade represents a complex system of sequential, interdependent steps that WLWH navigate as healthcare users to receive appropriate care and treatment for themselves and their newborns.[46] PMTCT typically entails women as healthcare users having access to services such as antenatal care (ANC); HIV testing and counselling (HCT); prophylactic ART; education on safe delivery and infant feeding; follow-up HIV testing at a 7-day postnatal visit, and family planning.[55-59] A vital component that was not traditionally part of the PMTCT programme but was later added is the provision of lifelong ART services for women.[46,55-59] This addition aligned to the WHO consolidated guidelines on PMTCT programming for the lifelong treatment option (previously known as Option B+).[55-57,59] Thus, the PMTCT cascade of care does not end at delivery of the baby as there is a need for long term follow-up. PMTCT using ART is a proven, efficacious intervention, and can reduce vertical HIV transmission to less than 2%. [20,55-57]

2.8.1 WHO Option B+ Policy

The WHO rationale for the Option B+ policy was based on two main components; 1) the need to accelerate the reduction of HIV transmission and 2) the need to simplify delivery of PMTCT services.[56,57,59] Many SSA countries participated in the adoption of WHO's Option B+ programming and policy changes to ART guidelines.[56] As stated by WHO,

> *"The advantages of Option B+ were the simplification of PMTCT and ART treatment regimens and service delivery; strengthening the linkages between reproductive health and ART programmes at all service delivery levels; protection against MTCT in future pregnancies and between discordant*

couples; avoiding stopping and re-starting ARVs, which allows for one public health message, namely ART is for life".[56]

Historically, over the past fifteen years, PMTCT of HIV in resource constrained settings had both scientific and operational issues.[57-59] PMTCT has focused primarily on optimal HIV testing and counselling strategies from an opt-in approach to routine, healthcare provider-initiated rapid testing and counselling with same-day results, infant feeding guidance (from no breastfeeding or short duration breastfeeding with rapid weaning to breastfeeding at least through 12 months) with appropriate antiretroviral (ARV) coverage, and changes to shorter course of zidovudine or single dose NVP to longer and more effective ARVs throughout the risk periods of pregnancy, labour and delivery and breastfeeding.[57-59] WHO made the call that all HIV-positive pregnant breastfeeding women should start on Option B+, a FDC pill with the benefit that this approach would be simpler to register to women.[46,57-59] However, the acceptance of the new regimen from WLWH remained unknown at the time.[46,57-59]

PMTCT programmes in different countries were recommended to continuously monitor and review the programme components to effectively implement the FDC pill to promote long term health for the mother and infant pair.[56] It is important to understand that success of the programme was largely dependent on execution and the delivery of PMTCT services for Option B+, it was also dependent on the resources provided and made available to support the patient.[59]

The following sections provide an overview of PMTCT programme research conducted in SSA and low-or-middle income SADC countries, with resource-constrained settings similar to SA. The following sections (2.8.2-2.8.7) highlighted themes that emerged across the different countries. These sections also provide insights into the different countries (including WHO's first site of Malawi) adoption and adaptability of Option B+ (now known as PMTCT lifelong treatment) programme. The following countries indicate the knowledge gaps and lessons learned, informing this study to move forward with future programming strategies. [58-59]

2.8.2 PMTCT Education in Ethiopia

Research in Ethiopia showcased the experiences of WLWH and their reasons of attrition from Option B+ programme in the Northwest.[60-61] Studies highlighted that there were socioeconomic barriers such as educational status and financial constraints including, the lack of transport and food, that contributed to the issue of adherence to the programme.[60-61] The qualitative research interviews with women and the

findings supported a larger meta-analysis that was conducted in SSA and stated that poverty and the lack of education influenced adherence to the treatment protocol. [60-61] In Ethiopia, education is considered to be a major source to help generate a higher income. [60-61] However, most of the community that accessed PMTCT services, resided in rural areas, associated with a low level of education and poor socioeconomic status. [60-61] Challenges included stigma, discrimination, and the absence of disclosure with a partner or family member(s) that created barriers for attrition from PMTCT care. [60-61] Studies suggested male involvement, availability of the regimen and support groups enabled women to re-enroll into the Option B+ programme, who would have been LTFU. [60-61]

2.8.3 PMTCT Adherence Counselling on Breastfeeding and LTFU in Kenya

In Kenya, a retrospective cohort and prospective quantitative research study identified many potential challenges for PMTCT programming prior to scaling up in resource-limited settings. This included, high infant LTFU and incomplete clinician adherence to the clinical guidelines.[60,62] Two key findings highlighted those changes could be adopted by the PMTCT programme in response including; 1) failure to provide ARVs to neonates born to mothers who received more than four weeks of ART may have contributed to higher transmission rates and; 2) mixed feeding was not reported all the time and may have contributed to HIV transmission rates amongst the mother-infant pair.[62] Much like other SSA countries, Kenya documented high LTFU rates, however competing health priorities, parental fear of a HIV-positive test result, family/employment obligations and unreported deaths are recognised as contributing factors.[58,61] Immunisation services were not available at the HIV clinic; thus, mothers attended their priority immunisation clinic over the HIV clinic. [62] The study highlighted some mothers may have chosen their own health care needs as well above their child, especially if the child was asymptomatic. [62] The programme response to implementation challenges included; using an outreach team to locate mother-infant pairs; aggressive adherence counselling for pregnancy and breastfeeding and; assigned clinicians responsibilities to combat clinician forgetfulness in completing blood work and reviewing logs.[60,61] The programme was in the process of implementing an electronic medical records system for polymerase chain reaction (PCR) tests.[60,61]

2.8.4 PMTCT Support to HCWs and Community Buy-in in Nigeria

In Nigeria, research implementing PMTCT interventions by identifying community gatekeepers was conducted.[63] Studies highlighted context specific diagnostics across several communities in Jos, Plateau

State, where it lacked HIV treatment centres.[63] Women were unable to utilise any of the existing centers because of conflict related to the partitioning of Jos, calling for specialised strategies and collaboration to scale-up to affected communities. [63] Sites were upgraded and received precaution materials and medical supply, cleaning utensils, and disinfectants.[63] Clinical and support staff received job aids, charts, standard operating procedures, and protocols for PMTCT. [60,63] Furthermore, to help close the existing challenges related to distrust in communities, six community resource members were identified of same ethnoreligious dispensation.[60,63] These six members provided support in affected communities to help strengthen the relationship to receive care, as people attended training and capacity building sessions. [60,63] The programme implementation in Nigeria highlighted the; 1) need to strengthen the relationship between service providers and users and; 2) importance of preparedness and upskilling community members/staff, to contribute to the overall success of the programme especially in resource constrained and conflicted areas.[60,63]

2.8.5 SADC Programmes

2.8.6 PMTCT Pilot with Same-Day Initiation in Malawi

Malawi was the number one country with the highest HIV prevalence rate when WHO first rolled out its PMTCT Option B+ guidelines.[57,60,64] Higher prevalence may have been a result of people living with HIV living longer.[55-57] The Malawi programme pioneered Option B+ and its early results were impressive, 60% for ART initiation in the nation for women.[57] Operationally, the universal treatment approach posed issues including electronic medical records for tracing, and overall retention. [57,60,64]

A significant finding was that women who were not given ART on the same day of receiving their HIV-positive test result (known as same-day initiation (SDI)) did better with retention.[57,60,64] This finding suggests the critical components are the quality of ART counselling and support provided at the initiation stage. Understanding that not all women are ready to start ART with SDI and that peer support and tracking should commence early in the initiation stage.[57,60,64]

In addition, delivery of the programme differentiated depending on the contextual setting, urban clinical sites had higher LTFU, suggesting counselling and support in large clinical settings amongst women may have lacked the understanding of messaging with Option B+.[56-57,65] Data also suggested that higher LTFU rates with pregnant women on the programme compared to non-pregnant eligible women in ART treatment clinics, at the time, could be due to better adherence counselling received.[64,65] More

time to prepare to start ART, motivation for treatment and more experienced/trained HCWs at the clinics were all contributing factors.[64] The take-away message from the Malawi programme was many woman still did not start on ART though provided with medication at their initial visit, readiness counselling is crucial, and that messaging from civil society and community to support Option B+ was needed.[56-58,64,65]

2.8.7 PMTCT Peer Support and Partner Involvement in Tanzania

PMTCT guidelines were implemented in Tanzania and according to UNAIDS, although there was large programme coverage (84%), the rate of vertical transmission remained high at 11%.[58] Research indicated that risk of virological failure was 76% higher in woman <20 years old, and higher in woman in their third trimester versus first trimester.[66] The odds of MTCT were 69% lower amongst women who started ART early before pregnancy. [66] Studies emphasise that peer support to mothers significantly resulted in higher one-year ART retention (78%) and higher viral suppression.[66,67] Findings highlight the need for the male component in peer support to mothers and to further improve PMTCT lifelong ART into routine healthcare.[58,66]

2.8.8. Informing the SA healthcare system: WLWH on PMTCT in hospital settings

In the previous sections, an overview of PMTCT programme research conducted in SSA and low- or middle-income SADC countries in resource-constrained settings similar to SA was provided. This highlighted themes that emerged across the different countries were presented and provided insights for the focus of this thesis of WLWH and their experiences of the lifelong treatment programme at the RMMCH. It is important to recognise these as areas that can better inform the South African healthcare system to better serve WLWH on PMTCT in hospital settings. Some of the knowledge gaps and key lessons that arise from the literature include:

1) Patients should be monitored closely and consistently, and when their treatment regimen changes.[20,57] When a patient leaves the hospital or clinical setting it is important for proper tracking and tracing to be executed between the hospital and referral clinics in SA.[61,62] WLWH on the move may encounter different challenges in attending the facility and seeking care. Healthcare systems need to be accommodating to all different patient journeys.[61,62]

2) SDI should take place in clinical settings that have the resources to provide thorough education and counselling support to patients in the long-term.[59-60] This is due to the overwhelming amount of information that patients undergo when first finding out about their HIV-positive status.[59,65]

3) An important factor to consider for women that are on the move is that they not return to the facility because of a negative experience that underwent with a HCW.[58,62] Upskilling HCWs and regular training may be essential in building rapport with WLWH on the move. [23,51-53]

4) A knowledge gap exists with the ability to provide services on a platform at RMMCH that could potentially reach the migrant WLWH on the move overtime.

5) Patients require quality care and support to help them understand adherence is important- especially in high risk situations when there may be inconsistency in taking treatment and breastfeeding. [61]
6) Support does not end at delivery of the baby and post-natal follow-up can be challenging as patients are on the move.[23, 48-50] Healthcare systems are needed to ensure that this is embedded into the programme to prevent future risk of HIV transmission cases between mothers and their babies.[58,62]

2.9 South African Government's Reasons for Promotion of PMTCT Lifelong Treatment

SA NDoH and government officially adopted PMTCT lifelong treatment and the Option B+ guidelines later in 2015 by WHO, the decision was largely influenced in the claim that it was cost-effective.[56-57]

Malawi had pioneered the roll-out of the changes to the PMTCT programme and utilised an equity based approach where the country was able to rapidly expand access to ART for HIV-positive pregnant women in hard-to-reach areas.[56] However, after three years from its adoption, the country is undergoing issues with LTFU, uptake by pregnant HIV-positive women, and lacked indicators to monitor adherence of patients on Option B+ at the time.[56,63]

Cost-benefit analyses of Option B+ in SA demonstrated that 65% of vertical transmissions could be averted with its implementation, and benefits outweighed any additional costs ($23000 per infection) compared to higher prices in previous ARV regimens with Options A and B, new child infections and, sexual transmissions.[66]

From the economic standpoint, Option B+ was adopted and promoted in SA.[66-68] It is important to understand that this cost-benefit analysis simulated births, breastfeeding and HIV infections and therefore did not consider the healthcare settings in which the PMTCT services are provided and if and how the execution of the programme services would have an impact on the number of infections. [66-67] For example, in poor resource constrained settings that lacked educational and counselling support, if it was more likely that vertical transmission of HIV would occur due to lack of educational support that may have led to treatment interruption.[66] Costs reflect gradual expansion overtime with WHO, therefore the expected savings could be achieved if the context allows for it, including sufficient resources for infrastructural development and the increased number of HCWs "*through task shifting, decentralisation, increased training, and higher salarie*s". [68-71] Therefore, a knowledge gap existed with a need for acceptance from both healthcare users and, buy-in from service providers to help promote and deliver all programme components effectively, and strategise when resources were not made available.[66-67,69]

2.10 Challenge of Integrating PMTCT Programming for Lifelong Treatment in Hospitals

The roll-out of PMTCT programme with lifelong ART occurred in healthcare settings across SA in 2015. [23,58,68] Providing a standardised approach that incorporated the healthcare environment, remains challenging due to structural and organisational factors that play into the provision of care.[38,39,68,70,71] This includes factors such as the lack of resources (i.e. stock outs), negative staff attitudes and buy-in from HCWs, to better understand their actions towards patients that contributes to a long-term disruptions in their continuum of care.[38,39,68,70]

Lack of integration and the inability to sustain rapid policy changes from policy actors and government officials, including the NDoH and WHOs guidelines have proved to be detrimental to the PMTCT and HIV cause at times, especially when looking at *'health system readiness for such changes'* to occur, and that '*proper measures are set in place to facilitate the change'*.[68-70]

Pressure to follow suit can end up with a higher burden and detrimental effects upon countries and their HIV outcomes if the programme is not carefully executed.[20,70-72] Malawi is no longer the country with the highest HIV prevalence rate and currently sits at number nine worldwide, however SA rests at number four since the roll-out of PMTCT programming in 2015.[40,56]

There are many contributing factors that make up the programme effectiveness and whether it remains sustainable in healthcare settings, such as public or state hospitals.[20,72] This does not necessarily mean that one programme can be effectively rolled out and sustainable years to come because of contextual (including organisational and structural) changes that can occur.[65] Therefore, research is needed that incorporates not only policy and practice but provides a platform for healthcare users (WLWH utilising PMTCT care) to voice their opinions to better understand operational effectiveness.[20,72,73,74] For example, the act of breastfeeding is a challenging issue with PMTCT provision.[20]A better understanding is needed of how HIV is changing the healthcare users practices, which can inform the development of interventions like counselling and postpartum support to be contextually responsive to migrant WLWH.[33,72,73,74]

2.11 RMMCH: High Mobility Environment

In January 2015, RMMCH located in the city of Johannesburg was one of the first to implement the PMTCT lifelong treatment option.[45] RMMCH provides a delivery service for women from the Coronationville, Westbury and western Johannesburg catchment areas in Region B that borders four other regions (Figure 2.1).[17,18] Region B is often associated with more developed areas and suburbs, but this is not the case in Coronationville, where vast patterns of migration occur.[17,18,75] Coronationville has experienced rapid urbanisation which resulted in the establishment of informal settlements in the early 1990s.[17,18,75] Coronationville has a population of 7348 people, comprised of 2500 people living in informal settlements of which 60.8% are females.[17,18,75] Sixty-eight percent of its entire population are internal migrants and approximately 44% of the population is unemployed.[17,18,75]

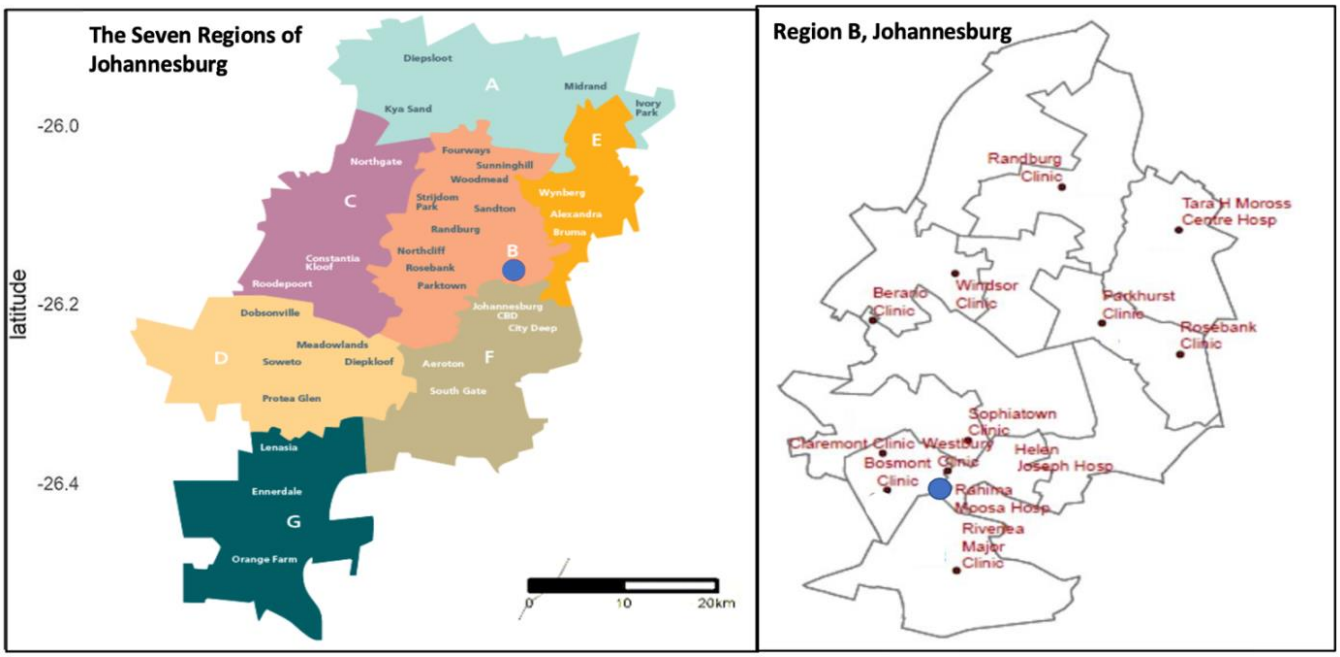


Figure 2.1 Regional map of Johannesburg, Region B

Source: Joburg Regions- About Region and ArcMap AHI

https://www.joburg.org.za/about/regions/Pages/Region%20B%20-%20Northcliff%20Randurg/Region-B---Northcliff-Randurg.aspx

RMMCH, formerly known as the Coronation Women and Children Hospital, is a public sector Region B hospital that provides specialist services for women and children. The institution has 110 general paediatric beds, 30 neonatal beds and a six-bed intensive care unit.[18] The HCWs see more than 36,000 outpatients and have more than 12,000 births annually.[18] Approximately 25 clinics refer patients to the ANC service at RMMCH, creating a busy maternal healthcare environment.

RMMCH is located in Coronationville, a site associated with high mobility and in Gauteng, a province where individuals use services outside of their districts and catchment areas.[11,13,17,18] According to data collected at RMMCH, in March 2018, 64% of the maternal population accessing maternal newborn child health services (MNCH) were recorded as non-citizens of SA and underwent the challenging public healthcare system and its impact on service provision at RMMCH.[18] An estimated 70.4% of maternal deaths in SA were associated with HIV infection by 2017.[18] Therefore, the success of programmes for PMTCT is critical for reducing maternal and child mortality and morbidity rates, reducing HIV risk for children, and overall building health awareness and empowerment for women to take control of their health decision-making.[20,26,,57]

Women who attended ANC outside of RMMCH, deliver their babies untested at times and therefore when attending RMMCH cannot receive PMTCT directly at RMMCH. There is a 98.7% testing rate for mothers being discharged from the hospital. A total of 6901 babies were born in 2017 alone to non-SA citizen women and recorded by the postnatal clinic (PNC) for HIV outcomes, amounting to 26% of all the 26, 467 babies born at RMMCH in 2016.[18] In 2017, 2732 HIV-exposed infants were captured, 667 (24%) had missing citizenship from the mother. Of the remaining 2065, 1171 (57%) were recorded RSA national and 894 (43%) were recorded as not being RSA citizens. RMMCH currently has crude statistical data captured at the facility specifically on PMTCT outcomes for typologies of non-national women.

Previous research conducted at RMMCH has demonstrated that implementation of the PMTCT lifelong treatment option has made the management of patients difficult because of the; (a) easiness to default and become LTFU (not take medication for more than 3 months or visit the clinic); (b) inconsistent delivery across clinical departments of counselling and support services for SDI of treatment and; (c) lack of understanding by service providers.[18,,73,74] Therefore, strengthening PMTCT lifelong treatment must occur on different levels, while many "HCWs have been known to place the burden of responsibility on the patient, negotiating the patients' health beliefs and values to fit a pre-existing healthcare structure that may often ignore cultural sensitivity".[33,75]

Therefore, there is a need to explore the intersections of migration, mobility in the inner CoJ and, PMTCT lifelong treatment for women to better understand their individual experiences. The literature highlights considerable knowledge gaps and the need for a better understanding of; patient mobility; the experiences of patients who move (some with the explicit intention of accessing public healthcare); service provider experiences of providing health care in high mobility context and; the impacts of migrant status on healthcare systems.[21,25,30,33] More importantly, a literature gap exists in exploring and determining typologies in relation to mobility of women and whether there are similarities or differences in the experiences of utilisation of maternal healthcare programming such as PMTCT in a high mobility environment like RMMCH. This is a missed opportunity that could potentially help address gaps in PMTCT healthcare service provision and programming. By exploring the experiences of different migrant WLWH and their mobility typologies, then by analysing further similarities and differences in their challenges in PMTCT care, this could help target interventions and overall help alleviate the burden on both patients and the healthcare system, especially during COVID-19.

2.12 Conclusion

In Chapter 2, a background on the topic of research and both the HIV epidemic and, the COVID-19 pandemic in SA was provided. This research has emphasised the importance of migration and mobility as a social determinants of health. SA's national health policies provided relevancy to the argument that migrant women and healthcare utilisation is an important area left off the agenda. A full overview of PMTCT lifelong treatment, the history of WHO's Option B+ policy and its adoption of PMTCT policy into programming in resource-constrained settings both in SSA and SADC countries was provided. This included Malawi where the lifelong ART treatment programme was pioneered. This chapter then reflected on reasons for the SA government to promote and adopt PMTCT lifelong treatment guidelines and the challenges that came with the integration of PMTCT programming for lifelong treatment into hospitals. An in-depth description of the context and study setting of RMMCH was provided. The rationale for selection discussed this state hospital both specialising in PMTCT and being a high mobility environment where many migrant WLWH utilise PMTCT care. After highlighting the knowledge gaps of existing literature, the thought provoking reasoning as to why the perspectives of the WLWH should be considered, and the dangers of repeating the history of existing literature was explained. This clearly sets the groundwork for the overview of the conceptual framework and rationale for this research study (Chapter 3).

CHAPTER THREE: THE CONCEPTUAL FRAMEWORK

3.1 The Accessibility Framework

The accessibility framework (Figure 3.1) was originally developed by McIntyre et al. and was adopted for The utilisation of PMTCT healthcare services conceptual framework (Figure 3.2).[73] This framework was developed as a basis to explore access 'as a policy-relevant concept in low and middle-income countries'.[73] The foundation of this model was to reframe what access could mean to healthcare as it remained blurry across different countries, including SA.[73] More importantly, this framework defined access to healthcare as 'the empowerment of the individual to use healthcare and as a multidimensional concept' dependent on the interaction between healthcare systems and the healthcare users in communities.[73] The framework identified three dimensions of availability, affordability, and acceptability to 'evaluate access more directly'.[73] The aim of this framework was to essentially help inform policy-makers by bringing together the healthcare provided and the recipient of the care to help develop policies to promote empowerment to service users.[73]

Initially in Chapter 6 (Paper 1) the 'accessibility framework' was used as a lens to analyse whether SA underwent similar issues as Malawi, the country who first adopted WHOs Option B+ policy.[18,73] The framework was used to evaluate access of WLWH as the healthcare users. Paper 1 analysed Option B+ PMTCT programme at RMMCH in 2015 through the three dimensions of:

Availability (physical dimension)

"Availability can create differences in access to services. In some settings the provision of counselling and support services for the programme may be sacrificed as a result of resource constraints. Availability is concerned with whether appropriate health care providers or services are supplied in the right place and time to meet the needs of these HIV-positive pregnant women. This includes location of facilities, hours of operation, drug supply of ARVs, willingness of service providers, information, and the quality of health care for the individual."[18,73]

Affordability (financial dimension)

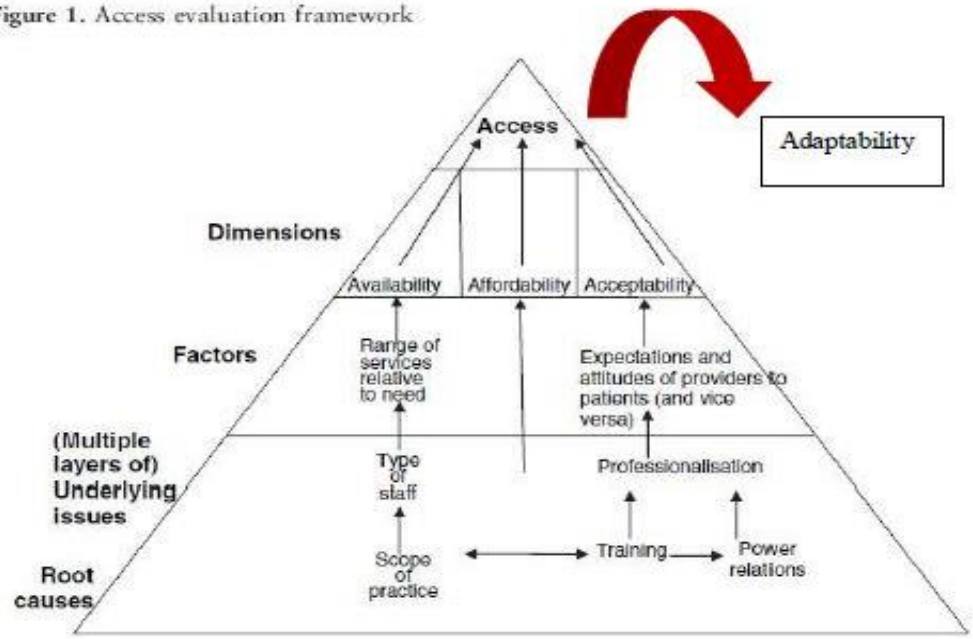
"Affordability is concerned with the individual's ability and willingness to pay in order to access healthcare services. HIV-positive pregnant women may not be able to afford transport costs to and from the hospital as well as additional medicine charges, diagnostic tests, special diets, childcare costs, etc. Affordability of the Option B+ PMTCT programme can be measured by opportunity costs, what the patient must forgo in order to meet the costs of using the programme. This can include when a woman takes time off work to retrieve her ARVs from the hospital. In this way, while the effects of the programme might be similar across patients the opportunity costs may be very different and dependent on the context in which the costs are incurred."[18,73]

Acceptability (cultural dimension)

"Acceptability is concerned with the fit between provider and patient expectations of each other. This includes perceptions towards characteristics of age, gender, ethnicity, and language which impacts the relationship of the healthcare worker and patient. Respect and the ability to listen to symptom descriptions, undertake examination, explain illness, and discuss treatment alternatives conducted by the healthcare provider are very important, especially at the first point of contact with the patient. The ability to create a comfortable environment no matter what resources there are and minimise burden and avoid stigmatisation will affect adherence and the willingness to follow the programme."[18,73]

However, an important dimension of *adaptability* that was then discovered and was added to the three dimensions of access from the findings of Paper 1 (Figure 3.1).[18,73]

Figure 1. Access evaluation framework



Note: Due to space constraints only one example is given for each of availability and acceptability. Clearly many factors can influence each dimension.

Source: McIntyre, D. I., Thiede, M., & Birch, S. (2009). Access as a policy-relevant concept in low-and middle income countries. *Health Economics, Policy and Law, 4*(02), 179-193.

Note: The adaptability concept has been added to Figure 1. Access evaluation framework.

Figure 3.1 Access evaluation framework

3.2 The Dimension of Adaptability

It is crucial in understanding barriers to the short and long-term sustainability of the programme. Understanding the environment and the contextual dimension, in which a PMTCT programme operates can address policy implementation and programme issues. This could help inform how adaptable Option B+ PMTCT programming is on a larger scale. The national guidelines had been developed at the time, but adaptability may remain problematic to successful roll out of the programme outside of RMMCH.[18,20,39,73]

The accessibility framework was a basis for "*understanding the opportunities and constraints that influence health care seeking behaviour of different individuals in different settings in a systemic and integrated way*" (p.180).[73] It is important to further explore the concept of adaptability because of the need that existed to determine whether the programme and successful policy implementation could be

transferred between different population settings.[18,20,73] Many healthcare professionals had highlighted in key informant interviews that they could not say whether it is effective or not in 2015.[18]

Adaptability questioned whether the Option B+ PMTCT programme and policy was transferable outside of RMMCH at the time of roll-out. A main concern was with RMMCH providing MNCH and PMTCT services to many women outside their catchment area of Region B. Although SA nationals were predominantly the women interviewed at the time, there was an opportunity to explore mobility and its impact on women utilising care at RMMCH.[18,73] However, it was important in acknowledging that by using 'access' as a concept this would not include those who have not accessed PMTCT services for comparison.[18,73] Therefore, 'utilisation of care as a proxy for access' was further explored in the following framework.[18,73] In Papers 2, 3, and 4 the framework was employed further to explore mobility typologies of migrant women as healthcare users.[18,73]

3.3 The Utilisation of PMTCT Healthcare Services Conceptual Framework

The utilisation of PMTCT healthcare services conceptual framework (**Appendix B)** was developed by the primary researcher and adapted further for use in this PhD research (Figure 3.2). The conceptual framework was developed with the purpose of both, exploring women's experiences of utilisation of the PMTCT lifelong treatment programme and, healthcare workers and key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels. Figure 3.2 indicates below where each of the study objectives sit within the conceptual framework. The framework provides guidance in exploring utilisation and migration in a high mobility context and, providing PMTCT services within a high mobility context in the inner CoJ, during the pandemic.[18]

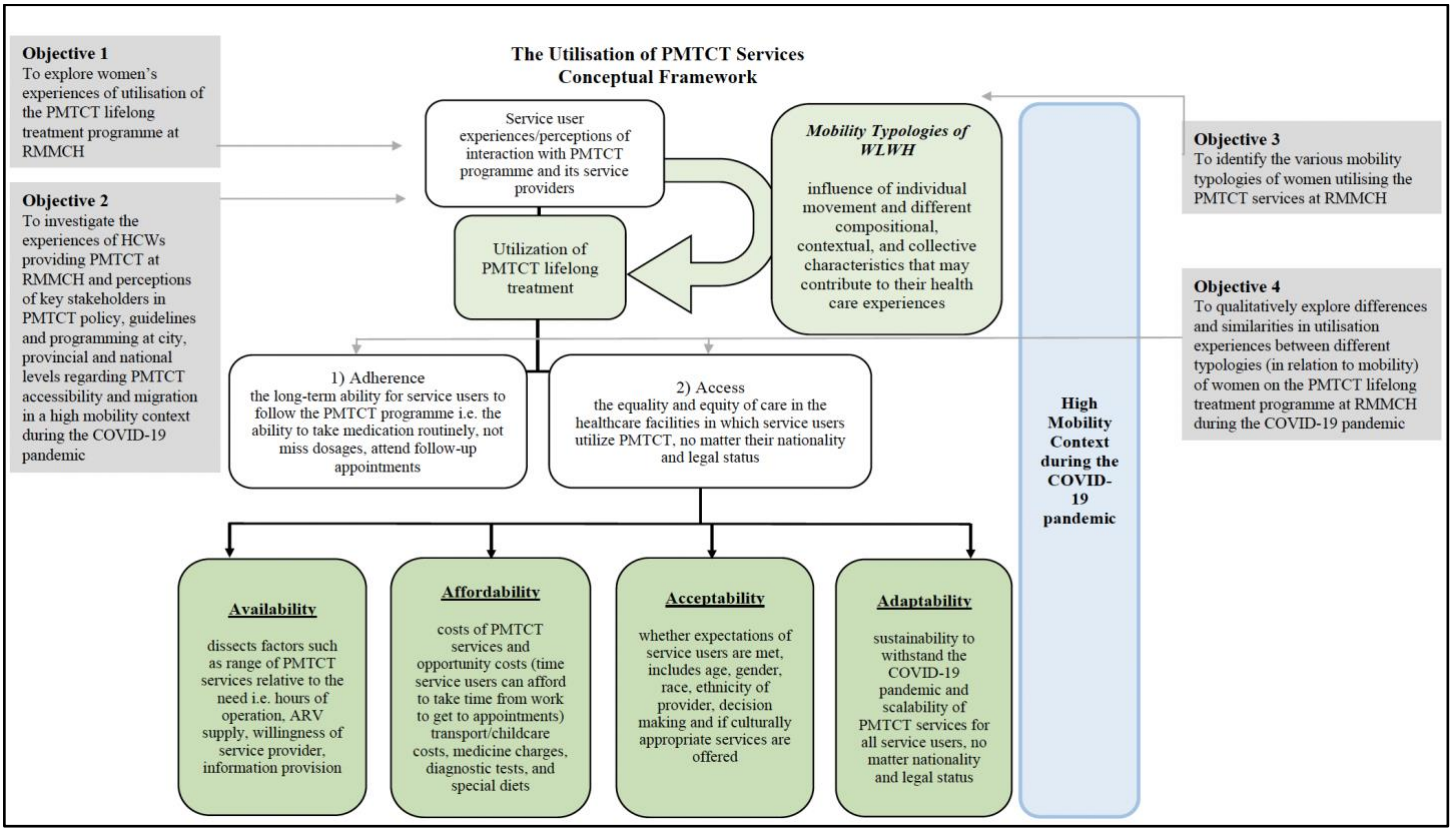


Figure 3.2 The utilisation of PMTCT healthcare services conceptual framework and indicated objectives

For the purpose of this study, utilisation is defined as the healthcare user's experiences and perceptions of their interactions with the PMTCT programme components and its service providers within a high mobility context.[18,73] 'Utilisation of care as a proxy for access' and included the users' perceptions regarding access of the service and adherence to the PMTCT lifelong treatment. The framework was applied to explore access and adherence barriers and facilitators in relation to PMTCT services at RMMCH.[18,73]

Furthermore, the framework was developed to help guide the study, bringing together concepts of utilisation for PMTCT healthcare services. This framework includes concepts of healthcare utilisation. Utilisation is made up of 1) *adherence* issues to the programme and 2) *access* is comprised of four dimensions: *availability; affordability; acceptability* and *adaptability*.[18,73]

The dimensions have been expanded on in terms of the population being explored, migrant WLWH who are highly mobile utilising PMTCT at RMMCH. *Adherence* is conceptualised as the long-term ability for these different women to follow the PMTCT programme. The framework applied in this study

conceptualises adherence as the ability for the woman to take her medication routinely, not miss dosages, and attend follow-up appointments.[18,73]

Accessibility refers to the equality and equity of care in the healthcare facilities these women utilise PMTCT in, no matter their nationality and legal status.[18,73] *Availability* dissects the factors such as the range of MNCH/PMTCT services relative to the need, for example, the hours of operation, ARV supply, willingness of service provider to take the time to provide information in a demanding clinical environment, and in a pandemic.[18,73] *Affordability* refers to costs of PMTCT services and opportunity costs (time off from work that a woman can afford to take to get to the hospital), including transport costs, medicine charges, diagnostic tests, special diets, and childcare costs.[18,73] *Acceptability* refers to whether the expectations of these women are met, which includes age, gender, race, ethnicity of provider, decision making and whether culturally appropriate service are offered (i.e. multi-lingual counselling service).[7,61] Acceptability also includes the woman's non-medical expectations of HCWs treatment of dignity and respect of their culture.[18,73] *Adaptability* refers to the sustainability and scalability for the PMTCT programme for highly mobile women, no matter nationality and legal status.[18,73]

The framework was used to explore the individual stories of migration, the different mobility typologies that arose from the data, and how this affected overall healthcare user experiences regarding access and adherence to the PMTCT lifelong treatment and care during COVID-19.

3.3.1 Rationale for the conceptual framework for research

For this study, the conceptual framework allowed for exploration of both healthcare user and provider experiences of PMTCT services. In addition, it explored if and how key stakeholders involved in the development and implementation of policy and programming related to PMTCT at city, provincial and national levels, understand and engage with migration and mobility.

The framework allowed for an assessment of similarities and differences in experiences of PMTCT amongst different groups of women defined by mobility typology. These typologies were identified from the migration and mobility patterns reported by migrant women utilising PMTCT services at RMMCH (e.g. internal migrant moved to inner CoJ for more than one year, etc.). By allowing the data to determine the typologies, rather than defining the typologies *a priori*, the study aimed to avoid the

pitfalls of previous studies that assume solely these typologies are limited to a dichotomy of citizen versus migrant.

CHAPTER FOUR: STUDY RATIONALE AND METHODOLOGY

4.1 Problem Statement

The utilisation of PMTCT services is challenging for WLWH in the inner CoJ.[11,12] SA's healthcare system has failed to integrate vulnerable populations such as, highly mobile WLWH into its provision of treatment and care.[8,13] Although HIV prevalence has increased and may be a result of people living longer, the concentrated urban areas have migrant WLWH that still require quality PMTCT care.[12,13] These women in particular, are struggling with the services provided and overall healthcare programming to meet their needs.[12,13] Disease burden is a clear sign when a healthcare system is "inequitable" and "inefficient" in incorporating the populations impacted to take measures to transform its service provision.[8] The denial of HIV transmission and its harm in the early 90s has led to the need for "aggressive" and "transformative" regimens for PMTCT.[8]

The updated PMTCT protocol and guidelines by WHO adopted as part of the NDoH's HIV and AIDS and STI National Strategic Plan, has grappled with addressing the complexities of mobility and health care access in high mobility contexts.[16,36] Better understanding the challenges faced by these individuals could improve healthcare system responsiveness for highly mobile WLWH. [16,36] Therefore, re-engineering hospital services may be needed to help provide better services long-term to individuals and improve the healthcare system as a whole.[8]

RMMCH provides PMTCT healthcare services to an increasingly large 'non-national' (non-SA citizens) and mobile population since it was first offered by the public health sector.[11,17] 'Non-national women' who are seen as a politically weak group have not gained visibility on SA's health policy agenda and are at an elevated risk of facing inequalities and unfair treatment by HCWs when utilising PMTCT services in the CoJ. [10-11] A problem exists with the lack of understanding about how migration and mobility affect women's experiences of utilising PMTCT services, and their experiences of the PMTCT lifelong treatment programme at RMMCH.

Research is needed for a better understanding and more nuanced characterisation of migrant women that goes beyond the narrow conceptualisations, often used in the literature, based on nationality versus citizenship. This understanding is important in the context of CoJ, where mobile populations are not only

non-nationals. It is not well understood whether there are similarities and differences in PMTCT service utilisation between groups of women according to typologies of mobility.

Furthermore, the COVID-19 pandemic has impacted healthcare systems worldwide, and more specifically the impact on HIV services, of which majority of SAs' population (made up of over 40% of internal migrants) relies on.[10,11,16,19] The pandemic caused SA to take strict measures limiting population mobility by enforcing a lockdown and border closures. Therefore, COVID-19 had ultimately impacted the provision of PMTCT care, highlighting existing challenges to PMTCT programme delivery. The COVID-19 pandemic including lockdown and restriction measures influenced PMTCT service provision across the country. The extent in which the pandemic had impacted utilisation, specifically for the vulnerable groups, such as WLWH who are highly mobile remained unknown.

4.2 Purpose of the Study/Justification

It is important to better understand the high mobility context because this was the setting where women are utilising PMTCT services at RMMCH, and potentially influenced their utilisation experiences. Studies were lacking but much needed to analyse if and how the mobility profiles of women, who are on the PMTCT programme at RMMCH, had an impact on their utilisation experiences. This included their overall ability to adhere to lifelong treatment.

The purpose of this study was to have iterative findings to indicate the various mobility experiences and not tell the one single story of migrant women, falling into the same rhetoric that literature tells us.[10] Its aim is to reveal, qualitatively, the mobility profiles and experiences of women accessing PMTCT in a high mobility context. This was to enable improved understandings of how these user experiences are impacted by a high mobility urban context.

This PhD is a novel contribution to knowledge by, identifying typologies of women using care in a high mobility context, and extend research beyond predefined migrant typologies that tend to limit descriptions to the experiences of non-national migrants versus RSA citizens. This allowed for identification of similarities and differences in the utilisation experiences between the different typologies of women. This study also included both HCWs and key PMTCT policy and programming stakeholders at city, province, and national levels, thus allowing for more nuanced and tailored strategies responsive to the service needs of mobile women.

The study site, RMMCH, had already adopted the national guidelines for PMTCT lifelong treatment and was in the monitoring stages, providing a platform to analyse patient perceptions on the programme. RMMCH, is a space of high mobility and associated with different migration patterns.[13,19]Approximately 87% of women using the ANC and PNC are non-SA citizens. [13,18,19] RMMCH was highly feasible as the one study site because of the 43% migrant WLWH accessing PMTCT services, and provided scientific value in answering the study research question.[13]

Previous research (Chapter 6, Paper 1) conducted at RMMCH explored qualitative experiences of women accessing Option B+ when it was first rolled out in 2015. Findings suggested that there is a large number of women delivering at RMMCH and accessing PMTCT and of these, many undergo considerable barriers including; 1) providing identifying documentation to access RMMCH; 2) language and communication in receiving healthcare information from HCWs; affecting adherence.[18] This research focused on the experiences of national women and had informed the development of this study to better understand what typologies of migrant WLWH were utilising care at RMMCH and, explore what their experiences were (i.e. challenges in adherence) in utilisation of PMTCT.

This study explored PMTCT utilisation experiences by all national women at the time the PMTCT guidelines were rolled out, in the high mobility context of RMMCH. The challenging healthcare environment had affected overall views and experiences of WLWH going on ART for life.[15] This study explored the specific experiences and perspectives of 1) hospital staff (hospital clerks, linkage officers, nurses, physicians, and healthcare management); 2) key PMTCT policy and programming stakeholders at city, province, and national levels and; 3) healthcare users (women on PMTCT programme). This provided an in-depth understanding of; if and how healthcare staff's treatment towards patients had impacted the accessibility and adherence (as measures of utilisation) for different typologies of women on the PMTCT programme and; the knowledge and perceptions of key stakeholders of PMTCT policy, guidelines and programme response on city, national and provincial levels that impacted both the HCWs and patients.[16,26]

In addition, this research advanced the knowledge in particular for migration and migrant WLWH by also qualitatively exploring the differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

4.3 Aims and Objectives

The aim of this study was to qualitatively investigate WLWH utilisation experiences of the PMTCT programme as healthcare users at RMMCH, by identifying and exploring the differences and similarities between different mobility typologies of the WLWH. The study further aimed to investigate HCWs perceptions as service providers of PMTCT, and perceptions of key stakeholders in policy and programming at city, provincial and national levels regarding PMTCT utilisation in a high mobility context during the COVID-19 pandemic, to identify PMTCT healthcare service provision and programme gaps. The study aimed to identify the various mobility typologies of women utilising PMTCT services and explored the differences and similarities between the different mobility typologies for both accessibility and adherence, as measures of utilisation of the programme during the COVID-19 pandemic.

The following are the objectives of this study:

1) To explore women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH;
2) To investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic;
3) To identify the various mobility typologies of women utilising the PMTCT services at RMMCH and;
4) To qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

4.4 General Methodology

4.4.1 Study setting

This research study was situated in Johannesburg, SA at RMMCH. RMMCH is a public hospital in Coronationville and it provides PMTCT services in the CoJ. Coronationville consists of 7348 people, 2500 of which are in informal settlements, 61% females, 68% internal migrants, and 44% unemployed.[17] In 2015, RMMCH, was first to implement PMTCT lifelong treatment.[18] It is a site associated with high mobility and different migration patterns in Gauteng, where patients use services outside of their

districts/catchment areas and it informs conditions for applicability to the broader migrant population in SA.[18] Approximately 25 clinics refer to RMMCH, no matter their nationality or legal status to the ANC service and 87% of women using the ANC and post-natal clinics are non-SA citizens.[18] HCWs see approximately 36,000 outpatients and over 12,000 births annually, creating a very busy maternal healthcare environment.[18] RMMCH adopted national guidelines for PMTCT lifelong treatment and was in its monitoring stages, therefore RMMCH provided a platform to analyse experiences of different migrant mobility typologies on the PMTCT programme.

4.4.2 Delivery of PMTCT at RMMCH

The following flow chart (Figure 4.1) represents how the PMTCT works at RMMCH. Pregnant women who test positive are initiated onto ART on the same day, where they received HCT at the antenatal clinic, are provided ARV supply for one month, tested for the viral load (VL) and T-lymphocyte cell bearing CD4 receptor (CD4), and booked for a follow-up appointment one month later. When the woman returns in a month, they are re-tested (VL/CD4s recorded) and provided a three-month supply of ARVs. At delivery the mother is tested again for VL and CD4 and the baby is HIV tested using a PCR test. The mother had to return for the PCR results seven days later to find out the results of her baby. Test 2 (1 month after initial visit/SDI) and Test 3 (3 months later after their initial visit and anytime thereafter until birth of the baby) indicate recruitment points for participants into the study **(**Figure 4.1).

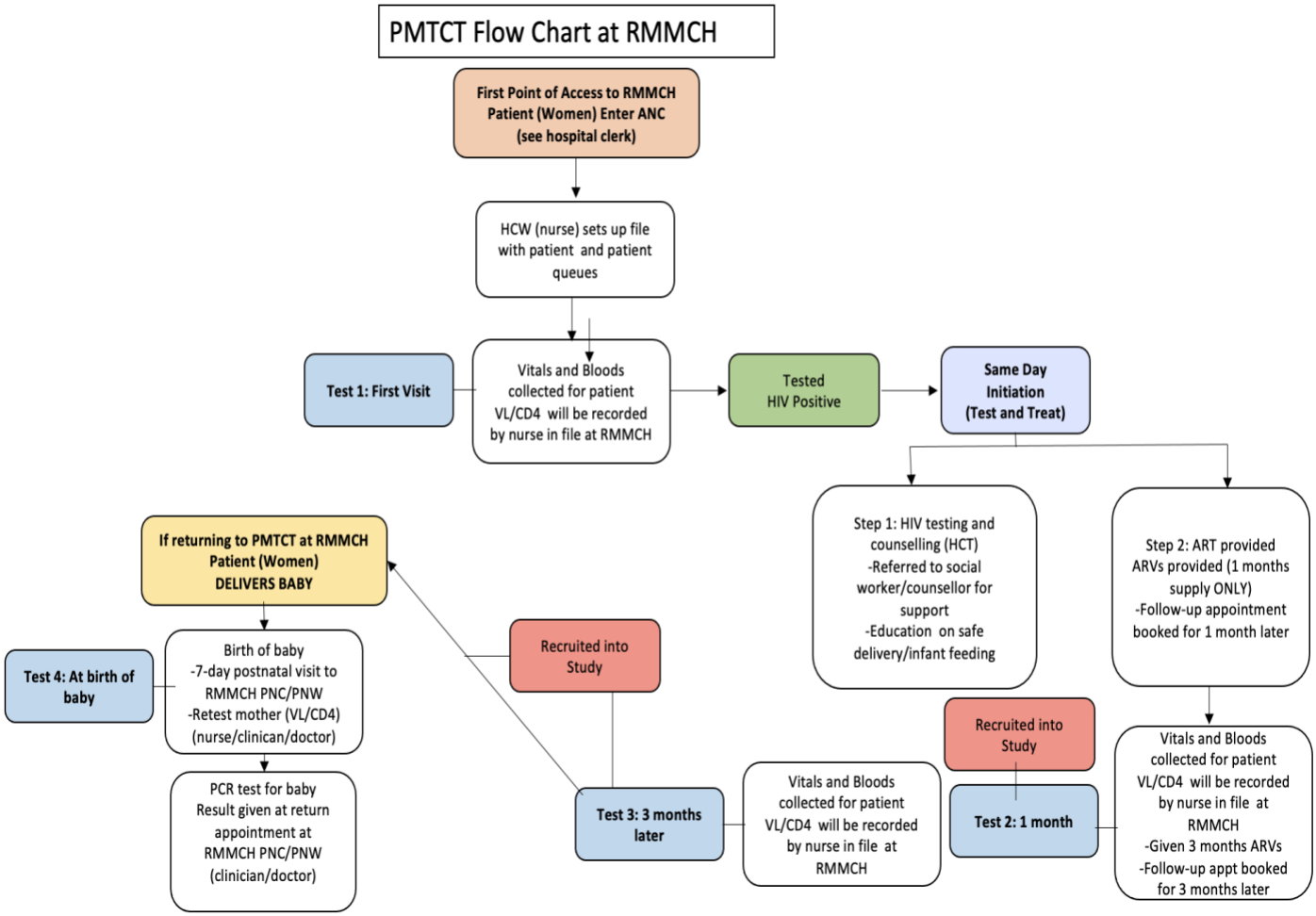


Figure 4.1 PMTCT flow chart at Rahima Moosa Mother and Child Hospital (RMMCH)

4.4.3 Rationale of Study Design

A qualitative study design was used to explore the experiences of these women on lifelong treatment at a highly mobile healthcare facility in urban inner CoJ, SA. RMMCH served as a state (public) hospital that had adopted lifelong treatment since 2015 and was in the implementation stage of the new PMTCT national guidelines. This provided a platform to analyse different typologies of WLWH and their utlisation experiences, through the lens of the PMTCT programme. This study was critical in unraveling methodological nationalism and the simplistic understandings of the repetitive story told time and time again in literature about migrants. This study design provided qualitative methodology that can be used towards developing migrant typologies for future research in migration and health. Qualitative methodology can help break away from methodological nationalism by diving into the intersections and complexities at an individual level. It revealed much needed strategies to close PMTCT programming

and policy gaps- based on more than what a nationality, citizenship or piece of documentation defines as a migrant.

4.4.4 Approach

Descriptive, cross-sectional research design applying qualitative methods. This qualitative study was comprised of two stages (**Appendix C/D**).

Stage 1 Qualitative component addressing objectives 1 and 2 and 4, was included:
Stage 1a: in-depth interviews with HCWs and key stakeholders involved in PMTCT policy, guideline, and programming at city, provincial and national levels to explore to gain insights on PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic;
to explore their experiences and perspectives on providing care to women in a high mobility context.
-Stage 1b: in-depth interviews with a sample of women to explore their mobility and their experiences of utilising PMTCT services (e.g. treatment by HCWs, accessibility issues and adherence) informed by The utilisation of PMTCT healthcare services conceptual framework; and to identify mobility typologies.

Stage 2 Informed by stage 1b Qualitative component addressing objective 3 was developed and included:

Stage 2a: Determining typologies that arose from the collected data on 1) migrant status (i.e. nationality, document status, refugee, asylum seeker) 2) geography (i.e. intraregional, rural to urban), 3) temporality (i.e. length of time spent in location(s)), 4) motivations/casual classifications (i.e. job seeking, family reunification) 5) socio-demographic (i.e. age of patient, household income, employment, and education); and 6) users clinical characteristics (i.e. year of HIV diagnosis, attendance rate/number of healthcare facility visits, duration on PMTCT lifelong treatment, date of delivery, and outcome of baby (HIV status)) to help guide and categorised the different typologies and stories that arose from the data. Typologies are different classifications assigned to the participants based on the six abovementioned categorical variables and the participants overall experiences shared in terms of accessibility and using PMTCT services.[36]

A thematic analysis was used and explored similarities and differences in reported utilisation experiences across typologies of healthcare users, healthcare providers, and policy and programme makers/implementers.

4.4.5 Ethical Considerations: Protection of Human Subjects

Ethics approval for the study was granted by Human Research and Ethics Committee (HREC) at University of Witwatersrand March 2021 (Phase 1 approval was granted in December 2019) (**Appendix A**). Provincial clearance was obtained by Gauteng and National clearance and City of Johannesburg (GP_201912_003). Authorisation from RMMCH was granted to conduct the study in Coronationville (approval HREC Number: M190816 MED19-07-084) (**Appendix A**).

This study research on sensitive participants (i.e. migrant/WLWH) ensured protection of human subjects. Participants remained anonymous and not identified in the study results.

There may have been distress associated with participating in the study. A distress protocol (**Appendix I**) was followed for participants if a participant became distressed or uncomfortable (i.e. uncontrollably shake/cry) by the nature of telling their stories and experiences (i.e. migrant journeys, ill treatment, etc.) during the interview and throughout the data collection/analysis phases.[20,36,74] RMMCH executed the potential strategies to address their needs during the interview, the following actions were taken by the interviewer. Firstly, the interviewer would suggest that it is appropriate that the interview be terminated. Secondly, if the participant wished this to happen, the interview would be completed. Thirdly, time would be spent with the participant and assistance provided, within the scope of interviewers' abilities, to discuss their concerns and support them, if appropriate. Fourthly, the participant would be recommended to speak to a RMMCH health professional to discuss their concerns. Lastly, a follow-up phone call would be made by the interviewer the following day to ensure that the participant is alright. During this time, the information regarding counselling services in the community and at RMMCH would be provided both throughout the research study to participants. Details of the RMMCH counsellor and community counselling services would be sent to all prospective and study participants **(Appendix I)**. Provision of a counsellor at RMMCH was provided as a referral service to participants if needed.

To mitigate any disturbance at RMMCH, a small meeting room in the antenatal clinic was used to hold patient interviews to not interfere from the daily services provided while HCW interviews were conducted in the privacy of their own offices.

The translator signed confidentiality agreements and non-disclosure for the study. All study forms were translated into different languages by University of Witwatersrand Translation Services. Participants provided written consent, if they were unable to write, oral consent (**Appendix J**) was provided with the attached form filled out. Potential participants that are illiterate were provided with an oral consent form and a witness to sign to confirm the PI had read and clarified any questions for the participant. Study participant information sheets with attached consent forms (**Appendix K**) were completed by all participants before the interviews commenced. Two written consent forms were completed separately by each participant; one giving permission to conduct the interview and the other to audio record the interview.

To facilitate the selection of participants, HCWs, patients, key stakeholders in PMTCT policy, guidelines and programming at city, provincial, and national levels were provided with information sheets (**Appendix K**) and consent forms for recruitment into the study. Participants of ages 18 and older were provided a Consent Form (**Appendix K**) to partake in the study. Participants were made aware that the study is completely voluntary, and they have the right to withdraw from the study at any time with no consequences. Participants may have chosen not to answer any questions for the interview and were made aware study results would be available upon completion of the study. To ensure participant confidentiality and anonymity, ID numbers were added to interview audio recordings, and transcription records. Linkages of participants' personal information and the study ID numbers remain confidential. The study ID numbers list were kept on the PI computer and locked in a password protected folder. The data from the participant interviews were kept anonymous and confidential and results were aggregated, to ensure that participant responses cannot be linked to them. All identifiers were removed as soon as transcription were complete. The electronic version of the transcripts and digital audio files were stored on a password-protected external hard drive and computer with access limited to the PI and supervisor(s). All data will be deleted from the computer and hard drive, ten years after study completion. Hard copies of the interview transcripts from all study participants were kept in a locked cabinet in ESRU at RMMCH during the project and will be destroyed ten years after study completion.

4.4.6 Study Population and Sample

Prior to Stage 1a, please note Paper 1 consists of 55 female patients (HIV infected) that are SA nationals enrolled in the PMTCT service at RMMCH and attended the ANC and postnatal ward (PNW) and 12 frontline workers such as nurses, doctors, and managers in hospital, that served both at city, provincial and national levels at the time the PMTCT guidelines were rolled out in 2015 at RMMCH.

Stage 1 consists of the study population and sample for Paper 2 and 3.

Stage 1

1a: The study population for Stage 1a included 10 healthcare staff and key stakeholders involved in the PMTCT lifelong treatment programme at RMMCH (hospital clerks, linkage officers, nurses, physicians from Paediatrics/Obstetrics and Gynecology (OBGYN) and PMTCT programme manager) working at the facility in 2019 and involved in PMTCT policy, guidelines and programming at city, provincial and national levels.

1b: The study population for Stage 1b included 40 female patients (HIV infected) enrolled in the PMTCT service at RMMCH and attending ANC and PNW at RMMCH. A sample of 10 female patients (HIV infected) enrolled in the PMTCT service at RMMCH and attending ANC and PNW at RMMCH was first used to pilot the tool before execution of the 40 interviews.

A purposive sample approach was used to recruit patients that were on the PMTCT lifelong treatment programme and HCW participants at RMMCH.[18-19] Participants were not excluded based on language and a translator was used on site.

The inclusion criteria for Stage 1a (healthcare staff and key stakeholders for PMTCT policy, guidelines, and programming) included: currently had contact or involvement with patients on PMTCT at the time of data collection; had contact with patients on the programme since its initiation in 2015 and/or who currently had contact or involvement with developing or implementing PMTCT policy, programme, or guidelines since its initiation in 2015, and works in the public healthcare sector at district, provincial, or national level. A sample of 10 (until data saturation is reached) of HCWs that are involved in PMTCT across RMMCH antenatal clinic, PNC, OBGYN units were recruited for the study via email by the PI and previously informed about the study from the Director of the Empilweni Services and

Research Unit (ESRU) and Paediatric HIV clinic (Empilweni) at RMMCH. The email consisted of a link where if interested, potential participants could sign up for a time best suitable to participate in the study. Furthermore, these potential participants were contacted for recruitment via, phone, email and in person with a snowball technique using NDoH with backing from the RMMCH Director of ESRU.

The inclusion criteria for Stage 1b included:

HIV-infected women whom are either pregnant, newly delivered or those in post-natal follow-up, between the ages of 18 and older (identified reproductive age group according to WHO guidelines for the Option B+ policy in PMTCT programming), enrolled on the PMTCT programme and have already been on the lifelong treatment for at least 3 months at RMMCH, and speak one of the languages that could be translated by the translator (from University of Witwatersrand Translation Services) at RMMCH or with help from a counsellor.[74,75] Purposive sampling is a form of non-probability sampling that is selected based on characteristics of a population, also known as selective or subjective sampling.[74,75] A sample of 40 users (until data saturation was achieved) who met the inclusion criteria were purposively selected (based solely on their enrolment status in the PMTCT programme) and recruited from the ANC clinic and PNW and clinic with the help of a nurse. The nurse identified from among users attending the antenatal clinic or PNW on the data collection days which patients are HIV-positive and specifically on the PMTCT lifelong treatment programme (as first point of contact is with frontline nurses in waiting rooms).[74,75] The nurse first asked the patient if they were interested in this study and if the patient was, they would queue with others to be introduced individually to the PI in a separate room.

Stage 2

This stage involved comparative analyses, using the data collected for objectives 1,3 and 4. The study population and inclusion criteria were the same as those for Stage 1b.

4.4.7 Data Collection

1a consisted of 12 semi-structured with HCWs and key stakeholder participants and 1b consisted of 10 pilot semi-structured interviews and 40 semi-structured interviews, one hour each, conducted with patients. The interviews were scheduled during clinic hours for patients and working hours for

healthcare worker participants. Semi-structured interviews followed a qualitative interview guide (**Appendix E/F/G**) that integrated The utilisation of PMTCT healthcare services conceptual framework.[18,20] The interview guides focused on specific domains of The utilisation of PMTCT healthcare services conceptual framework for discussion and it allowed the researcher to explore and facilitate a systematic data collection. The style and structure of the interviews used techniques to encourage discussion, including open-ended and informal questions when interviewing to make the participant feel comfortable to discuss their experiences, perspectives, and stories.

The semi-structured interviews explored utilisation experiences (adherence issues and accessibility). Utilisation variables that were explored were in relation to: a) adherence (i.e. reported adherence such as missed dosages of ARVs), adherence challenges and severity with taking medication, stigma in household, disclosure to partner, etc.) and the 4A dimensions of The utilisation of PMTCT healthcare services conceptual framework which included affordability (e.g. income, opportunity costs and family obligations), availability (e.g. perceptions of clinic hours in relation to working hours), acceptability (e.g. acceptance and understanding of the healthcare worker, perceptions of interactions with HCWs e.g. trust of HCWs, ill-treatment, etc.), and adaptability (e.g. PMTCT programme services adaptable to meet the needs of these women attending RMMCH). For example, patients were asked an opening question, '*Please describe your experience with the PMTCT services you access at RMMCH?'* Throughout the interviews, probes were used to offer clarification and encourage elaboration from the participant on specific issues or topics that were domains of interest.

1a consisted of 12 semi-structured interviews (**Appendix F/G**). Issues with PMTCT healthcare provision and treatment of patients were discussed with HCWs and asked questions such as: '*What are your experiences with providing PMTCT services at RMMCH? Please describe your experiences specifically, for high mobility patients? How would you say women attending the service feel about the care they receive?*

Furthermore, the successes and challenges with developing and implementing PMTCT policy, guidelines and programming in a high mobility context were explored with key stakeholders at city, national, and provincial levels that were asked, *'Please describe your successes and challenges with PMTCT policy in SA? Gauteng? Johannesburg? Can you elaborate on this specifically for the migrant and mobile populations?'*

1b consisted of 40 semi-structured interviews, the 10 pilot interviews informed the revisions to the interview guide to expand on what the PMTCT programme entailed (i.e. taking ARVs, attending follow-up appointments, medical examinations of the mother and infant pair) to participants because many did not know it by the clinical abbreviation.

All the interview guides (**Appendix E**) were expanded on to include COVID-19 as it was commonly spoken about amongst participants when answering questions about PMTCT experiences.

The interviews were audio-recorded where consent to record was provided (**Appendix H**), and continued until data saturation was reached, where no new information was being provided by participants. A record of the study was maintained through memos, journaling concepts, categories, or possible corroboration that occurred at specific points in time throughout the data collection periods. The purpose of the memos was to maintain a process log and capture any observations at specific points of time when the interviews were conducted (i.e. body language of participants when answering questions). To ensure accuracy and understanding of the participant responses, the PI asked participants to reiterate for further clarification. The audio-recorded interviews were transcribed verbatim to secure accurate participant responses. Typed notes were taken throughout the interviews for the purpose of cross-validation with the audio recordings and final interview transcripts. The interviews in Stage 1b also collected data on the following six categorical areas (Table 4.1).[36,73]

Table 4.1 Examples of the factors/variables involved in the of development migrant typologies

Categorical Area	Factors/Variables
Migrant Status	nationality; documentation status; asylum seeker; refugee status; displaced persons; job-seeker; migrant-worker
Geography	rural to urban migrants; intra-urban migration; inter-regional migration; internal migration; cross-border migration; return migration
Temporality	time in transit; frequency of trips (weekly/monthly commuting); seasonal migration; contractual migration; short-term migration; location of facilities visited
Socio-demographic status	age of patient; family structure; household income; employment status; and education level
Motivations/causal classifications	job seeking; family reunification; asylum seeking; refugee resettlement; delivery of baby; studies
Clinical characteristics	year of HIV diagnosis; attendance rate/number of healthcare facility visits; duration on PMTCT lifelong treatment; date of delivery; and outcome of baby (HIV status)

4.4.8 Data management and Analysis

Semi-structured interviews were transcribed first verbatim by the PI and by the translator for assistance (from transcription services at University of Witwatersrand) with non-SA languages (i.e. Farsi, French, Portuguese) and SA languages (i.e. Tswana, Sotho, Zulu, and Xhosa), if participants could not conduct interview in English language. A translator from University of Witwatersrand Translation Services that could translate non-SA languages was used to ensure that poor translation did not occur. For example, by using a patients' family member to translate in the interview this could be open to bias. Journal notes were used to capture field notes on what languages surfaced at RMMCH because not all translation may have been available for all languages on site. Audio-recorded interviews were inputted into NVivo (QSR International Pty Ltd., 2018) speech recognition software. The transcribed data was analysed in two-

steps; 1) audio recordings and note taking were done simultaneously throughout the interview process and 2) audio recordings were replayed, transcribed, and inputted into NVivo. A secondary check was completed by the translator to improve validity of the transcribed interviews. Transcriptions were coded separately using domains identified in the interview guide.[18]

Stage 2 consisted of a thorough analysis where the transcribed data and data collected on the following six categorical areas including its associated variables (Table 4.1) were involved in the development of the migrant typologies.[36,73] These typologies were then used to compare and draw similarities and differences between participants. Typologies that had surfaced from the data analysis before the 40 participant interviews were completed, were then balanced to ensure that non-national and migrant women were represented. The nurse appointment list was used to help identify patients booked for PMTCT services in the ANC who identified as a non-SA national.

NVivo was used to draw conceptual relations with open coding for themes to emerge for thematic analysis that were clustered by characteristic similarity according to The utilisation of PMTCT healthcare services conceptual framework. Axial coding was used in the data analysis, as part of relating codes such as categories and concepts to each other by utilising a combination of inductive and deductive reasoning.[76] Consensus was then arrived at the third version of the coding scheme.

A triangulation technique was used to crosscheck and validate semi-structured interviews and ensured the credibility of the findings, committee members (made up of the supervisor/co-supervisors) as analysts reviewed the findings from transcription along with literature journaling for social cues, reflection, and continuous refinement to hone the most prominent themes and relationships. The written and electronic record from NVivo 12 of the coding scheme and interpretative processes used in the data analysis included all files and any changes made to the database. The validity of a study is dependent on the reproducibility of the research design and analysis.[76] Furthermore, memos allowed the PI to maintain a record of analytic decisions and any alterations made throughout data collection and analysis.

A qualitative analysis to compare thematic issues that emerged between different typologies as a reflection on whether reported issues of utilisation experience differentiated across groups was analysed using NVivo software. Inter-coder reliability and integration of quality checks were completed with supervisors to ensure cross-checking for codebook/themes.[76]

4.5 The Impact of the COVID-19 Pandemic on the Study Timeline

Prior to COVID-19, Chapter 6 (Paper 1) data collection and analysis occurred during the roll-out of the PMTCT Option B+, known as lifelong treatment programme. This paper questioned the component of adaptability and whether the PMTCT programme and lifelong treatment policy was scalable for highly mobile WLWH. A main concern was with RMMCH providing PMTCT services to many women outside their catchment area. Although SA nationals were predominantly interviewed at the time, an opportunity was presented to explore mobility and its impact on women utilising care at RMMCH. This was then further explored in the data collection and analysis in Papers 2 and 3.

It is important to reflect on the impact of the COVID-19 pandemic on this research study, providing insight into what unplanned changes and adaptations to the data collection and analysis periods occurred (indicated in Chapters 7 (Paper 2) and 8 (Paper 3)). The following challenges were presented at each stage and the actions that are listed were taken to move forward with the research.

Data collected on participants experiences of the PMTCT programme proved to be impacted by the COVID-19 pandemic. Therefore, the IDI guide questions remained but probes were used when participants spoke about COVID-19. It was important to include the aspect of the pandemic because it would not have been a true representation of the stories told by participants speaking to their experiences and challenges with utilisation of PMTCT care and, providing the services. The pandemic highlighted the pre-existing challenges in the healthcare system as discussed throughout the papers. For example, prior to COVID-19 in Paper 1 (Chapter 6) with educational components of the programme in roll-out of the guidelines, there was not much time to execute proper counselling. This became even more strenuous with social distancing and capacity restrictions in Chapters 7 (Paper 2) and 8 (Paper 3). Therefore, incorporating the COVID-19 impact was important to the study analysis as a true representation of the context in which the research was conducted in for both patients, HCWs, and key stakeholders.

The implementation of hospital regulations for COVID-19 protocols and procedures delayed the process of data collection because of the lack of space to follow social distancing in the clinics and wards. A tent was set up outside the ANC to provide a ventilated area for patients to sit and wait until their number was called to enter the facility to receive their care. The recruitment of participants had to be adjusted for the first two months because potential participants would have to return outside or move to another area of the hospital to complete the interview process. This had to be conducted in a

segregated area, outside the hospital to limit the amount of noise for audio recording and maintain privacy/confidentiality of the patient. Many patients feared staying longer at the hospital because of the risk of SARS-CoV-2 transmission.

Before the second wave, there was an attempt to switch to online data collection using contact cards that were translated into different languages. The cards were provided to potential participants with a cell phone number linked to a tablet to audio record the call with the translator and PI. However, this proved to be challenging because many mobile women had different contact numbers and did not follow-up. Face-to-face interviews proved to be the most effective after the peak of second wave because the patient then had to wait before receiving the next service. The clinic flow went back to being solely in the ANC inside the hospital and the recruitment points worked effectively within the ANC.

Another challenge during data collection was when a member of the research team contracted SARS-CoV-2 infection. Immediate action was taken to file a letter with HREC as no forms or procedures were in place on how to deal with reporting specifically COVID-19 impacts on research. Therefore, data collection was on hold for approximately two months, hospital protocol and procedures were followed for COVID-19 that included isolation periods, contact tracing and follow-up calls with patients, staff, and any persons in contact with the member. In addition, daily check-ins from the research team were conducted to ensure a speedy recovery. When able to resume data collection, the third wave was at its peak and protocols became more strict, and resulted in obtaining a private and secure office space with ventilation available for only a few hours at a time on a rotation schedule.

There were benefits of data collection being moved to online for healthcare workers and key stakeholders. This proved to be effective in obtaining a longer duration of time for the interview. There were blocked off times for interviews, uninterrupted and could be conducted after working hours. These participants were able to join a Zoom call and then transcription could occur directly. However, the challenge of conducting interviews on a Zoom call was limited connectivity, some participants turned off their video, making it difficult to read body language at certain times.

The take-away messages from conducting migration and health research during the COVID-19 pandemic are the following:

1) be flexible and willing to adapt;
2) reflection is crucial to ensure the intended objectives are achievable due to the ever-changing climate of the pandemic and;
3) a key lesson learned and worth mentioning (discussed in Chapter 2) is report on data that is not a true representation (if the COVID-19 impact on participant experiences was excluded) would have given misconceptions. Although, interferences with the study timeline occurred and adaptations had to be executed, the silver lining of the pandemic is that it provided a dynamic process. This ensured data collection procedures were in place to gather migration and health data and incorporate better data that considers the complexities of migration.

4.5.1 Rigour

In qualitative studies, the investigator is the main tool for data collection and analysis. The investigator uses their own expertise and knowledge in analysing the data. Therefore, the investigator must be able to use their own personal assumptions that may influence data interpretation to help guide them. Inter-coder reliability and integration of quality checks were completed with supervisors to ensure cross-checking for codebook and themes and limit bias. Any assumptions were articulated and disclosed to enhance credibility and validate the findings of the study results. Triangulation was used to enhance authenticity of the research process and findings, to ensure that different experiences of study participants were presented.[18,76]

4.5.2 Potential bias and Limitations

Qualitative interviews allowed for different typologies of migrant WLWH to share their experiences and tell their stories. This is a main contribution to provide important insights of ongoing experience of WLWH regarding PMTCT access during the COVID-19 pandemic. The strength in self-reported methods is that it allows participants to both describe their own utilisation experiences (including adherence issues and accessibility to PMTCT) in-depth.[18,76]A limitation may be with the self-reported bias on duration of adherence of an individual.

RMMCH is a site associated with high mobility and different migration patterns in Gauteng where individuals use services outside of their districts/catchment areas and informs conditions for applicability to the broader migrant population in SA. This research unraveled the popular notion often used in literature, a dichotomy that compares nationality and citizenship to reduce migrant categories to the ownership of documentation. The mobility typologies identified are not exhaustive of all typologies that exist. However, the transferability of using the methodology in identifying typologies for future research in migration and health is broadly applicable both in the SA population, where movement between provinces and regions of the city occur. There are opportunities for broader applicability to other countries that are in resourced constrained healthcare settings. However, limitations may be sampling in rural remote areas where limited population movement may occur when compared to urban areas. Urban areas like cities are where most vast movements occur even outside SA, often associated with livelihood seeking as previously mentioned.

Qualitative studies are often criticised by research methodologists as not addressing issues of generalisability, but this highlights that qualitative methods are useful for understanding a situation in great depth.[76] Semi-structured interviews, are verbal reports that are largely dependent on the interviewees' responses that gave in-depth data of PMTCT user experiences. Body language is also an important factor when interviews were conducted to help read into the participants behaviour that goes beyond just their responses. A limitation would be if any of the interviews were conducted online without video during the COVID-19 peak period of the second wave. It is acknowledged that qualitative interviews may be subject to individual bias, recall bias, or inaccurate articulation.[74,76]Therefore, in the qualitative component of this study it was important to cross-check interview data from multiple data sources by using triangulation.[76]

To control for potential bias and help assure the PI with the use of nurse(s) who worked in the clinic to help recruit HIV-positive women, patients were recruited through a non-probability technique by the principal investigator (PI) to select subjects because of their accessibility and proximity in the antenatal care (ANC) and postnatal clinics (PNC) and wards, OBGYN and the Department of Paediatrics and Child Health at RMMCH. To control for differences in age and levels of education, scoping was completed within the clinics and wards to obtain a sampling weight to account for the demographics of women at the hospital.[18]

Furthermore, the PI and translator both identified as a women of colour, one woman is South African. To enhance validity of the research, it is important to acknowledge the positionality of both females

interacting with other mothers and women utilising maternal healthcare services and how this may have influenced how participants open up, build rapport, and discuss their individual story at times.[75] Participants may have felt more comfortable and could relate to the investigator/translator that were not healthcare workers at RMMCH knowing it would not have a direct impact on their services used at the hospital. For example, a patient participant may fear reporting negatively about an interaction with a nurse because they feel that they may be treated differently when using PMTCT services at the ANC.

As a qualitative researcher, the PI acknowledges their role in the research and that prior experiences of interviewing women at RMMCH on PMTCT that were 'SA nationals' should not be assumed as the single narrative for all SA national women or, all women on the move regionally, provincially, or internationally. The research process consisted of documenting any assumptions and beliefs of the research team in reflection notes and engaging in discussions throughout the research process to limit any confirmation or reporting biases.[74,76] For example, that all non-nationals experience mistreatment at the facility, or that all mistreatment is a xenophobic attitude from all healthcare workers. It was important to understand each experience is reported as the individual level.

CHAPTER FIVE: RESEARCH OUTPUTS

5.1 Timing

The Gantt Chart (**Appendix L**) indicates the timeline for the completion of the PhD research by publication.

5.2 Funding

A financial budget (November 2017- February 2021) (**Appendix M**) was provided for this stand-alone study. Wits School of Governance, Life in the City Grant fully supported this research study for 3 years until February 2021.

5.3 Student Deliverables

The PhD research was executed by publication and was submitted to the indicated journals. The papers individually addressed the specific objectives outlines in **Appendix N**. The following describes each paper and its contribution to the thesis as a whole:

'*Option B+ Program for the Prevention of Vertical Transmission of HIV: a Case Study in Johannesburg, South Africa'* (Paper 1)

This paper addressed Objective 1, to explore women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH. Paper 1 looked retrospectively at the Option B+ policy and programming impact on PMTCT in 2015, and allowed for a better understanding of the roll-out of the guidelines and the impact on both, patients and HCWs. This paper questioned the component of *adaptability* and whether the PMTCT programme and the lifelong ART policy was scalable for highly mobile WLWH. A main concern was with RMMCH providing PMTCT services to many women outside their catchment area. Although SA nationals were predominantly interviewed at the time, an opportunity to explore mobility and its impact on women utilising care at RMMCH was presented. Therefore, this was further explored in the data collection and analysis of Chapter 7 and 8 (Papers 2 and 3).

In addition, Chapter 6 (Paper 1) contained data on the experiences and perspectives of both HCWs, including frontline workers such as nurses, doctors and managers in hospital, that served both at city, provincial and national levels at the time the PMTCT guidelines were rolled out at RMMCH. An in-depth discussion is provided in Chapter 9 (Paper 4) when looking back at what changes have or still need to be made to the programme and policy spaces to move forward.

'Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers' (Paper 2)

In this paper, Objective 2 (to investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels. regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic) is addressed.

Chapter 7 (Paper 2) explored the perspective of HCWs and their provision of PMTCT services to the large number of migrant women that utilise treatment and care at RMMCH, in a high mobility context. Paper 2 uncovers the challenges that are pre-existent and showcases how the COVID-19 pandemic shone light to these barriers. Paper 2 findings revealed five main themes that emerged: (1) Facilitators and barriers to adherence, that included the need for multi-month dispensing for the long term supply of antiretrovirals (ARVs) and the fear of contracting COVID-19 at the hospital that disrupted patients' continuum of care; (2) Healthcare providers work environment, where participants felt overwhelmed with the high patient demand and the lack of infrastructural resources to follow social distancing protocols; (3) Financial challenges and opportunity costs, PMTCT proved difficult for migrants due to border closures and documentation required to receive care, this resulted in treatment interruption and left many unable to receive support at the facility due to capacity restrictions; (4) Interpersonal interactions, mistreatment, and xenophobic attitudes existed toward the migrant HIV population; and (5) "Programme sustainability" revealed three key areas for strengthening: longer duration of time allocated with counselling for same-day initiation, the increased use of technology, and translation services for migrants.

Paper 2 data collection occurred during the COVID-19 pandemic, and it inevitably had an impact on the PMTCT programme, its service provision by HCWs and, its utilisation by WLWH. Therefore, the

PMTCT service provision and utilisation involved the aspects of both mobility and migrant typologies, as well as the COVID-19 impact on the provision and use of these services.

Paper 2 concludes that it is important to take what was learned during the pandemic and integrate it into routine service delivery, which includes long-term medication supply to reduce risk with multiple visits to collect medication, and the use of technology to alleviate the high-burden of patient demand. Healthcare policies that work toward inclusion and sustainability for migrants are needed to improve the integration of safer and practical methods of PMTCT provision into health systems.

'Addressing the Migrant Gap: Maternal Healthcare Perspectives on Utilising Prevention of Mother to Child Transmission (PMTCT) services during the COVID-19 pandemic, South Africa' (Paper 3)

In Chapter 8 (Paper 3), the perspectives of the highly mobile WLWH are further explored. Paper 3 investigated the different mobility typologies that surfaced from the data. Paper 3 stands as a contribution that challenges the popular notion in literature that often uses citizenship, nationality and the simple ownership of documents to predetermine migrant categories. Paper 3 employed an approach of analysing different compositional, contextual, and collective characteristics to form typologies of different WLWH. The development of the typologies brings together a nexus of migration and health, where factors and variables of migrant status, geography, temporality, socio-demographic status, motivations/causal classifications and clinical characteristics intersect. This analysis included the six categorical areas and its associated variables (Chapter 4, Table 4.1) that were involved in the development of the migrant typologies and to help draw similarities and differences between these WLWH, as PMTCT service users.

Paper 3 not only aimed to identify these typologies (Objective 3) but explored how belonging to a specific mobility typology may have affected the healthcare received and, the individuals' overall experience during the COVID-19 pandemic.

Paper 3 also addressed Objective 4, to qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

It is important to note that the data collected for Chapters 7 and 8 (Papers 2 and 3) occurred during the COVID-19 pandemic. Therefore, the PMTCT service provision and utilisation involved the aspects of both mobility and migrant typologies, as well as the COVID-19 impact on the provision and use of these services.

This exploratory assessment is novel, as it sought to understand the high mobility context and challenge the commonly held notions of healthcare users being viewed as homogeneous groups of national versus non-national. This sequential study contributed a qualitative way to measure various migrant and RSA national typology utilisation experiences for the PMTCT programme. This study captured more rich data and to improve the ANC system at RMMCH. It is crucial to incorporate *the perspective of patients* in policy implementation. Utilisation experiences are key at in informing whether the lifelong treatment PMTCT programme is being adapted into state hospitals effectively. This PhD provided extensive research on how to address gaps in the healthcare system, policy, and programming space for different typologies of highly mobile WLWH.

5.4 Dissemination of Study Findings

To disseminate the findings from the research study, a presentation was given to all healthcare staff at RMMCH and key stakeholders in PMTCT policy, guidelines and programming at city, provincial, and national levels. Attendees had either participated or showed interest in the topic of research. The research was presented at local, national, and international conferences (**see List of Presentations and Publications on page v-vi**). To reach the patient participants and the community attending RMMCH, an information booklet and fact sheet available in different languages was provided. This included information on lifelong treatment, important findings and recommendations that could inform and spread awareness about ways to combat challenges with utilising PMTCT.

This research is beneficial to the scientific community and society because discovering the different typologies of women, how they feel as users (no matter their nationality and legal status) in a difficult SA healthcare setting, can be applied to address the challenges patients undergo with PMTCT service provision across healthcare facilities.[30] The national guidelines have been developed but utilisation remains problematic for many reasons such as accessibility and adherence issues in rigid healthcare environments that experience structural and organisational challenges.[30,32,77] This research can strengthen response to PMTCT services in a context of high mobility. This information is vital for HCWs in what

changes could be made to provide a more informative approach for prevention and continuum of care and will contribute to HIV and migrant mobility literature.[30,32,33]

CHAPTER SIX: PAPER ONE

Paper 1: Bisnauth MA, Coovadia A, Mbuagbaw L, Wilson MG, Birch S. Option B+ program for the prevention of vertical transmission of HIV: a case study in Johannesburg, South Africa. Frontiers in Public Health. 2020 Oct 28;8:533534 (published). Impact factor 6.46.

Bisnauth– 85% (conceived original idea, conceptualisation, developed theory, conducted the research, performed analysis, wrote the manuscript);
Coovadia- 15% (conceived original idea, supervise findings, commented and approved the manuscript)
Birch (conceived original idea, supervise findings in 2015)
Mbuagbaw and Wilson (data collection and provided feedback in 2015).

At the time of this thesis submission, Paper 1 was published as an original article in the *Frontiers Journal of Public Health.* For the purposes of this thesis, figures and tables as well as their captions have been placed in the appropriate places within the text of the article and general formatting is aligned with the requirements of the specific journal.

Paper 1 addressed Objective 1, to explore women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH. Paper 1 looked retrospectively at the Option B+ policy and programming impact on PMTCT in 2015, and this allowed for a better understanding of the roll-out of the guidelines and the impact on both, patients and HCWs. This paper questioned the component of *adaptability* and whether the PMTCT programme and the lifelong ART policy was scalable for highly mobile WLWH. Please note Paper 1 contributed to 15% of the block thesis format as approved by the School of Public Health. Data collection occurred prior to Paper 2 and 3. Paper 1 analysis included 55 interviews of patients and 12 healthcare workers. Paper 1 is included to provides insights of South African 'national' women experiences of PMTCT and emphasise the importance of why migrant typologies need to be explored in the following papers.

A main concern was with RMMCH providing PMTCT services to many women outside their catchment area. Although SA nationals were predominantly interviewed at the time, an opportunity to

explore mobility and its impact on women utilising care at RMMCH was presented. Therefore, this was further explored in the data collection and analysis in Papers 2 and 3.

In addition, Paper 1 contained data on the experiences and perspectives of both HCWs, which include frontline workers such as nurses, doctors and managers in hospital, that serve both at city, provincial and national levels at the time the PMTCT guidelines were rolled out at RMMCH which provides for an in-depth discussion in Chapter 9 when looking back at what changes have or still need to be made to the programme and policy spaces moving forward.

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Option B+ Program for the Prevention of Vertical Transmission of HIV: A Case Study in Johannesburg, South Africa

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Background: South Africa's National Department of Health adopted WHO's 2013 consolidated guidelines on ARVs for HIV treatment and prevention in 2015, including changes for Prevention from Mother-to-Child Transmission (PMTCT) through *Option B+*, aimed to reduce the HIV prevalence rate amongst women by placing them on lifelong treatment, irrespective of their CD4 count. As a result, these guidelines were implemented for the PMTCT programme at Rahima Moosa Hospital. Little is known about the impact of these guidelines on the work of healthcare workers (HCWs) and no research had focused on how these changes have affected adherence for the patients.

Objectives: The purpose of this research project was (1) to explore the impact of the Option B+ PMTCT programme on the work of healthcare professionals, and (2) to understand pregnant HIV-positive women views and experiences with ART for life, as a way to better manage the Option B+ PMTCT programme.

Design: Qualitative semi-structured interviews with a phenomenological approach was used.

Setting: Data collection at the antenatal/postnatal clinics/wards, OBGYN and Department of Paediatrics at RMMCH in Johannesburg.

Method: A qualitative study design is used with a phenomenological approach. The methodology used semi-structured interviews with healthcare professionals and patients. The thematic analysis was used within an accessibility framework to guide the identification of domains that emerged from all transcribed data. A convenience sample in the antenatal clinic, postnatal clinic, antenatal ward, OBGYN, and Department of Paediatrics and Child Health at RMMCH. The study is situated in Johannesburg, South Africa.

Results: The findings demonstrated that work has become difficult to manage for all healthcare professionals because of (1) the need for strengthening indicators for tracking to decrease loss to follow-up (LTFU); (2) inconsistency in delivery of counselling and support services and the need for communication across clinical departments; and (3) the lack of compassion and understanding by service providers. The difficult healthcare environment has affected overall views and experiences of pregnant HIV-positive women going on ART for life. All patient participants (n = 55) responded that they chose to take the fixed-dose combination (FDC) for life to protect the health of the baby and felt ART for life can be stopped after giving birth, unaware of the long-term benefits to the mother.

Conclusion: The Option B+ programme emphasised a need for the provision of continuous counselling and support services for women with same day initiation of ART. There is a need for better internal communication and collaboration amongst HCWs across all units of RMMCH for attainment in treatment outcomes. HCWs communication to patients is essential in helping

patients build trust in service delivery, decreasing the LTFU and promoting adherence. The ability to understand functions of the work environment in which a PMTCT programme operates in is essential in addressing policy implementation and programme issues for ease of adaptability of Option B+ programming on a larger scale across all units of RMMCH. Implications for future research include the need to address changes within the healthcare system at both clinical and management levels. It is crucial to incorporate the perspective of patients in policy implementation; uptake and adherence are key indicators in informing whether the Option B+ PMTCT programme is being adapted into state hospitals effectively. There needs to be extensive research on how to strengthen indicators for long term scalability and sustainability of the programme. Future evaluations need to address how interdisciplinary collaboration within healthcare facilities improves the management and understanding of Option B+ programme.

Keywords: HIV/AIDS, maternal health, PMTCT programme, qualitative, accessibility, South Africa, patient-centered care

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6.1 Introduction

South Africa (SA) had a significant number of 88,000 new infections amongst females between the ages of 15–24 years old in 2018.[78] People living with HIV (PLHIV) in SA accounted for 7,195,500 with a HIV prevalence for 15–49 year olds of 18.79%.[79] Furthermore, the reproductive ages of 15–49 year old females account for an alarming 42% HIV prevalence in the country indicating that there is still major work to be done to help reduce the risk of transmission, especially amongst women and mothers.[78] Furthermore, an estimated 70.4% of maternal deaths in South Africa were associated with vertical transmission of HIV infection.[80] HIV prevalence in pregnant women attending antenatal care (ANC) remains extremely high and ~300,000 children are born to HIV-infected mothers each year across the country.[81,82]

The World Health Organisation (WHO) stated that prevention of mother to child transmission (PMTCT) of human immunodeficiency virus (HIV) is particularly a major issue.[80] PMTCT is a clear

example of a maternal and child health programme that was offered across SA since 2001.[55] The PMTCT cascade represents a complex system of sequential, interdependent steps that women living with HIV (WLWH) navigate as healthcare users to receive appropriate care and treatment for themselves and their newborns.[56] PMTCT typically entails women as healthcare users having access to services such as ANC, HIV testing, and counselling (HCT); prophylactic antiretroviral treatment (ART); education on safe delivery and infant feeding; follow-up HIV testing at a 7-day postnatal visit, and family planning.[83,84] A vital component that was not traditionally part of the PMTCT programme is the provision of life long antiretroviral treatment (previously known as Option B+) services for women as an addition aligned to the WHO consolidated guidelines.[55] Option B+ aimed to reduce the HIV prevalence rate amongst pregnant women by placing all pregnant women on ART for the rest of their lives, irrespective of their CD4 count, on triple ARV drugs in the form of a fixed dose combination (FDC) pill start the same day the patient is diagnosed as being HIV-positive.[56] The FDC was introduced, made up of three drugs; tenofovir (TDF), lamivudine (FTC/3TC), and efavirenz (EFV) used in the first-line regimen which National Department of Health in SA adopted because it was simpler to manage, more effective, and cheaper to have women take only one pill once a day instead of three or more ARVs multiple times a day.[84]

Thus, the PMTCT cascade of care does not end at delivery of the baby as there is a need for long term follow-up. PMTCT using lifelong treatment is a proven, efficacious intervention, and can reduce vertical HIV transmission to <2%.[56]

In 2015, South Africa's National Department of Health (DoH) adopted WHO's 2013 "National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults" on the use of ARVs for treatment and prevention of HIV infection across all age groups and populations, based on providing a broad continuum of HIV care across the country.[80] The Government of South Africa had adopted these guidelines as a rapid approach to reduce new HIV infections amongst children by 90% and reduce the number of HIV related maternal deaths by 50% to strengthen the existing national healthcare system of Africa and improve its effectiveness.[85,86]

The adaptability of PMTCT HIV programming is critical for reducing maternal and child mortality and morbidity rates.[80] Adaptability is a concept that should be explored when looking at provision of PMTCT services in a healthcare setting where many women access care. We needed to better understand

what components of Option B+ were working for women accessing PMTCT services. It is important to explore the concept of adaptability because there is a literature gap that exists when determining whether Option B+ is successful in policy implementation in terms of scalability and sustainability. Adaptability determines whether the programme can be transferred between different population settings. For example, some studies emphasise the importance of evaluating the Option B+ PMTCT programme in South Africa since there is not enough research for the long-term outcomes of this programme.[73] Many HCWS have highlighted in key informant interviews that they cannot say whether it is effective in the long term.[73]

Therefore, the aim of this research was to understand both the experiences of the pregnant HIV-positive women who were placed on ART for life and the effect on healthcare service providers in the demanding public healthcare setting of the hospital that was first to implement Option B+ PMTCT in Johannesburg. The objectives of this study was; (1) to explore the impact of the Option B+ PMTCT-programme on work of HCWs, and (2) to understand these patient experiences with lifelong ART, to better manage the programme. We will answer the following research questions; (1) *What are pregnant HIV-positive women's views and experiences about lifetime treatment with ARVs* and; (2) *How has Option B+ PMTCT affected the work of HCWs?*

This exploratory study of Option B+ implemented at RMMCH will add to existing literature by providing research on the experiences of the PMTCT lifelong programme roll-out and insight on women and their adherence to PMTCT programming.

6.2 Methods

6.2.1 Study Site

One of the regional public sector hospitals that was first to implement Option B+ PMTCT was Rahima Moosa Mother and Child Hospital (RMMCH), the study site that will provide insight to explore perceptions of women first going onto the lifelong treatment programme. RMMCH provides healthcare specialist services for women and children. The institution has 110 general paediatric beds, 30 neonatal beds and a six-bed intensive care unit. The healthcare workers (HCWs) see more than 36,000 outpatients and have more than 12,000 births annually. Approximately 25 clinics refer patients to the ANC service at RMMCH, creating a busy maternal healthcare environment.[86] RMMCH is located in the suburb of

Coronationville comprised of 2,500 people living in informal settlements of which 60.8% are females, many women with poor health outcomes.[86]

6.2.2 Ethical Approval

Ethics approval for the study was granted by The Hamilton Integrated Research Ethics Board (HiREB) at McMaster University located in Hamilton, Canada. Authorisation was obtained from the Human Research Ethics Committee (HREC) at the University of Witwatersrand, South Africa in 2015 and from RMMCH, Johannesburg to conduct the study in Coronationville (approval HiREB Number: 15-264-S/HREC Number: M150495).

6.2.3 Study Design

This qualitative study conducted 67 semi-structured, audio-recorded interviews with pregnant HIV-positive women (n = 55) and HCWs (n = 12).

A phenomenological approach was used to investigate lived experiences of HIV-positive pregnant women and HCWs under the Option B+ PMTCT programme. Patients and HCWs perceptions of HIV were investigated to learn more about their perspectives and stories prior to the implementation of Option B+. For example, patients were asked "How did you feel when you first found out you were HIV-positive?" Whereas, HCWs were asked, "What are some of the challenges with adherence to Option B+ with your patients?" This study explored the specific phenomenon between HCWs (nurses, physicians and healthcare management) and patients, providing in depth understanding of how the Option B+ programme is now impacting the work of HCWs and the adherence of patients.[87]

6.2.4 Theoretical Framework

The accessibility framework (see Figure 1) has been adapted by McIntyre et al. for access to PMTCT lifelong treatment based on three dimensions of accessibility; affordability, availability, and acceptability to help guide the research.[73] Each dimension represents a potential barrier to PMTCT care. However, the framework has an additional concept of "adaptability" of PMTCT services in healthcare settings. It is important to explore the concept of adaptability because there is a literature gap that exists when

determining whether Option B+ is successful in policy implementation in terms of scalability and sustainability.

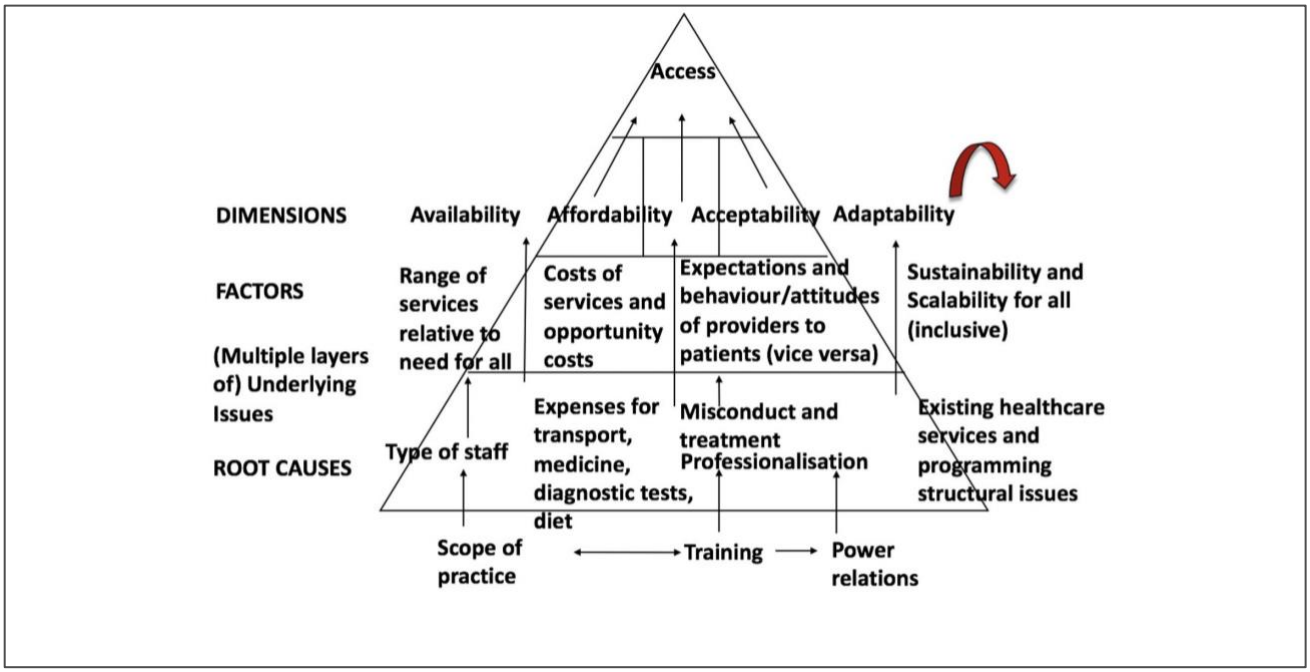


FIGURE 1 | The enhanced accessibility framework [adapted from (73)]. The adaptability concept has been added to figure. Accessibility evaluation framework

6.2.5 Recruitment of Participants

Study participants were selected to gain a selected representation of views from the identified groups of; pregnant HIV-positive women and HCWs at RMMCH. Participants were not excluded based on race or language. The inclusion criteria included pregnant women between 15 and 49 years old, be HIV-positive and either newly enrolled or on Option B+. Newly enrolled HIV positive women on the programme had to have at least their first dose of the FDC pill or been on treatment for at least one month and were included to provide insight on their experience with switching or starting on a new treatment regimen. HCWs had to have involvement with patients on Option B+ or/and the initiation of the programme at RMMCH for at least the past six months since its inception (January 2015).

HIV-positive patients were recruited through convenience sampling, a non-probability technique by the principal investigator (PI) to select subjects because of their accessibility and proximity in the antenatal care (ANC) and postnatal clinics (PNC) and wards, Obstetrics and Gynaecology and,

Department of Paediatrics and Child Health at RMMCH.[88] To control for differences in age and levels of education, scoping was completed within the ANC and PNC clinics and wards to obtain a sampling weight to account for the demographics of women at the hospital. Assistance from the nurses was provided, who would first attend to the patients, those who were on Option B+ were asked if they'd like to meet with the PI and informed that their participation was completely voluntary in the study.

Staff from selected units and departments, which included HCWs and executive management at RMMCH, were recommended by the Director of the Paediatric unit and contacted via email by the PI.

HCWs and patients were provided with information letters and consent forms for recruitment into the study. Individuals that provided informed consent were then asked to participate in an interview with the PI. Potential participants that were illiterate were provided an oral consent form and a witness to sign that the PI has read and clarified any questions.

6.2.6 Sample Size

Participants were recruited consecutively until data saturation occurred where the PI is no longer hearing or seeing new information emerging from the data.[88] Thus, a total number of 67 interviews were conducted with 55 patients and 12 HCWs, which consisted of nine females (5 nurses, 1 paediatrician, 1 OBGYN, 1 neonatologist, 1 executive manager) and three males (2 paediatricians and 1 OBGYN). The reported mean for the experience in profession (number of years) for nurses is 21 years, paediatrician is 10 years, OBGYN is 6 years, neonatologist is 7 years, and executive manager is 8 years.

6.3 Data Collection and Analysis

6.3.1 Qualitative Semi-Structured Interviews

The interviews were scheduled during clinic hours for patients and working hours for HCWs. A small meeting room in the ANC was used for the patient interviews. HCW interviews were conducted in the privacy of their own offices. With permission, the interview was audio recorded and transcribed. Interviews were based on a discussion guide informed by The accessibility conceptual framework. All participants' information including demographics, journal memos including observations of participant behaviour during the interview was used with triangulation method in addition to the qualitative data entered using software QSR NVivo 10.0. Triangulation was used to enhance authenticity of the research process and findings, to ensure that different phenomenon of study participants were presented.

A record of the study was maintained through memos and journaling. The purpose of the memos was to maintain a process log and capture any observations at specific points of time from the PI, especially when conducting the interviews (i.e., body language of participants when answering questions). Furthermore, memos allowed the PI to maintain a record of analytic decisions and any alterations made throughout data collection and analysis. For example, behaviour from participants was recorded to help open discussion and analyse certain themes that emerged and explore them further in depth. The written and electronic record from QSR NVivo 10.0 of the coding scheme and interpretative processes used in the data analysis included all files and any changes made to the database. Furthermore, the timelines for the study allowed the PI to complete tasks in a timely manner in order to allow time to cross check and ensure validity of the findings. A member check was completed with HCWs to improve validity of the transcribed interviews. In order to ensure accuracy and understanding of the patient participant responses, the PI would ask patients to reiterate for further clarification.

Patients were asked about their experience, knowledge and education of Option B+, trust of HCWs and, obstacles that had any impact with medication adherence (i.e., family obligations, number of dependents, difficult working hours, lack of understanding HCWs, lack of accessibility to the local healthcare facility, and lack of income). HCWs were asked whether they understood obstacles that impact adherence for their patients. Interviews allowed for both HCWs and patients to discuss certain aspects of their relationship such as trust and understanding of each other. The HCWs were asked information on their experience in relation to The accessibility framework to better understand their provision of Option B+, trust of their patients' medication adherence and, challenges they themselves encounter with their patients including awareness of opportunity costs their patients may undergo.

Data analysis consisted of comparing the transcribed interviews, literature, reflection, and continuous refinement to hone on most prominent themes and relationships. The research conducted inductive and deductive analysis simultaneously. Inductive reasoning allows for the PI to avoid separating stages of design, data collection and analysis but work forwards and backwards between data, conceptualisation and period of collection.[89]

All electronic transcripts were transcribed verbatim by the PI. There was no translation needed, all participants spoke English. The process of data reduction began with open coding; all interviews were first transcribed during the interview and audio recording, then re-listened to and re-read to identify possible meanings and concepts throughout the data collected. In addition, a journal with notes was

maintained to track the progress of the study and included memos related to the analysis of the data, including concepts, categories, or possible corroboration that was occurring at specific points in time throughout the data collection. The transcribed data were analysed using a two-step method, first the audio recording and note taking was done simultaneously throughout the interview process and, secondly the audio recording was replayed and transcribed.

A thematic analysis was used with The accessibility framework to guide the identification of domains that emerged from all transcribed data including the audio recorded interviews and transcripts with the help of QSR NVivo 10, software, a qualitative data programme that helps organise the volume of data was used to help draw relations and common themes throughout the data that was entered and analyzed using The accessibility framework.

The domains of interest that were explored included the following; stage of pregnancy; initial interaction with Option B+; adherence history; challenges with FDC such as stigma; acceptance and management of regimen; availability of PMTCT services; affordability including opportunity costs of missed time from work to access care; social and cultural barriers; relationship with HCW; and knowledge of Option B+.

The PI and research supervisor informally compared perceptions of the data and contributed to the coding scheme. Transcriptions were coded separately and a triangulation technique was utilised to cross verify data sources. To ensure the credibility of the findings, a secondary analyst reviewed the findings and coding from transcribed interviews.

The second phase of analysis used axial coding. The observations and any questions that were recorded in memos assisted in developing of an initial coding scheme. Consensus was then achieved on the third version of the coding scheme. These major categories were aggregated from the raw data collection and then QSR NVivo 10.0 was used to reduce and identify themes across all sources of data. Themes that were identified were compared to determine relevance and value in describing the Option B+ PMTCT implementation at RMMCH.

6.4 Results

6.4.1 Demographics of Patients and HCWs

Self-reported demographic data was collected from 67 participants which included 55 HIV-positive pregnant women from the ANC maternity and PN wards and 12 HCWs including nurses, Paediatricians, Obstetricians and Gynaecologists, Neonatologists, and managers. The average age of the HCW was 45.6 years old. In addition, the average years of work experience reported by HCWs in their current occupation was 13.5 years and consisted of 75% female and 25% males.

The average age of a patient participants was 33 years old; most women had a total of three dependents and had undergone at least one still birth. For the total of 55 patient participants, 36 were not married. 34 of the 55 patient participants were on Option B+ for six months and only 2 patients on Option B+ for less than a week. The average duration of interviews was one hour with participants.

The findings revealed that the implementation of the Option B+ PMTCT programme according to the national consolidated guidelines has been challenging for both patients and HCWs. The following four sections discuss the findings of how the programme impacted the healthcare environment for (a) patients; (b) frontline nurses; (c) physicians; and (d) managers for each of the four dimensions of access, availability, affordability, acceptability, and adaptability.

6.4.2 Availability (Physical Access): Is the Quality of Care Diminishing?

Availability can create differences in access to services such as, the provision of counselling and support services for the Option B+ programme may be sacrificed as a result of resource constraints.[73] Availability is concerned with whether appropriate healthcare providers or services are supplied in the right place and time to meet the needs of these HIV-positive pregnant women including; hours of operation, drug supply of ARVs, and willingness of service providers.[73]

6.4.2.1 Patients: Education—Is It Beneficial or Harmful?

Pregnant women feel the need to adhere only until giving birth, not understanding that ART is beneficial in the long term. Many of these women feel the need for more education to understand why they are

taking this drug beyond childbirth. A 38 year old patient, married and had undergone three miscarriages stated,

> *I don't feel like there is enough education here at RMMCH. I have gone to my local health clinic and they provided a three day workshop. I have done adherence events which were three hours each, teaching me about how to use ARVs.*

The lack of PMTCT knowledge posed a barrier to retention for the patient in understanding benefits of medication adherence. Knowledge translation should occur from the healthcare provider to the patient, but often it is impeded by unequal power dynamics causing the patient to feel intimidated or nervous to be proactive and ask questions. Patients during counselling sessions may view HCWs as authority figures. Many women reported it was difficult to understand what the nurses told them at times because it was unclear. Some women expressed that it was hard to ask questions in front of their peers and preferred to wait until they could do so in private. Whereas, a 35 year old patient and 8 months pregnant states,

> *I have participated in education workshops here at RMMCH and find it useful. I learned about using condoms when having sex, eating healthy food and to not just sleep around without protection. My local health clinic does not give me as much information. Though I feel comfortable asking questions at the clinic and it is not as far, I come here to receive more education.*

Education and information is not consistent across the local health clinics for Option B+ PMTCT which can be harmful when only parts of the educational messages get across to patients. Patients have become overwhelmed with information they receive from various sources which included local health clinics, healthcare workers, media sources, and family/friends.

6.4.2.2 Frontline Nurses: Issues Arising With the Available Information of Option B+

There is inconsistency in delivery of counselling and support services for patients at RMMCH. There is a lack of; communication across clinical departments because guidelines are taking time to be translated across the healthcare system in a manner that allows for consistency in messaging; compassion and understanding by service providers due to the emotional risks that HCWs are undergoing associated with changes to their work. The implementation of the new guidelines for the Option B+ PMTCT programme

had created frustration for both clinical and management levels at RMMCH. One nurse stated issues faced with communicating updated information because of the constant changes to the new consolidated guidelines,

> *Women are being educated. I think the problem is with all the changes we have to update our patients. There needs to be more education with the healthcare workers, then that gets transferred to the patient effectively. This way the patient is updated, and education can be emphasised. The woman cannot say they do not know. All sources they access need to align with the information they provide.*

6.4.2.3 Physicians: Support Is Needed

The RMMCH environment is very busy and there is a high demand for physicians to deliver good quality services. HCWs often transfer patients to different departments and units in order for the patient to receive better care and expertise for specific services they may need. Often, due to the busy environment, good quality services become sacrificed at times.

Physicians expressed how by the time the patient sees them, they understand that the patient had undergone testing by nurses and have had to go through the shock of findings out their diagnosis all in one day. By the time the physician speaks with the patient, they found them to be passive because they are complete strangers. Some physicians take it personally while others understand it is a process. One physician states, *"Healthcare workers don't understand at times; the patient has to be counselled repeatedly and in detail. It happens three times before the patient understands."*

Physicians express that there needs to be support groups for women to be able to open up and communicate what they are feeling, *"We use to run an important support group in the clinic on Fridays. Women liked being together, now they just sit in the general public."*

Findings suggested there was insufficient time and counselling services provided for pregnant women to absorb the shock of finding out her HIV diagnosis and starting lifelong treatment immediately. Option B+ had reduced the number of missed dosages for women through a one pill a day regimen. However, there was a lack of knowledge translation between HCWs and patients in understanding the benefits of the FDC. This posed a barrier to effective uptake in treatment and increased loss to follow-up.

6.4.2.4 Managers: Knowledge Is Power

The executive management level expressed that knowledge is power, women need to understand the benefits of lifelong ART in order to continue treatment. It is difficult to know whether patients are actually taking the medication because they are being told to do so or they actually understand the benefits clearly. This relied on knowledge translation from the HCWs consisting of both frontline nurses and counsellors and healthcare physicians. An executive manager stated,

> *The system is designed for doctors to be paternalistic to their patients when it comes to involving the patient in the treatment decision making process. This means no patient involvement, choice or patient authority- to enforce one direction. Partially because the pregnant HIV-positive women we see at the ANC, at no fault of their own, do not have education and little knowledge about what they are on. It is unfortunately the system that perpetuates the lack of patient involvement while they sit there waiting.*

RMMCH PMTCT committee had initiated administrative practices to help manage Option B+, which had challenges in education and awareness of ART and its integration into the already existent stigma and cultural beliefs in the surrounding South African community .

6.4.2.5 Monitoring and Evaluation of the PMTCT National Guideline Indicators

Management had utilised strategies that include education and training across departments that need to assist HCWs in better understanding the implementation of the programme at RMMCH. There was still a need to strengthen indicators of the programme to increase numbers of women on same-day initiation (placed on ART the same day as being diagnosed HIV-positive) in order to evaluate its success.

The development of the new national consolidated guidelines for specifically PMTCT promoted the proliferation of numerous policies and protocols. This led to developing indicators within RMMCH to help monitor and evaluate the Option B+ PMTCT programme. The revision for strengthening these indicators is ongoing. Indicators were recorded monthly at the ANC and daily registers are used to record patients. Reports will be done monthly and annually for total births in the facility, maternal health, immunisation, and HIV counselling and testing (HCT). The ongoing changes to indicators and recognising gaps in monitoring and evaluating outcomes of the Option B+ PMTCT programme had become challenging for RMMCH. A manager stated,

I am finding a big gap and it is quite scary what education is being told to our patients at times, they are falling off the grid and incorrect information is an example of the issues with the education component of PMTCT programme. The first person that speaks to a patient or the first interaction that patient has with information is what they will believe. It is hard to come in and now say something different to them. Incorrect information can act as a barrier.

There are no established indicators, causing inconsistency in measuring the effectiveness of Option B+. This in turn, impacted the clinical training of HCWs with their delivery of the PMTCT programme to patients at RMMCH. HCWs and management found it challenging to monitor the ongoing progress of Option B+ PMTCT for reporting at RMMCH. One administrator in the Empilweni HIV clinic emphasised issues with indicators that were arising,

The WHO created these guidelines with unrealistic indicators that do not address certain gaps. For instance, say you have one hundred pregnant women being tested for HIV, out of those hundred women, say there are 10 positive babies delivered. There isn't any indicator that has been developed to tell us that those 10 babies belonged to 10 positive women from those 100 that were tested. There is a huge loss to follow-up with these women. Therefore the outcome of what is measured is not telling us the entire truth.

6.4.2.6 Time Is Money

Often HCWs were under pressure due to the high demand of patients at RMMCH. Managing time is a challenge for HCWs and it had unfortunately caused them to deal with patients inappropriately impacting the quality of care provided. A manager stated,

We are not aware much of the complaints from the community we serve here at time. Once patients get here, the treatment is not exactly friendly from the nursing staff. It is a struggle to access our hospital sometimes for these women and I know clinicians are poor at identifying patients due to the high demand of patients that we see here. Our catchment area is not geographically large and I was not aware patients bought addresses. Pretty sure that someone who comes in may have a difficult time getting here but will keep silent about it.

6.4.3 Affordability (Financial Access): Multiple ANC Identification Cards

Affordability is concerned with the individual's ability and willingness to pay in order to access healthcare services which can be measured by opportunity costs where patients can or cannot afford to take time from work to get to the hospital.[73]

6.4.3.1 Patients: Opportunity Costs

Many patients expressed how balancing their daily duties of being a mother and wife was challenging with adhering to their ARVs and attending their local healthcare facilities or RMMCH. For instance, some patients were working but had to take time off work to make appointments at the hospital or return for follow-up. Women reported that sometimes they have a hard time with their managers, even though they provided a doctor's note to their employer. Patients expressed concern over their lack of income which makes it difficult for them to travel to RMMCH. One pregnant HIV-positive woman stated,

> *It is hard to get the taxi to go get the medication at times, I have to miss work and tell my manager I have to get medication. I get paid sometimes if I miss work, depending on if I provide a letter from the doctor. The little bit of money I make is only for groceries. . . it is very hard because I have my childrens' school fees, transport and other commitments. . . their father is not active.*

When patients were interviewed about if there were any challenges in retrieving ARVs, many would respond that it was "easy" to retrieve medication but explained they wait an average of 3 h. They would wake up early (before work if they are employed), rush their children to school and then wait in line to get their treatment. A 35 year old woman and thirty one weeks pregnant responded,

> *I get my medication at the hospital and clinic. It is easier to get meds from hospital. I make an appointment to get it. I have to wait long to get medication, maybe three hours or more. I have to be early to get through the line-up fast. I am working but it depends on the price,. I don't think I could afford the medication but if I had no choice then I would have to pay and be willing to do so. . . On your side here at RMMCH, it is not as long and I don't have to pay for medication.*

6.4.3.2 Frontline Nurses: Multiple Addresses

RMMCH had many patients that do not live in the catchment areas that the hospital serves. Often a patient would enter the interview room carrying her ANC card which provided the name of the local health clinic in which she may be referred from in order for the HCWs to understand if the patient is within catchment areas of RMMCH. Frequently, the address that she provided was different from the one written on the card, while in some cases the card was photocopied or was not authentic. Often, women were unable to afford the transport home from RMMCH. A nurse commented,

We provide money out of our own pockets to patients, so they are not left stranded at the hospital. . . It is the governments' duty to supply patients with medication. Our patients do not have medical aid, and most are not working. They lie about their addresses and if they do not live in surrounding areas, they have to go to the closest hospital where they stay. These pregnant HIV-positive women end up buying addresses for proof of residence and will pay community members in the squatter camps behind the hospital.

Unsuccessful tracing and LTFU were mostly due to incorrect addresses received, likely from women giving false addresses due to fear of stigma and discrimination associated with using their local facilities. This phenomenon exists as a way for patients to be referred to RMMCH as a specialised hospital. Patients may not attend their local health clinic and be staying with a partner in the squatter camps nearby the hospital. If RMMCH is their closest healthcare facility and the patient does not want to pay for private services then buying an address may appear attractive to patients.

6.4.3.3 Physicians: Understanding Opportunity Costs That Our Patients Face With Option B+ PMTCT

The work environment had become less effective with managing the large number of patients. The physician's role had changed from providing support for the patient to spending less time managing patient adherence and conveying the importance of benefits of lifelong ART. Option B+ had decreased the amount of time physicians spend with patients by diagnosing and initiating them on treatment the same day. Physicians were unaware of the opportunity costs pregnant HIV-positive women undergo to attend RMMCH. One physician states, *"None of the patients really complain if you don't specifically ask them. Once I know one is stable on the regimen, I don't function for after hours for their problems."*

6.4.3.4 Managers: ART Is Affordable

Executives perceived there was a major issue with affordability for these HIV-positive pregnant women when it came to ART. Managers felt that women have no choice but to have to take time off work and wait in the ANC for long periods of time. One executive manager states, *"Getting to the facility is needed, a woman's employer is not very sympathetic and if it isn't a sick day then they cannot afford to pay them. It has to come from their annual leave. This is one of the financial barriers these women are facing."*

6.4.4 Acceptability (Cultural Access)

Acceptability is concerned with the fit between provider and patient perception toward and expectations of each other, including perceptions toward characteristics of age, gender, 'race' or ethnicity, and language which impacts the relationship of delivery and recipient of care.[73] Respect and the ability to listen to symptom descriptions, undertake a thorough examination, explain illness and discuss treatment alternatives conducted by the healthcare provider especially at the first point of contact is important.[73]

6.4.4.1 Patients: Do HIV-Positive Pregnant Women Think/Feel They Have a Choice?

All 55 patient participants responded that they chose to take the FDC to protect the health of the baby and felt that treatment could be stopped after giving birth. They were unaware of the benefits of continuing treatment which is the largest barrier for effective initiation of Option B+. At times, the use of the word "Option B+" would confuse pregnant HIV-positive women thinking it wasn't necessarily "a must" stick to regimen for life. A thirty-two year old woman, married with three dependents responds, *"I feel like I have no option. I do this for the sake of the baby. I don't want to lie but I am bad with tablets. I care about the baby and don't want to play with its life and mine. I am responsible for another life."*

Patient acceptability of medication adherence and the changes in their ART regimen was influenced by the information they received about safe sex practices, serodiscordant relationships, breastfeeding, family planning, and child spacing that contributed to difficulty in adherence amongst pregnant HIV-positive women.

6.4.4.2 Unsafe Sex Practices

Forty three of the pregnant HIV-positive women interviewed thought that having unprotected sexual intercourse with a partner that was also HIV-positive was fine as long as they were both on ARVs. These women did not understand and were not aware that re-infection can occur. Patients thought that taking ART could mean engaging in unprotected sex and did not understand why their viral load was increasing whilst on treatment.

When these women were asked if they are sexually active, many would say they were not and then when proceeding with the interview, they would state that they engaged in sex last week. There was uncertainty in responses when asked if a method of prevention is used and how often. One 29 year old woman, not married and 36 weeks pregnant with her second child stated,

> *I am sexually active; the last time I had sex was two months ago. I use a condom every time and I don't want to make any mistake. I am now pregnant with this child. . . I don't know what happened, maybe the condom broke. . . I was having problems with my boyfriend. We would always use a condom, but for this pregnancy during the intercourse it was taken off. I felt like he knew something and took it off, always coming up with excuses during sex. . . like how he has a rash.*

6.4.4.3 Serodiscordant Relationships

When conducting interviews with the women, there was tension at times in the room when the question of, "*Is your partner aware of your status?*" was posed. Many women would respond that they have multiple partners but are not exclusive. A 40 year old woman, not married separated from her partner and is 32 weeks pregnant stated,

> *I am not sexually active, fortunately. The last time I was sexually active, I was still together with my partner, who knows I am pregnant. A condom was used regularly, except the first time when we met and then I fell pregnant. I cannot say I regret it; I am an adult and responsible for my actions. . . My partner knows I am taking the ARVs and he is angry at me actually. He says it is going to take time because he is HIV-negative and asked for some time to go and heal.*

Furthermore, women disclosed at times that their spouse was HIV-negative and did not know she had engaged in sexual intercourse many times without use of a condom or other types of protection.

6.4.4.4 Breastfeeding: Miscommunication of Messages

A serious concern with misunderstanding the programme by patients was discovered when majority of pregnant women it was not a risk to stop their ART during breastfeeding after delivery. Women would sit in the waiting room of the ANC and hear education sessions, but most importantly did not actually understand the messages communicated to them entirely. This aligned to data collected that woman's body language, confused facial expressions, twisting of the body, and scratching of the head demonstrated uncertainty.

When participants at times were asked, "*Did you attend any of the education sessions in the waiting room ran by the nurses?*" Many participants would respond, *"Yes."* It is one thing to attend the information sessions that are provided in a lecture style format from the nurses in the waiting room- but to actually listen, understand and actually apply what is being taught to the patient was a challenge. When patients were asked, "*What did you learn from the education given in ANC?*" Many participants state, "*Breastfeeding when the baby is born is good. . . Is it true I can do that? [Only on ARVs]...oh. . .* " or "*I learned that I can breastfeed regardless of my status.*"

HCWs communicated messages to the patients but sometimes the patient will only understand part of the message which can be more harmful in the end. If the patient decides to breastfeed, they need to be carefully pre-counselled about adherence to ART and exclusive breastfeeding. At the time, post breastfeeding and 18 month HIV tests should be done as well. If the patient has a viral load of <1,000 copies/ml then the baby should preferably not be breastfed and infant formula can be substituted.

6.4.4.5 Family Planning and Child Spacing

There is a large dependence on partner(s) for support from a large number of pregnant HIV-positive women interviewed. When questioned, "*What does your partner think about you taking ARVs?*" A 26 year old woman revealed,

I had sex about three days ago. Sometimes I use a condom and now that I am drinking medication around my partner I am more careful and make sure to use a condom. . . My partner does not know what my treatment is for and he sees me drinking it. They say I must not tell the partner and they may not like that I have HIV. This baby was not planned and I do not want to lie to you. I will tell him after at the clinic and disclose the status after the birth of the baby.

Many of these women were unable to disclose HIV-status with partner and feel the need to hide their ARV medication. This is largely due to the fear of losing their partner(s) and not having support to provide for their dependents and newborn child.

RMMCH focused largely on mother and child with its delivery of Option B+ PMTCT. It had caused an issue with excluding the important male figure in family planning methods. Therefore, if a woman received her HIV-status and information is provided to her about disclosing to her partner(s), there is a barrier for the family unit to progress further because psychosocial support and adherence counselling services along with family planning would not be provided to the male counter-part.

Patients on average had three dependents and one still birth. One woman stated,

I am 37 years old and not married but I have a partner. My first child died in 2007 and it was a still birth. I did not get to keep him at birth. I have been pregnant a few times, all died and one even buried at the age of five. I am 5 months pregnant with my next baby; this will hopefully be my first living child.

An issue that presented itself was that women are likely to stop treatment in between pregnancies. Child spacing needed to be addressed in educational sessions with one-on-one counselling to these pregnant HIV-positive women for their own health. It is crucial in order to reduce the risk of transmission between mother and child, especially if she is not practicing safe sex and not using protection in between births.

6.4.4.6 The Fixed Dose Combination (FDC): More Manageable?

Patients found swallowing the FDC pill difficult in the first two weeks of starting ART or switching to

Option B+. Patients found it easier to manage one pill a day after two weeks. There was an average of 0 to 3 missed dosages for women that were on FDC over a period of 6 months.

Patients found that taking the FDC reduced stigma at home and in the community because it was easier to hide one pill bottle in their purse than have many multiple bottles of ARVs. Women found it was easier to manage one pill and take it at night before going to bed.

However, all patient experienced side effects such as dizziness, tiredness, nausea, and vomiting but on average felt better on the one pill a day after the first two weeks when starting the FDC. When patients were asked if anything changed in their ability to take the medication, many responded that the pill has become part of their daily routine. For example, one woman, 35 years old, not married and 39 weeks pregnant with her second child responded,

The pill may be really big and hard to swallow at first. I never miss any dosages –maybe with time sometimes because I drink it at night and usually take it at 9 p.m. and sometimes I am a few minutes late. I think I would go crazy if I missed it because I have made it part of my life.

Furthermore, many of these women expressed that they were shocked at first finding out their HIV status, but those who felt comfortable explained that they had a support system. A 35 year old woman stated,

> *Yoh! I felt I was about to die and the world was ending. I was angry and confused and even blaming myself. I wouldn't say I was depressed and I always find someone to talk to -like my mother. I trust her the most. I didn't go through denial, I accepted it and moved forward and why, is because I suspected my partner and it was that kind of situation. I wouldn't blame him and I didn't know if I had it. I just want to see my life go on and I don't know if I am angry still, I just want to move on. I panicked at the moment and felt like killing myself, and I want to beat this. I am not sure if I want a partner.*

Pregnant HIV-positive women were not given adequate time to absorb the shock of their HIV status which is challenging for uptake of the programme. They underwent testing, disclosure of HIV status and were initiated onto treatment for Option B+ all in a day. These women were bombarded with a large amount of information and needed time and guidance to adjust for going onto lifelong treatment.

6.4.4.7 Frontline Nurses: First Point of Care

Frontline nurses were the first HCW that a pregnant HIV-positive woman comes into contact with at RMMCH. Nurses each attend to an average of 21 patients a day. Many of the pregnant HIV-positive women nurses see a day had been on Option B+ for a maximum of 6 months. These nurses usually work with patients for many reasons, some of which include; vital sign tests; blood tests; medication distribution; non-stress tests; monitoring heartbeat; patient comprehensive reporting; make beds; urine tests; temperatures, etc. Therefore, there has to be acceptance from the frontline HCWs in understanding the new guidelines in order to correctly provide information to their patients.

Nurses gave women the opportunity to ask questions and tell them that they should feel free to come and ask any questions they may have and can do so in private. One nurse stated what she does to provide the best possible care to her patients,

> *I teach them and tell them the importance of why they are attending the ANC and education, making sure they know why they take the medication. If she wants to speak to you privately, you listen to her and give her the best advice you can. It's hard you aren't with her 24-7, once she goes home it depends on her.*

Many nurses think that Option B+ is effective because the FDC is easier to manage as one pill instead of taking three ARVs. Patients are doing better on one pill that have children dependents because it is one ARV dosage in the evening and able to send their children to school and go off to work. Nurses found more women were accepting the FDC, though some were reluctant because they were scared of the side effects and the stigma that still exists about HIV/AIDS. One nurse expressed, "*Most women stick to the regimen; some are in denial. Adherence is increasing, unless they are telling us lies. When I speak with a patient, what they tell us we have to believe what they say about their adherence."*

6.4.4.8 Physicians: Inconsistency in Thorough Counselling and Follow-Up

Physicians recognised that one of the biggest challenges is the opportunity for proper counselling that could influence pregnant HIV-positive women to make informed choices about treatment for life. Pre-therapy counselling is missing by definition of Option B+ PMTCT. The difference between Option B and Option B+ is that under Option B, the woman had the opportunity to digest the diagnosis of HIV and to decide whether she wants to take the ARVs for life, until she gave birth, or until the time she stops

breastfeeding but with Option B+ though that choice is eliminated. This was overwhelming for an increased proportion of women not knowing their HIV positive and on the same day prescribed antiretroviral therapy for life. There was clearly an opportunity for more counselling with the Option B+ PMTCT programme.

HIV-positive pregnant women had difficulties in understanding immediate ART initiation. Similar views on same-day testing and initiation on ART and viewed same-day testing and initiation on ART as "too rapid" for clients to be able to process. One healthcare worker in the OBGYN department stated,

> *A woman, a mother comes into the hospital and may enter our antenatal clinic thinking she is just fine and healthy. Then a nurse asks her, to run a test, after of course waiting approximately from 6 a.m. to mid-day. She is tired, exhausted and carries on to pre-test thoroughly. Her test results come out as HIV-positive after cross-checking, the counsellor now sees her for post-test counselling. . . Keep in mind now that she has not even seen the doctor yet. She waits to hear that she has an HIV-positive status. Now she may be very upset, not know how to register what is going on, and barely has any time at this particular moment to process before she is given an FDC pill and told that this will help her. . . whether or not she fully understands the benefits, who knows.*

This had caused inadequate space for counselling, and long waiting periods to see a HCW. The patient is rushed for testing and treatment which deters the patient from returning. At RMMCH, women still had to visit multiple departments in a single day with long waiting times. This can overall impact the patients experience and acceptance of Option B+ PMTCT and her ability to return for future follow-up appointments.

6.4.4.9 Managers

Management had noticed a major issue with pregnant HIV-positive women with adherence declining after giving birth. An executive explained why this may be,

> *Women are motivated to take these medicines because there is a purpose to it during pregnancy, to prevent transmission for their unborn baby. Once the baby is out, that purpose becomes lost and there may be no incentive to maintain adherence.*

6.4.5 Adaptability (Contextual Access): Is the Option B+ PMTCT Programme Scalable Outside RMMCH?

Women participating in the Option B+ programme are sources of valuable information that can help inform the Option B+ policy. However, there is failure across the current literature specifically in South Africa to involve patient perspectives. Research has found that the aspirations of increasing adherence may be more difficult than expected by key stakeholders.[4] This may be a sign that the adaptability of a policy is dependent on all actors involved in Option B+ including the perceptions of the healthcare workforce, and the HIV-positive pregnant women.

6.4.5.1 Frontline Nurses

Frontline nurses suggested that scalability of the programme outside of RMMCH may require more research in adapting the programme to other healthcare facilities. This would mean system planning and ensuring that the programme is sustainable. A nurse commented, *"It is going to take time and way more research to understand whether the programme can scale-up outside of RMMCH. All we know from research is that pregnant mothers are defaulting. . . "*

6.4.5.2 Physicians

When physicians were asked about whether the Option B+ PMTCT programme would be effective, many could not comment because of the lack of long term data about sustainability and scalability of the programme. One HCW in OBGYN unit stated,

> *"It is very difficult to evaluate the long term sustainability of the Option B+ programme. I cannot comment even on the effectiveness of Option B+ in the short term. I have to look at long term data that further reduces PMTCT and it is currently not available for Option B+. This programme was only introduced in January this year at RMMCH and I don't think there is sufficient data yet for South Africa."*

6.4.5.3 Managers

The perception of an executive that manages the Option B+ PMTCT programme at RMMCH aligned

with much of the HCW views, that there was insufficient data to analyse whether the programme would be scalable outside of RMMCH. RMMCH is still undergoing programme implementation issues and would need to strengthen its system planning model before rolling out of the programme occurs. A manager stated,

> *As a project manager for PMTCT, my main function is to make sure the programme is running well and implemented properly at the facilities. . . We have only introduced Option B+ for five to six months now. To be honest, I can't really say if it is really working because there has not been any evidence.*

6.4.6 Principal Findings

6.4.6.1 Patients

The findings suggested that patient acceptability of medication adherence and the changes in their ART regimen is influenced by the information they received. The quality of care made available to patients can affect their overall experience which contributed to decision-making for a patient. In addition, patients' willingness to incur opportunity costs and return to RMMCH was largely dependent on their experience. Patients require education and continuous support to understand the benefits of Option B+ PMTCT and ART for life. All 55 patient participants responded that they chose to take the FDC to protect the health of the baby and felt that treatment could be stopped after giving birth, unaware of the benefits for the woman to continue treatment.

6.4.6.2 Frontline Nurses

The findings nurses suggested for nurses that the Option B+ PMTCT programme had created emotional risk factors for frontline staff. Until frontline nurses are accepting of how their work had changed then the patient experience may be undermined. The initiation and maintenance of the programme had increased responsibilities for HCWs in patient care which include; good quality care, delivery of educational sessions, communication and consistent messaging for patients, monitoring ART adherence, and the provision of thorough counselling.

6.4.6.3 Physicians

The findings suggested for physicians that the healthcare work environment had become more ineffective with managing the large demand of patients. The physicians role had changed from providing available support for the patient to spending less time managing patient adherence and conveying the importance of benefits of ART for life. Physicians are unaware of the opportunity costs pregnant HIV-positive women undergo to attend RMMCH. However, increased access to ART does not resolve internal issues with HCWs. There are issues with ART initiation, viral load monitoring, thorough counselling and support groups, communication between department transfers, privacy, and overall quality of care for patients.

6.4.6.4 Managers

The findings suggest that the hospital organisation had initiated positive administration practices to help manage transmission of HIV in PMTCT. Option B+ has challenges in education and awareness of ART and its integration into the already existent stigma and cultural beliefs in the South African community. The executive staff had utilised strategies that included PMTCT HIV strategies. Educational lectures and training across departments need to assist HCWs in better understanding the implementation of the programme at RMMCH.

There was still a need to strengthen indicators in order to better manage the implementation of the programme. RMMCH had an increasing number of foreign national mothers that use the facilities up until they give birth which had contributed to the inability to trace a patient. There is a heavy burden of maintaining up-to-date tracking information with paper-based systems and lack of telephone numbers in records and unclear addresses.

Studies suggest that tracing should be done the first week once a patient misses an appointment because it is the most critical period, since after treatment is initiated it is crucial that the woman remain on ART.[90]

6.5 Discussion

The research demonstrated that work had become difficult to manage for all HCWs because of the; (1) need for strengthening indicators to decrease loss-to-follow-up; (2) inconsistency in delivery of counselling & support services and; (3) lack of compassion and understanding by service providers. The difficult healthcare environment had affected overall views and experiences of these women going on ART-for-life. All patient participants (n=55) responded they chose to take the FDC pill to protect the baby's health and believed lifelong ART could be stopped after delivery, unaware of the long-term benefits.

There are major challenges with the national guidelines. These changes affect the policies and procedures at RMMCH both at the clinical and management levels. Research studies tend to focus on the output of healthcare programming without including the user perspective before implementation. Therefore, by including pregnant HIV-positive women's experience of the Option B+ programme is informative in understanding the patients' perception about going on ART for life to better understand strategies in implementing an adaptable approach for adherence.

6.6 Strengths and Limitations

Policy often excludes the voices of those that are most impacted by its implementation. The strength of this study was its ability to provide a platform for pregnant HIV-positive women to share their lived experiences with lifelong ART. The study was able to explore the perceptions of HCWs from both clinical and management levels and how their work has been impacted by the national consolidated guidelines as a way to inform Option B+ PMTCT programming. Qualitative research develops concepts that can provide better understanding and speak to the concerns of those who provide healthcare and the interaction with their recipients.[88]

The use of body language of the PI may have affected the results through moderator bias. Therefore, acknowledgment and disclosure of the PI's perspective enhances the credibility of the study.[89,91] The use of triangulation strengthened the validation of the data in the study. In addition, because of the study's diverse and large sample, the study findings may be transferrable to other settings that are implementing this programme.

This study focused on one hospital system in Johannesburg, South Africa, which limits the ability to make assumptions about the findings beyond the local context in which this study was conducted. Though the study was conducted six months after introduction to the Option B+ programme, the study had delineated many issues earlier on that could be considered in shaping the programme aspects, for example peer group support and knowledge transfer/education for HIV positive women.

Additionally, a convenience sample of HCWs was selected for qualitative interviews based on recommendations from the Head of the Paediatric and Child Health department and Director of the ESRU. In order to mitigate the limitation of biased selection of the HCWs, a purposeful random sampling method could be used to increase credibility of the study. To gain a maximum representation of views, ensuring that patients were not subjected to selection bias based on their ability to speak English, can increase the validity of the research.

6.7 Recommendations and Conclusions

For lifelong treatment programming to function and be successful in other settings for HIV-positive pregnant women, certain components need to be addressed to ensure adaptability; by providing continuous counselling and support services for women with same day initiation.

RMMCH needs to improve their internal communication and collaboration amongst HCWs across all units to develop consistency for the use of indicators for the programme and understanding of individual roles in delivering consistent messages and services to mothers. Communication is essential in helping patients build trust in service delivery, decreasing the LTFU and can alter the patient perception on long term adherence. Most importantly, an HIV-positive pregnant woman needs to understand the long-term benefits of FDC for both herself and her baby. This will help build trust in services utilised by these pregnant women and alter their perceptions on medication adherence holistically after delivery of the baby. A recommendation is for collaborative sessions that are feasible for HCWs with existent training sessions which can be managed with a rotation schedule for workers to come together and give their input.

A challenge for HCWs was the ability express sympathy for the patient. In highly constrained resource settings, a recommendation is to have support workshops for healthcare workers engaged in this work to manage and cope better. It is important to maintain the health of RMMCHs staff. Support

workshops can allow healthcare workers to come together and build closer relations to each other, understanding that they are all undergoing changes in their work.

Maintaining open communication and working on compassion and patience will make workers more aware that their attitude and behaviour toward patients can impact the quality of care the patient receives. It is recommended that training workshops be held for frontline nurses and physicians.

It is crucial to understand the barriers to the short and long-term sustainability of the Option B+ programme. Understanding the environment in which a PMTCT programme operates can address policy implementation and programme issues and hence inform how adaptable Option B+ programing is on a larger scale. The national guidelines have been developed but adaptability may remain problematic to successful roll out of the Option B+ programme outside of RMMCH.[86]

Implications for this research include the need to address changes within the healthcare system at both clinical and management levels. It is crucial to incorporate the perspective of patients and frontline HCWs alike in policy implementation; uptake and adherence are key indicators in informing if the Option B+ PMTCT programme is adopted into state hospitals effectively. This can help address issues before policy implementation is executed. Often, stakeholders and policymakers come together to create a policy to do what they see may be best from a top down approach. However, by using a community based approach, implementation plans can take place as a discussion by including the patient and healthcare workers at the table and spark open dialogue between the key actors and those impacted by the implementation. Community based approaches can empower individuals, such as these HIV-positive pregnant women to acknowledge expectations about themselves, their behaviour and potential. The involvement of the patient living with the illness in the community can provide insight as to how Option B+ could be integrated and adapted to meet the unique needs and values of the surrounding community at healthcare facilities undergoing high resource constraints.

In addition, extensive research needs to be done on how to strengthen indicators for long term sustainability of the programme in conducting a longitudinal study comparing system planning between healthcare facilities and state hospitals. Collaboration across the departments of RMMCH and can provide perspective and insight as to what indicators need to be strengthened for the Option B+ PMTCT programme. This can be executed through interdisciplinary department meetings and training may encourage dialogue between staff internally and report any issues and concerns they may be experiencing with the programme to upper management. RMMCH has existent clinical training sessions done

specifically with frontline nurses. By including the physicians and counsellors that work within the departments, this can overall strengthen the communication between HCWs. Remember all HCWs can provide feedback as to how their work environment is managing these indicators, which may be entirely different depending on which department they work in. Future evaluations need to address if interdisciplinary collaboration within hospitals can improve the management and understanding of Option B+.

Furthermore, many pregnant women were interested in learning more about the ARVs they were on, especially FDC and why they had to take it. Limited information is provided from the education that nurses give in the antenatal clinic. It is recommended that instead of delivering education and information in a lecture style format, it should be conducted as interactive sessions to stimulate the patients and keep them engaged. Interactive sessions allow pregnant HIV-positive women to build mentorship and a network where they can form healthy relationships which can improve their adherence to ART.[90]

Womens' perceptions of their partners' approval of their HIV status have been identified as a strong predictor of willingness for women to return to the antenatal clinic.[92] RMMCH provides women with counselling but often males are not allowed into the facility which acts as a barrier to uptake. A recommendation is to provide additional support groups where the male partners can attend to increase open communication by including the male in child spacing and family planning methods.

This research will contribute to the HIV/AIDS prevention programme literature in the health policy field. In our increasingly globalised world, it is important to determine how processes and policies in one country can be successfully adapted to another country.[86]

DATA AVAILABILITY STATEMENT

The datasets for this manuscript are not publicly available to protect confidentiality and HIV status for participants. Requests to access the datasets should be directed to Melanie A. Bisnauth, melaniebisnauth@gmail.com.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The Hamilton Integrated Research Ethics Board (HiREB) at McMaster University located in Hamilton, Canada and the Human Research Ethics Committee (HREC) at the University of Witwatersrand. Written informed consent to participate in this study was provided by the participants/participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

The authors retained full control of the primary data. The content of the research in this document has been completed by MB and recognises the contributions of the authors. This study benefited from the participation of a wide range of partners, medical professionals, HIV specialists and researchers. The author is grateful for the guidance provided by the committee members for manuscript management. All members read, commented on, and approved the final manuscript.

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CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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LINKAGE

Linking Notes between Chapters 6 and 7 (Papers 1 and 2)

This section contains information to clarify the link between Chapters 6 and 7 (Papers 1 and 2). In depth discussions in findings of individual papers are in the discussion sections of each paper, while an overall discussion follows in Chapter 9.

The studies in Chapter 6 and 7 contain data on the experiences and perspectives of both HCWs, which include frontline workers such as nurses, doctors and managers in hospital, that serve both at city, provincial and national levels, as well as patient perspectives which analysed all women accessing and using PMTCT services at a state hospital, RMMCH.

Chapter 6 (Paper 1) looked retrospectively at the Option B+ policy and programming impact on PMTCT in 2015, this allowed for a better understanding of the roll-out of the guidelines and the impact on both patients and HCWs.

In Chapter 7, Objective 2 is addressed- to investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels. regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic.

Paper 2 explored further in-depth, the perspective of HCWs solely and their provision of PMTCT services to the large number of migrant women that utilise treatment and care at RMMCH, a high mobility context. Paper 2 uncovers the challenges that are pre-existent and showcases how the COVID-19 pandemic shone light to these barriers. Findings revealed five main themes that emerged in Paper 2: (1) Facilitators and barriers to adherence, which included the need for multi-month dispensing for the long term supply of antiretrovirals (ARVs) and the fear of contracting COVID-19 at the hospital that disrupted patients' continuum of care; (2) Healthcare providers work environment, where participants felt overwhelmed with the high patient demand and the lack of infrastructural resources to follow social distancing protocols; (3) Financial challenges and opportunity costs, PMTCT proved difficult for migrants due to border closures and documentation required to receive care, this resulted in treatment interruption and left many unable to receive support at the facility due to capacity restrictions; (4)

Interpersonal interactions, mistreatment, and xenophobic attitudes existed toward the migrant HIV population; and (5) “Programme sustainability” revealed three key areas for strengthening: longer duration of time allocated with counselling for same-day initiation, the increased use of technology, and translation services for migrants.

Chapter 7 (Paper 2) data collection occurred during the COVID-19 pandemic, and it inevitably had an impact on the PMTCT programme and its service provision by HCWs and its utilisation by WLWH. Therefore, the PMTCT service provision and utilisation involved the aspects of both mobility and migrant typologies, as well as the COVID-19 impact on the provision and use of these services.

Paper 2 concludes that it is important to take what was learned during the pandemic and integrate it into routine service delivery, which includes long-term medication supply to reduce risk with multiple visits to collect medication, and the use of technology to alleviate the high-burden of patient demand. Healthcare policies that work toward inclusion and sustainability for migrants are needed to improve the integration of safer and practical methods of PMTCT provision into health systems.

CHAPTER SEVEN: PAPER TWO

Paper 2: Bisnauth MA, Coovadia A, Kawonga M, Vearey J. Providing HIV prevention of mother to child transmission (PMTCT) services to migrants during the COVID-19 pandemic in South Africa: insights of healthcare providers. Health Services Insights. 2022 Jan;15:11786329211073386. (published). Impact factor 2.09.

Bisnauth– 80% (conceived original idea, conceptualisation, developed theory, conducted the research, performed analysis, wrote the manuscript);
Coovadia- 5% (conceived original idea, supervise findings, feedback and reviewed the manuscript);
Kawonga- 5% (conceived original idea, supervise findings, feedback);
Vearey- 10% (conceived original idea, conceptualisation, developed theory, supervise findings, feedback and reviewed manuscript).

At the time of this thesis submission, Paper 2 was published as an original article in the *SAGE Health Services Insights Journal.* For the purposes of this thesis, figures and tables as well as their captions have been placed in the appropriate places within the text of the article and general formatting is aligned with the requirements of the specific journal.

Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers

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ABSTRACT

Background: In March 2020, COVID-19 entered South Africa, resulting in 2.9 million cases, the country took preventative and precautionary measures to control the spread of COVID-19 infection. These measures limited population mobility especially for migrant women living with HIV (WLWH) and the provision of PMTCT services. The purpose of this research was to explore the challenges of the COVID-19 pandemic on PMTCT provision by healthcare providers and understand what strategies could be implemented with lifelong antiretroviral therapy (ART) for migrants to better manage the programme.

Methods: Twelve in-depth interviews were conducted with healthcare providers across city and provincial levels on how the changes to the healthcare system with COVID-19 affected highly mobile patients' adherence and utilisation of PMTCT services. A thematic content analysis was used for emerging themes and guided by The utilisation of PMTCT services conceptual framework.

Results: Five main themes emerged: (1) *Facilitators and barriers to adherence*, which included the need for multi-month dispensing for the long term supply of antiretrovirals (ARVs) and the fear of contracting COVID-19 at the hospital that disrupted patients' continuum of care; (2) *Healthcare providers work environment*, where participants felt overwhelmed with the high patient demand and the lack of infrastructural resources to follow social distancing protocols; (3) *Financial challenges and opportunity costs*, PMTCT proved difficult for migrants due to border closures and documentation required to receive care, this resulted in treatment interruption and left many unable to receive support at the facility due to capacity restrictions; (4) *Interpersonal interactions*, mistreatment, and xenophobic attitudes existed toward the migrant HIV population; and (5) "Programme sustainability" revealed three key areas for strengthening: longer duration of time allocated with counselling for same-day initiation, the increased use of technology, and translation services for migrants.

Conclusions: It is important to take what was learned during the pandemic and integrate it into routine service delivery, which includes long-term medication supply to reduce risk with multiple visits to collect medication, and the use of technology to alleviate the high-burden of patient demand. Healthcare policies that work toward inclusion and sustainability for migrants are needed to improve the integration of safer and practical methods of PMTCT provision into health systems.

Keywords: HIV/AIDS, COVID-19, maternal health, PMTCT, migration, accessibility, South Africa

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7.1 Background

The COVID-19 pandemic has resulted in high mortality for South Africa's (SA) HIV population, resulting in an over-whelming 550 000 deaths in less than six months alone since its first confirmed positive case in March 2020.[43,,93,94] A large proportion of the cases came from Gauteng province, home to the largest migrant population in which rests the city of Johannesburg—full of vast population movements from internal (individuals moving intraregionally or interprovincially) and cross-border (individuals moving between neigh-boring countries) migration.[93] Most migrants (60%) are located in the peripheral and urban areas of Johannesburg, 32% of which are women, and cross-border migrants that do not access healthcare for fear of being asked for official documentation and deportation.[5,93] The pandemic has added a layer to the pre-existent structural discrimination that has largely influenced health-seeking behaviours and social exclusion of both internal and cross-border migrant women within healthcare facilities.[98,99] Migrant women

utilising maternal healthcare and HIV services face many of the barriers and challenges that disrupt their ability to adhere to medication and treatment which requires long-term discipline.[7,25,55]

The impact of COVID-19 on migrants access and utilisation of the healthcare systems during the pandemic is little understood.[94] The increased mobility across long distances resulted in significant risks for migrants accessing healthcare services and a call for government own COVID-19 prevention strategies.[94] Though the SA constitution indicates the right to access healthcare for all who live in SA, and the national health policy provides for free primary healthcare access for all in the country with no mention of nationality and legal status, interpretation of the legislation is less inclusive in practice.[94,24]

Healthcare service cutbacks for provision of counselling and support to help both internal and cross-border migrant women living with HIV (WLWH) has also resulted in adherence challenges.[6] Border closures during lockdown challenged the second 90 (90% of people living with HIV who know their status being on antiretroviral therapy) with the loss to follow-up (LTFU) because mobile women remained difficult to trace when attending different facilities to access care.[2,94,24] Research also suggests ill treatment by healthcare providers can impact access to care for foreign nationals, such as the phenomenon of medical xenophobia (MX) in the contemporary SA public health system.[95] MX refers to the negative attitudes and practices of healthcare professionals toward migrants and refugees based purely on their identity as a non-South African, which impacts the services that are provided for and accessed by patients.[95] Studies point out examples of MX which include declining non-nationals entrance into a healthcare facility and healthcare providers placing non-nationals in a longer queue.[26] This care is often not the best care available due to the presumptions that there is an increased burden on the SA public healthcare system causing stigma and fear of the spread of COVID-19 with migrants.[26]

Research shows that both internal and cross border migrants during COVID-19 faced challenges in access and utilisation of healthcare services.[5] Despite existing evidence on the diverse population movements within SA, the public healthcare system, on which majority of the population relies, has struggled to integrate mobility or migration.[2,93]

7.1.1 PMTCT Lifelong Treatment

PMTCT is a clear example of a maternal and child health programme that was offered across SA since 2001.[55] The PMTCT cascade represents a complex system of sequential, interdependent steps that WLWH navigate as healthcare users to receive appropriate care and treatment for themselves and their newborns.[56] A vital component that was not traditionally part of the PMTCT programme but was later added was the provision of lifelong ART services for women by the World Health Organisation (WHO) consolidated

guidelines.[18] Thus, the PMTCT cascade of care does not end at delivery of the baby as there is a need for long term follow-up. PMTCT using ART is a proven, efficacious intervention, and can reduce vertical HIV transmission to less than 2%.[56]

In January 2015, Rahima Moosa Mother and Child Hospital (RMMCH)[1] located in Johannesburg was the first public hospital to implement PMTCT lifelong treatment.[18] RMMCH reported 64% of their maternal population accessing maternal newborn child health services were recorded as non-citizens of SA and are a part of the challenging public health service provision.[18] Women who attended ANC outside of RMMCH, were often untested for HIV and delivered their babies at the hospital without an early PMTCT intervention.

The aim of this research was to; (1) explore the challenges of the COVID-19 pandemic on PMTCT provision by healthcare providers to further investigate the encounter between service providers and users and; (2) understand what strategies could be implemented with COVID-19 to address challenges with lifelong ART for migrants to better manage the programme.

7.2 Methods

7.2.1 Research Design

This qualitative study included in-depth interviews (IDIs) conducted with healthcare providers across different units of RMMCH that provided PMTCT services or interacted with service users, specifically migrant women. IDIs were aimed to investigate healthcare providers perceptions on challenges of the COVID-19 pandemic on PMTCT provision and understand what strategies could be implemented with lifelong ART for the highly mobile population.

This design was chosen to stimulate interaction and discussion, creating an opportunity for open input on the challenges and strategies related to The utilisation of PMTCT services conceptual framework during the pandemic based on participants' experiences.[76]

7.2.2 Conceptual Framework

The utilisation of PMTCT services conceptual framework (Figure 1) was used to explore healthcare providers' experiences of providing PMTCT services to highly mobile users during the COVID-19 pandemic. Utilisation is defined as the healthcare users' experiences and perceptions of their interactions with the PMTCT programme components (i.e., healthcare providers' treatment of them, and interactions with any hospital staff from point of entry). This includes their perceptions regarding accessibility of the service as well as adherence of their patients to the PMTCT lifelong care. Utilisation is made up of (1)

adherence issues to the programme and; (2) *access* which comprised of 4 dimensions: *availability; affordability; acceptability; adaptability*.[73] *Adherence* is conceptualised as the long-term ability for these women to follow the PMTCT programme which includes the ability to take medication routinely, not miss dosages, and attend follow-up appointments.

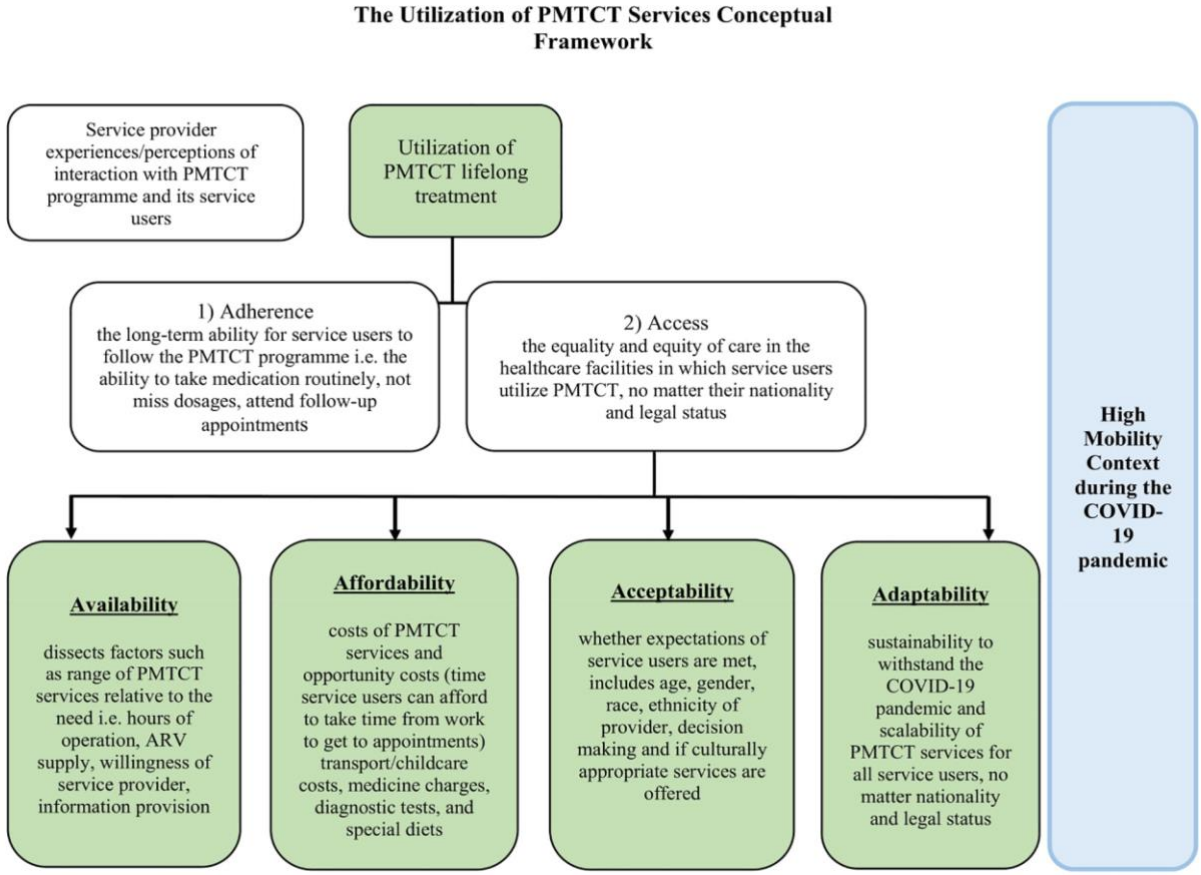


Figure 1. The utilisation of PMTCT services conceptual framework

Accessibility is a component of utilisation that refers to the equality and equity of care in the healthcare facilities in which these women utilise PMTCT, no matter their nationality and legal status.[18,73] *Availability* dissects the factors such as the range of maternal, newborn child health services (MNCH)/PMTCT services relative to the need that is, hours of operation, ARV supply, willingness of service provider, and information provision.[18,73] Affordability refers to costs of PMTCT services and opportunity costs (time a woman can afford to take time from work to get to the hospital), including transport costs, medicine charges, diagnostic tests, special diets, and childcare costs.[18,73] Acceptability refers to whether the expectations of the women are met, which includes age, gender, race, ethnicity of provider, decision making, and whether culturally appropriate service are offered.[18,73] Acceptability also includes the individuals' non-medical expectations of healthcare providers' treatment of dignity and respect of their culture.[18,73] Adaptability, however, refers to the sustainability and scalability for the PMTCT programme for all women, no matter nationality and legal status.[18,73]

7.2.3 Procedure and Data Collection

IDIs were conducted in the privacy of participants offices at RMMCH or on an audio recording platform (Zoom) where consent was provided due to capacity restrictions of COVID-19. Participants were recruited through purposive sampling and had to meet the following inclusion criteria: had to be 18 years or older; a healthcare provider at RMMCH; works in the public healthcare sector at district, provincial, or national level and; had to have contact with service users on PMTCT since its initiation in 2015 at RMMCH. Participants were not excluded based on race or language. Participants were only excluded if they were newly employed with no previous interaction with patients on PMTCT.

A semi-structured interview guide was used that comprised of the following main topics: (1) adherence, (2) access, (3) availability, (4) affordability, (5) acceptability, and (6) adaptability. For example, some questions asked were, *"What documents are needed to utilise PMTCT at RMMCH for non-national women? What ways would you improve the services made available for PMTCT at RMMCH? Specifically for mobile populations? What strategies would you implement at RMMCH to improve PMTCT use? Do you think mobility has an effect on a women's uptake/adherence with the PMTCT lifelong treatment programme? Why?"*

The guide was developed by the researchers, which consisted of an HIV medical specialist, migration, and public health epidemiologists who had experience in this field. The topics in the interview guide were structured in a logical and constructive way and were based on findings from literature review and information on the framework. Participants were recruited consecutively until data saturation occurred where the principal investigator and research team were no longer hearing or seeing new information emerging from the data. To establish rapport, interviews started with demographic questions, then moved to challenging topics (i.e. any mistreatment toward patients) with open-ended questions.

7.2.4 Data Analysis

IDIs were audio recorded and transcribed verbatim, all transcripts were anonymised but roles and perspectives that were important to answering the question. A thematic content analysis was used to analyse the data using NVivo QSR 12 (QSR International Pty Ltd., 2018). The round of open coding was completed by two authors independent of each other, after which the codes were discussed and recoded until consensus was reached.[76] A triangulation technique was used to cross check and validate IDIs and ensured the credibility of the findings amongst the research team that reviewed the findings from transcription along with literature journaling for social cues, reflection, and continuous refinement to hone the most prominent

themes and relationships.[76] Descriptive statistics were reported for demographics of the participants including proportions for categorical variables using Stata 14.

7.2.5 Ethical considerations

The Human Research Ethics Committee (HREC) at the University of Witwatersrand, South Africa approved this study in 2019. Provincial clearance was obtained by Gauteng Province and The National Health Research Database (NHRD No: GP_201912_003) and the City of Johannesburg. Authorisation from RMMCH was granted to conduct the study in Coronationville (HREC Protocol No: M190816 MED19-07-084). Participants gave verbal informed consent before the start of the IDI was audio recorded.

7.3 Results

7.3.1 Participants

The IDIs included 12 participants both on city and the National Department of Health (NDoH) provincial levels (female: 92%) with a mean age of 43 years (range 25-49 years) across the neonatal intensive care unit (ICU), post/antenatal clinics, Obstetrician-Gynaecologists (OBGYN), and HIV/AIDS, STIs and TB (HAST)/nursing management units, four of which served 15 years or more at RMMCH.

Table 1. Demographics of participants

Variable (number of responses)	Proportion
Age years (12)	
18-24	1
25-49	7
50+	4
Gender (12)	
Woman	11
Man	1
Transgender	0
Occupation (12)	
HIV Specialists	2
OBGYN	1
Neonatologist Paediatricians	3
HAST/Nursing Management	1
Nurses	3
Counsellors (linkage officers)	2
Time served at RMMCH (years) (12)	
1-4	3
5-9	2
10-14	3
15+	4

(Table 1). Management was involved with the provincial PMTCT committee which included training and provincial guidelines. IDIs were 45 to 52 minutes.

7.3.2 Themes

The utilisation of PMTCT framework which included (1) adherence and (2) the four dimensions of access; availability, affordability, acceptability, and adaptability was used to organise subthemes that derived from IDIs (Table 2).

7.3.2.1 Adherence: Facilitators and barriers for adherence to PMTCT health care services. The adherence theme was composed of the subthemes "multi-month dispensing (MMD)," and "fear."

Multi-month dispensing (MMD). The pandemic increased strain on both healthcare providers and users, who were unable to access the hospital as they regularly would which led to disruption and higher risk of LTFU. A Neonatologist indicated that the healthcare system had not been informed of the changes with COVID-19 in respect to dispensing ARVs for migrant mothers that are highly mobile,

> *"The problem is the first year of the child's life, it is good to go because every time the child goes to the clinic for an immunisation, then the mom can get the medication and get a viral load (VL) done in the month, but it is after that everything just falls to pieces in the long-term now with COVID-19. It's like now the mom is not going to go to the clinic for the child and then you can't give her the medication and she's moving around. I think we really need to consider this with long-term care"* [IDI 10].

Table 2. Themes and subthemes

	Themes	Subthemes
Adherence	Facilitators and barriers for adherence to PMTCT health care services	Multi-month dispensing ARV medication (long term supply) Fear of contracting/falling ill COVID-19 at clinic
Access		
Availability	Healthcare providers work environment	Appointment booking systems to reduce high burden referrals Lack of infrastructural resources: Space Educational training
Affordability	Financial challenges and opportunity costs to receive PMTCT care	Lockdown Border closures Limited transport systems Job loss/financial restrictions
Acceptability	Interpersonal interactions (between healthcare providers and users)	Communication, language barriers Documentation (forms of identification), fake addresses Mistreatment, xenophobic attitudes
Adaptability	Programme sustainability	Same day initiation (SDI) Technology Translation

Counsellors elaborated on challenges that were seen regularly with adherence and VL completion at the ANC with women that move around frequently. Strategies to help address this was discussed,

> *"I feel like with those highly mobile patients we should be allowed to give them treatment that isn't just one month, but a longer period so that at least they have it. If we can do this during COVID-19 times then I don't see why two or three months of medication, or six months and a VL can't be done"* [IDI 8].

Therefore, it's not that multi-month medication dispensing to ease access of ARVs for mobile patients cannot be done, the pandemic of COVID-19 increased the dire need to do so and demonstrated that it was possible.

Fear. Particularly migrant women; feared the pandemic and falling ill; were more often turned away from healthcare facilities and; were unable to obtain their medication or utilise services. A paediatrician explained that there are already time constraints to conduct thorough counselling for migrant women that are virally unsuppressed during COVID-19,

> *"Patients were scared to come because they thought-I am going to come to the hospital and get COVID-19, so then they wouldn't come for their appointments. The ones that aren't virally suppressed, to be honest with you, we will get the history from them but we don't always get the time to counsell in detail [. . .]. We might ask what happened, the mom will say for example, during COVID-19, they told her she had to be quarantined and she couldn't go and get her medication. She stopped for two months, and you don't blame her because there were stories that some clinics were turning foreigners away, so that we can understand"* [IDI 11].

Counsellors expressed that cross-border migrant patients voiced their concerns about the care received from other staff, left feeling scared and neglected. A counsellor described that she took it upon herself to ensure that cross-border migrants feel comfortable, *"I speak to them and make them feel welcomed. Sometimes they are scared or a nurse has rubbed them the wrong way- they shout and yell. We talk to them and hear their problems but it is so overwhelming that we don't get much time"* [IDI 9].

Access

7.3.2.2 Availability: Healthcare providers work environment. Participants discussed facilitators and barriers of COVID-19 including; appointment booking systems, the lack of space, and educational training.

Appointment booking systems. RMMCH had an increased burden of patient referrals from outside their catchment area before the COVID-19 pandemic. Doctors expressed frustration with the healthcare system disruptions and clinic closures due to increased COVID-19 cases,

> *"I think we are going to see the effect of these first, second, third waves, and the fall-out from maternal cases because of COVID. I have had rubbish like the other day, they said they are going to close the one clinic which delivers babies in our area and just send all the patients to us because they had one positive patient, two weeks ago in their clinic. We are going to hit problems like that and it is going to impact on care. We will lose babies and mothers because of it."*

COVID-19 placed pressure on the healthcare facility to make changes in an efficient and effective manner to cope with patient demand. Implementation of a booking system that respected social distancing, reduced

the overwhelming number of HIV pregnant women served daily. An HIV Specialist highlighted the positive outcome due to the pandemic,

> *"At the moment, we have about 130 women every Monday at the clinic. We have managed to alleviate two hundred deliveries because you can't even manage everyone to be in our booking system. Somehow to achieve just getting a booking system was massive and COVID-19 thankfully helped us with that because we were able to wave the COVID-19 banner and suddenly it happened. I think the clinic itself is a much more happier place"* [IDI 2].

RMMCH serves a 40% migrant population and had a good reputation for not turning people away upon arrival to ensure the patient received care, *"Some clinics refuse to give Road to Health cards to foreigners. In that case, we try and work with the clinic or try to get one from here, it all depends on where they were born"* [IDI 11]. However, with the impact of COVID-19, it caused changes to their booking system and provision of PMTCT,

> *"We have a minimal amount of patients as first visits so what we introduced recently since the beginning of COVID is that all our patients must have made an appointment at the facility they attended before, that facility makes an appointment with our ANC for the patient to come in. The patient cannot just arrive without an appointment"* [IDI 2].

This increased difficulty for women that do not have documentation and are non-SA citizens. They were left to navigate a complex healthcare system and needed to be referred by a local clinic in order to access care.

Space. Healthcare providers described that COVID-19 precautions placed a burden on infrastructural resources for programme components like breastfeeding,

> *"It makes it a lot harder in our unit just simply because we've got a lot of numbers and we like the mothers to be there to breastfeed, so the risk for them was higher because they have to pump in an expressing room and we couldn't have as many people at one time. Also having so many people in the ward, we reached a lot of these shortages with alcohol sanitiser that could have resulted in more infection"* [IDI 3].

Educational training. Educational training that was previously conducted with large numbers of nursing staff had to be stopped during the pandemic because of risk exposure to COVID-19. Frontline nurses became overwhelmed and unfocused with PMTCT components,

"Now with COVID, [. . .] these guidelines had the two month supply of medication, it's not something that's new, since 2015 it has been in the guideline. It is just not implemented as well as it should be. Nurses are concerned about some things with the PMTCT service but they are not always ensuring that mothers get discharged with their medication. They need to be micromanaged to a certain degree" [IDI 4].

Management reinforced that though a pandemic is occurring, it was inexcusable to not follow pre-existing guidelines that were implemented for PMTCT.

7.3.2.3 Affordability: Financial challenges and opportunity costs to receive PMTCT care. Participants expressed that lockdown caused border closures and limited transport, impacting many internal and cross-border migrant patients, who lost their jobs and were unable to endure any opportunity costs to commute to receive treatment.

Lockdown, limited transport, and finances. Transportation during provincial lockdown across SA was a major concern for mobile women, a nurse provided insight, "*with COVID, you couldn't sit in a taxi with many people and it was a lot harder for patients to come because they didn't have the same access that they previously had. If someone had their own transport or had a family member that could transport them, then they would come*" [IDI 11].

An obstetrician indicated that duplication of appointments occurred frequently during the first wave and that migrants could not take time off work or travel from their home countries to keep visiting the facilities repeatedly,

"At one point, when we were initiating a lot then we would initiate the patient, treat the patient and then refer them out to carry on treatment at the local clinic. Then they said no, the patient must collect their treatment at the local clinic and come into us just for antenatal care, which is a huge duplication of visits for these women. I think they must just get their treatment with us while they are pregnant, otherwise it is extra visits for them. The problem is that they don't carry any kind of information and the majority has no idea what drugs they are on [. . .] and they have no documentation [. . .] clinics don't write down which treatment they are on [. . .], that is very poor. They don't put any of the recent bloods or anything so you end up repeating bloods again" [IDI 2].

7.3.2.4 Acceptability: Interpersonal interactions. Participants discussed facilitators and barriers of COVID-19 including; communication, documentation, and mistreatment.

Communication. Protective masks created a barrier for facial expressions and the ability to effectively communicate that could have been prevented otherwise if doctors had more time allocated to migrant patients who required more attention due to language barriers. A participant explained the interaction she had with a woman from Malawi, which provided an example of the increase difficulty with communication due to masks and the inability to speak the local language,

> *"There was a patient who had a hearing difficulty and didn't tell us. Only after some time, we realised that she wasn't understanding any of the counselling because she could only lip read. She would nod and then I would be upset because I was thinking, I explained this to you, why aren't you understanding [. . .]. She had a unsuppressed VL. I wonder if that was more a function of the fact that no doctors ever took time to talk to her and find out what her disability was. Because once we started talking to her, I got her brother's number [. . .], you often go very quickly and you miss something so important. With COVID, I think it just made it harder to consult patients and because you have a lot of people on the ward round, you feel stressed when you've got your mask on"* [IDI 11].

Particularly language barriers contributed to communication gaps for cross-border migrant women that didn't speak any of the local South African languages,

> *"We have a significant amount of foreign patients. The foreign patients are often from Zimbabwe* [and] *Malawi. We get a lot of patients speaking Chichewa and it is very difficult to actually communicate about the testing, the result, the feeding choice, and the adherence. If the patients can speak English, they are usually South African"* [IDI 3].

The barrier of language contributed to patient misunderstanding the importance of why the healthcare providers make the recommendations they do.

Documentation. The hospital remained reputable for providing care to those outside their catchment area, however RMMCH still had to obey laws in SA that required documentation of non-nationals in order to access specific services,

> *"We don't dismiss patients who are not South African. The only time we will ask is when the premature babies require oxygen at home and that is not our law. The company wants us to provide a SA ID [identification] and a residential address, and work permits are not adequate, you have to be a SA citizen. A large proportion of patients are from other countries and we know this because when you're counselling, you ask the persons' home language, it's often a minority language that's Chichewa or Shangaan from Zimbabwe. When we order things like home oxygen for babies who have a chronic*

disease, you cannot give foreign patients. They have to have their papers, either asylum seeker papers or permanent residency [. . .]" [IDI 11].

Turns out if the cross-border migrant does not have these documents, which happens often, then the child must stay at the hospital, *"Unfortunately then the child stays with us. We keep the child and this often happens, you will see children that are five months old, some with oxygen and we just hope that they grow and get off the oxygen"* [IDI 10].

Nurses elaborated on the issue that "foreigners" go to extremes and would lie about their addresses to utilise PMTCT,

"It's foreigners [who] have been turned away so as a result, all of them are flocking to us. Then there is this thing about addresses that they tell you they are living around the area and we don't turn anybody away. If they need our services we are able to give it [. . .] that is the biggest issue we are facing. They use fake addresses, fake IDs and sometimes they don't have an ID. They are illegally in the country and use the sisters' or aunts' ID. It's creating a problem in Gauteng. We don't turn away any patient but other hospitals they do, even if the patient is bleeding or is in labour" [IDI 6].

Mistreatment. Poor staff attitudes and behaviour existed toward cross-border migrants,
"I mean I hear it sometimes, that patients feel they are treated abruptly [. . .] I have seen people being made fun of. I know people complain and I know that there are issues. Yes they have a choice but it appears a lot of treatment is not appreciated [. . .] and it causes a lot of stigmatisation if a pregnant women or mother refuses treatment, that is one thing that can make patients become very isolated in a ward and kind of intolerated by nurses and doctors" [IDI 1].

Participants reported they have seen/heard a "lack of respect" in the work environment,
[IDI 8] "We have a lot of patients outside our catchment area, most of them are non-nationals moving around and their comfortability-it differentiates. You will be comfortable with someone who respects you. I am a healthcare worker but my attitude needs to say I am a healthcare worker, it does not necessarily mean to say that just because I am a healthcare worker I am going to mistreat you too. I think it all needs to go with respect, if I respect you as the patient and communicate with you in a proper way then it is possible" [IDI 8].

Nurses expressed frustration with the gaps in the healthcare system and used rhetoric toward migrants which included "causing drainage of hospital resources" from "those who do not belong there,"

"I think it needs to become a standardised thing so patients need to know that I must either have my ID or passport and if you get strict about it then at some point, those who do not have, are the ones that need to be picked up and shipped back to wherever, because everyone should have some form of documentation. We have been very laxed in terms of checking who is around and which patients are there. I don't want to deny care to anyone but it's not just with healthcare services, it's everywhere. If someone can't produce the documentation then they shouldn't be here, it just drains everything" [IDI 2].

Differences in service provision specifically toward cross-border migrants in comparison to local citizens was discussed with participants,

"As far as I understand, yes- but they may be treated differently and we have to be cognisant of that. A South African patient may be treated better than a non-South African patient because of other people's xenophobia or the stigma they have against patients [. . .] I have seen it quite strongly where I have heard people say to patients why didn't you give this patient this medication. I haven't seen it as strongly here but there is that feeling that patients from another country may be treated bad" [IDI 11].

7.3.2.5 Adaptability: Programme sustainability. Participants discussed facilitators and barriers of programme sustainability to withstand the COVID-19 pandemic for highly mobile migrant users, no matter nationality and legal status which included SDI, technology, and translation.

Same-Day Initiation (SDI). There was an alarming need for migrant patients to spend more time with counsellors because ART initiation occurred at the same time the patients' positive HIV status is disclosed to them. Highly mobile WLWH often struggle to return, decreasing retention in PMTCT care. An OBGYN emphasised,

"I think there needs to be more of a structured counselling approach, maybe some sort of programme that they work through on the visits that they come for, you can't add in any extra visits because its economically a problem as it is for these patients. I think that the linkage is poor between us and the clinics. I don't feel that we have a 100% good relationship, that when we are seeing them out I often feel that we are putting them out into the wild yonder. I don't really get that strong feeling that they are going to the clinics" [IDI 2].

Technology. Healthcare providers were tested with immense virtual changes to maintain safety, *"Everything became online and that was a massive change. I think it was a lot of adaptation. I think everyone did different things to try and still connect"* [IDI 11].

The referral system between clinics benefited from technology, where counsellors could follow-up patients referred out from the hospital to their regional clinics. *"As a region, we have a group chat. I call a clinic, then say, can I please speak to one counsellor and then tell them the patient is referred from RMMCH and that this patient will be coming, she didn't have her medication, can you please give it to her"* [IDI 8, Linkage officer]. Many highly mobile patients missed their follow-up appointments, and still remain a challenge due to the multiple/incorrect contact details provided. Participants suggested having an integrated system to coordinate with other countries for better tracking cross-border migrants could improve LTFU,

> *"If we had this system, it would definitely change things, not just for PMTCT but for everything. You could link for instance, this child was admitted two months ago at a different hospital, their x-rays, blood results, pharmacy scripts, all to one number. From a foreigner point of view, that would require some major coordination with other countries, that if they travel with their booklets and actually write down what they are receiving. Also with patients that thought maybe they were going to go back and fetch their treatment and then something prevents them travelling, so they don't"* [IDI 2].

In addition, staff believed reducing long queues and waiting times and having different access points in which migrants could pick up their ARVs was believed to increase adherence,

> *"I think where patients can pick up their medication from a private pharmacy and don't have to sit in long queues, those are stable. I definitely think that would probably help with adherence. I think the fact that there isn't really good paper trails and it is very difficult to see what people are on, and whether it is their disease, that is what hinders the care. I think it's a reasonable PMTCT programme but it has a bit of a way to go in order to achieve its targets"* [IDI 2].

Translation. Participants believed that many migrant patients on PMTCT have challenges when it comes to taking ownership over their health due to language barriers and the inability to communicate effectively. A doctor explained that when this occurred, they relied on other healthcare staff to assist with translation,

> *"We have learnt over the years that we need to ask them if they have enough medication, if they are running out, or other stuff they are on so we can prescribe and get it, so I think that is a limitation- that some of them are not empowered enough to say what they need. We try to get an interpreter, if we can't get a nurse in the ward to interpret for us because the language barrier may be significant, then we send them to the HIV clinic where there are counsellors, they then counsell the mothers and try to explain and intervene"* [IDI 3].

To overcome language barriers unique to migrants, the Google translation application was used to assist with mothers who did not speak any of the local languages,

> *"I worry that I am going to miss something because I cannot communicate properly with them. Things like Google Translate certainly have helped here and there but certainly [is] not the same as just trying to talk to someone properly and hear their story"* [IDI 2].

7.4 Discussion

7.4.1 Main Findings

In this study, we aimed to explore the barriers of a pandemic on PMTCT provision by healthcare staff to understand what strategies could be implemented with COVID-19 to address challenges with adherence to ART for the highly mobile population to better manage the programme.

Cross-border migrant women were reported to undergo many healthcare user challenges for PMTCT during COVID-19 due to the documentation required to access care and navigate a more complex healthcare system, now amplified by lockdown and border closures.[96,97] The duplication of appointments during the first wave of COVID-19 severely impacted migrants and their mobility leaving many unable to afford opportunity costs to travel from their origin country/province because of border closures and overall maintain their PMTCT care.[98,99]

The pandemic increased the dire need for multi-month medication dispensing to ease access of ARVs for highly mobile patients, and demonstrated that it was possible. COVID-19 has shone light to an already overburdened health-care facility and the existing gaps of a network of referral clinics across Gauteng province. Barriers of documentation, missing reports of VLs, and PCR test results have called for a synchronised plan with the South African government and the NDoH.

Migrant women will only build self-capacity if their trust in the healthcare system is reassured through alleviating stressors such as asylum papers and providing clear and concise messaging- including the importance of adherence to ART while breastfeeding. Education made available in different languages can serve mothers that do not speak the local languages for better understanding of the importance of adherence and risks of non-adherence to their baby, even after delivery.[95,100-102]

RMMCH has provided PMTCT for 40% of highly mobile patients outside the catchment area. Stretching its resources thin proved to be challenging while enduring the pandemic, which led to poor behaviour of staff from the overwhelming patient demand and everchanging work climate of COVID-19.[103,105]

Healthcare providers inability to spend sufficient time counselling and build rapport with migrants who need particular attention due to language barriers, increased the risk of LTFU. Unfortunately, stigma and mistreatment still exists with some healthcare providers toward the migrant HIV population. Immunocompromised HIV migrants remain vulnerable, often feared falling ill from COVID-19, and were unable to receive support at the facility due to capacity restrictions.[94]

Research has emphasised PMTCT lifelong treatment management for patients remains difficult because of inconsistent delivery across clinical departments of counselling and support services for SDI of treatment.[12,18] Strengthening PMTCT must occur on different levels, while many service providers have been known to place the burden of responsibility on the patient, negotiating the patients' health beliefs and values to fit a pre-existing healthcare structure that may often ignore cultural sensitivity.[77]

Therefore, the success of the PMTCT programme is critical for reducing maternal and child mortality and morbidity rates, reducing HIV risk for children, and overall building health awareness and empowerment of women to take control of their health decision-making.[24]

7.4.2 Recommendations

The NDoH PMTCT guidelines do not address the complexities of mobility and healthcare access in high mobility contexts.[55] Better understanding could reduce its challenge of reducing the mother to child transmission rate to less than 5%.'[43,74] Particularly for non-national women who are seen as a politically weak group that has not gained visibility on SA's health policy agenda, and are at an elevated risk of facing inequalities and unfair treatment by healthcare providers when utilising PMTCT healthcare services across Johannesburg.[76]There is a lack of understanding about how provision of PMTCT care in the healthcare environment can be strengthened for migrant women to better support their individualised needs.

COVID-19 alleviated over 200 deliveries in six months for RMMCH with restructuring the booking system of patients. Strategies to strengthen the PMTCT programme gaps with service provision include an integrated electronic database of records or travel book that cross-border migrants could carry with them. These can provide access to patient history within different regions, provinces, or in another South African Development Community (SADC) country and possibly combat lost PCR tests/records, address pharmacy scripts for dispensing and pick-up of ARVs, reduce duplication of appointments and costs for patients to travel, and the demand of healthcare providers.

COVID-19 changed the way staff worked and demonstrated that immense changes could be implemented through technology to alleviate issues with patient demands which included, chatgroups and SMS reminders. Constant and consistent quality improvement to the database at the hospital should be ongoing to reduce LTFU and poor adherence.

To address poor healthcare provider behaviour and attitudes, mental health support through Employee Assistance programming should be provided which includes, training, values clarification workshops, and team building exercises that can be conducted by a third party to mediate management and frontline healthcare providers.[27] There are larger systemic issues at play with xenophobia in the SA healthcare system that need to be addressed through mentoring and interdisciplinary training.[95,18]

In comparison to five years ago, a gap for structured counselling remains with PMTCT programming at RMMCH.[18] The clinical flow with counsellors must allocate time for patients, especially with the implementation of SDI.[96,100,107] Many women are initiated onto ART but there still remains a lack of understanding the importance of adherence after the birth of the baby, especially during the course of breastfeeding.[56,18]

A shuttle or transport service with different pick-up points could be provided by NDoH and RMMCH for highly mobile patients to ease the financial costs of traveling that was amplified for migrants, specifically those with multiple appointments during the pandemic.[24]
Health education was delivered primarily in English, which acted as a double-sword, providers felt that foreigners who do not speak the language, lose out on education. There is a potential to translate and distribute information, education, and communicative (IEC) materials to the larger migrant population attending RMMCH and its referral healthcare facilities.

7.4.3 Strengths and Limitations

This research explored qualitatively healthcare provider experiences of PMTCT in the high mobility context of Johannesburg during COVID-19. Qualitative interviews were conducted with different cadres of staff, this sample is a strength because, despite the small sample size, it has transferability and broad applicability with our results. A limitation is possible self-reported bias from participants, however the strength of self-reported methods is that it allowed participants to both describe their own provision experiences with PMTCT and HIV services in-depth.[101]

7.5 Conclusion

Future studies are needed that explore the patient perspective to better understand if and how the mobility profiles of women who are on the PMTCT programme may have an impact on their utilisation experiences, including their overall ability to adhere to lifelong care.[94] Furthermore, the major task for healthcare providers was to reinstate service delivery of PMTCT without putting themselves or patients at risk of

COVID-19 infection, and the use of technology to alleviate the high burden of patient demand. It is important to take what was learned during the pandemic and integrate it into routine service delivery, which includes long term medication supply to reduce multiple visits to the hospital and overall risk of COVID-19 transmission for HIV pregnant women. Healthcare policies that work toward inclusion and sustainability for migrants are needed to improve the integration of safer and practical methods of PMTCT provision into health systems.

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Author Contributions

Bisnauth and supporting authors conceived of the presented idea. Bisnauth and Vearey developed the theory. Bisnauth conducted data collection and performed the analysis. Vearey verified analytical methods used. All authors supervised the findings of this work. Bisnauth took the lead in writing the manuscript. All authors provided critical feedback and helped shape the research, analysis, and manuscript.

Ethics Approval

The studies involving human participants were reviewed and approved by the Human Research Ethics Committee (HREC) at the University of Witwatersrand, South Africa in 2019. Provincial clearance was obtained by Gauteng Province and The National Health Research Database (NHRD No: GP_201912_003) and the City of Johannesburg. Authorisation from RMMCH was granted to conduct the study in Coronationville (HREC Protocol No: M190816 MED19-07-084). Written informed consent to participate in this study was provided by the participants/participants' legal guardian/next of kin.

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Note

1. RMMCH is a public hospital site associated with high mobility where individuals use PMTCT services outside of their districts and catchment areas. Approximately 25 clinics refer patients to the ANC service at RMMCH, creating a busy maternal health-care environment. The healthcare providers see more than 36 000 outpatients and have more than 12 000 births annually.

LINKAGE

Linking Notes between Chapters 6, 7 and 8 (Papers 1, 2, and 3)

This section contains information to clarify the link between Chapters 6, 7 (Papers 1 and 2) to Chapter 8 (Paper 3). In depth discussions in findings of individual papers are in the discussion sections of each paper, while an overall discussion follows in Chapter 9.

Chapter 7 contained data on the experiences and perspectives of both HCWs that served at both city and provincial levels (Objectives 2) and were involved with the provision of PMTCT services at the state hospital, RMMCH. Chapter 7 explored further in-depth, the perspective of HCWs solely and their provision of PMTCT services to the large number of migrant women that utilise treatment and care at RMMCH, a high mobility context.

In Chapter 8 (Paper 3), the perspectives of the WLWH is further explored. Paper 3 further investigated the different mobility typologies that surfaced from the data. Paper 3 stands as a contribution that challenges the popular notion in literature that often uses citizenship, nationality and the simple ownership of documents to predetermine migrant categories, by analysing different compositional, contextual, and collective characteristics. The development of the typologies brings together a nexus of migration and health, where factors and variables of migrant status, geography, temporality, socio-demographic status, motivations/causal classifications and clinical characteristics intersect. This analysis included the six categorical areas and its associated variables (Chapter 4, Table 4.1) that were involved in the development of the migrant typologies and to help draw similarities and differences between these WLWH, as PMTCT service users.

Chapter 8 not only aims to identify these typologies (Objective 3) but explored how belonging to a specific mobility typology may have affected the healthcare received and, the individuals' overall experience during the COVID-19 pandemic.

Paper 3 also addresses Objective 4, to qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

It is important to note that the data collected for Chapters 7 and 8 (Paper 2 and 3) occurred during the COVID-19 pandemic. Therefore, the PMTCT service provision and utilisation involves the aspects of both

mobility and migrant typologies, as well as the COVID-19 impact on the provision and use of these services.

CHAPTER EIGHT: PAPER THREE

Paper 3: Bisnauth MA, Coovadia A, Kawonga M, Vearey J. Addressing the migrant gap: maternal healthcare perspectives on utilising prevention of mother to child transmission (PMTCT) services during the COVID-19 pandemic, South Africa. Global Health Action. 2022 Dec 31;15(1):2100602 (published). Impact factor 3.0.

Bisnauth– 80% (conceptualisation, data curation, formal analysis, investigation, project administration, resources, supervision, wrote manuscript, reviewed and edited manuscript, finalised manuscript)
Coovadia- 5% (conceptualisation, data curation, investigation, project administration, resources, supervision, reviewed and edited manuscript);
Kawonga- 5% (conceptualisation, supervision);
Vearey- 10% (conceptualisation, analysis, supervision, reviewed and edited manuscript).

At the time of this thesis submission, Paper 3 was published as an original article in the *Global Health Action, Taylor and Francis Journal.* For the purposes of this thesis, figures and tables as well as their captions have been placed in the appropriate places within the text of the article and general formatting is aligned with the requirements of the specific journal.

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Addressing the migrant gap: maternal healthcare perspectives on utilising prevention of mother to child transmission (PMTCT) services during the COVID-19 pandemic, South Africa

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ABSTRACT

Background: The COVID-19 pandemic has interrupted the prevention of mother-to-child transmission of HIV (PMTCT) programming in South Africa. In 2020, it was estimated that there were 4 million cross-border migrants in South Africa, some of whom are women living with HIV (WLWH), who are highly mobile and located within peripheral and urban areas of Johannesburg. Little is known about the mobility typologies of these women associated with different movement patterns, the impact of the COVID-19 pandemic on mobility typologies of women utilising PMTCT services and on how changes to services might have affected adherence.

Objective: To qualitatively explore experiences of different mobility typologies of migrant women utilising PMTCT services in a high mobility context of Johannesburg and how belonging to a specific typology might have affected the health care received and their overall experiences during the COVID-19 pandemic.

Methods: Qualitative semi-structured interviews with 40 pregnant migrant WLWH were conducted from June 2020-June 2021. Participants were recruited through purposive sampling at a public hospital in Johannesburg. A thematic approach was used to analyse interviews.

Results: Forty interviews were conducted with 22 cross-border and 18 internal migrants. Women in cross-border migration patterns compared to interprovincial and intraregional mobility experienced barriers of documentation, language availability, mistreatment, education and counselling. Due to border closures, they were unable to receive ART interrupting adherence and relied on SMS reminders to adhere to ART during the pandemic. All 40 women struggled to understand the importance of adherence because of the lack of infrastructure to support social distancing protocols and to provide PMTCT education.

Conclusions: COVID-19 amplified existing challenges for cross-border migrant women to utilise PMTCT services. Future pandemic preparedness should be addressed with differentiated service delivery including multi-month dispensing of ARVs, virtual educational care, and language-sensitive information, responsive to the needs of mobile women to alleviate the burden on the healthcare system.

8.1 Background

The COVID-19 pandemic has presented challenges for South Africa (SA) to further eradicate HIV/AIDS and reach the UNAIDS 90–90-90 targets.[43] Although SA has the largest number of people enrolled on an ART programme, there has been an increased number of people living with HIV (PLWHIV), which has increased by 4.4 million from 2002 to 2021.[103-106] A greater concern remains about the impact of COVID-19 on PLWHIV due to 'immunosuppression', 'multi-morbidities', and 'higher mortality' risks, especially for vulnerable populations including pregnant women living with HIV (WLWH).[106]

Data suggest that only three months of HIV Prevention of Mother-to-Child Transmission (PMTCT) service disruption could result in new HIV infections spiking by as much as 53% for children up to 15 years old.[98] PMTCT typically entails women as healthcare users having access to services such as antenatal clinical care (ANC), HIV counselling and testing (HCT), antiretroviral treatment (ART), education on safe delivery and infant feeding, follow-up HIV testing at a 7-day postnatal visit, family planning, and lifelong ART.[18,55] PMTCT using ART is a proven, effective intervention and can reduce vertical HIV transmission to less than 2%.[18,55]

A standardised approach remains challenging due to pre-existent structural and organisational factors that play into the provision of care. [18,26,55] In addition, the impact of the pandemic on HIV prevention for women is likely to be disproportionately high, as women bear the brunt of the HIV prevention service gaps.[98]

Research shows that the COVID-19 pandemic interrupted HIV services, but the extent to which PMTCT access, treatment, and service delivery were impacted in SA remains unknown.[106-108]

8.1.1 COVID-19 Impact: Migration and WLWH

In March 2020, the World Health Organisation (WHO) declared COVID-19 a pandemic and SA restrictions resulted in a lockdown and international border closures that limited the movement of individuals.[98,106] As the spread of COVID-19 continues across SA, the most populous province of Gauteng consisting of 16 million people, of whom 13.7% are HIV-positive and a fourth of whom are migrant women in the reproductive ages of 15–49 years, have contributed to 1.2 million SARS-CoV-2 cases.[106,108]

In 2020, the International Organisation of Migration (IOM) estimated that there were 4 million cross-border and internal migrants.[3,20,106-108] Cross-border migrants are defined as individuals who move from one country to another, and internal migrants are defined as individuals who transcend borders within a country. This includes an individual who moves within Gauteng but across the City of Johannesburg (CoJ) border in SA.

Statistics of SA suggests that approximately 60% of the migrant population is concentrated within the urban areas of SA, 32% are internal migrant women, and only 8% are cross-border migrants, many of whom are WLWH and who are highly mobile.[20,106-108] Highly mobile refers to an individual located within the peripheral and urban areas of the CoJ contributing to intraregional, interprovincial and/or cross-border migration patterns. Intraregional migration consists of individuals who move between the seven regional borders within Johannesburg, and interprovincial migration refers to individuals who move between the nine provinces of SA.[20,106-107]

The impact of cross-border migration on healthcare systems during the COVID-19 pandemic is little understood but remains a highly political issue for SA as a recipient country.[106] Migration disrupts access to healthcare, posing significant risks for WLWH, including cross-border migrants, especially during lockdown and border closure periods.[94] Cross-border and interprovincial migrants are often unable to access healthcare services in SA due to the requirements of documentation. This has placed restrictions on their freedom of mobility and calls for governments' own COVID-19 prevention strategies, both at provincial and national levels.[94] Migrant WLWH should be seen as a high-risk group and be advocated for when it comes to promoting respect and equal access to healthcare, especially for those without documentation.[16]

After the establishment of the Border Management Act, the 2017 White Paper on International Migration had a vision that 'South Africans must embrace internal migration for development while guarding sovereignty, peace, and security'.[16,32] Despite these data and existing evidence on the diverse population movements within SA, the public healthcare system, on whom most of the population relies, has struggled to consider mobility or migration.[94,16] The SA constitution indicates the right to access healthcare for all who live in the country, and the nation's health policy provides free primary healthcare access for all, with no mention of nationality and legal status. However, the interpretation of legislation remains less inclusive in its practice and the constitutional right to healthcare is often ignored.[16]

Research suggests that mistreatment including xenophobic attitudes and practices by healthcare workers (HCWs) can impact provision and access to care for individuals based purely on their identity as a 'non-national,' also known as a non-South African citizen.[16,109]Studies provide examples of declining 'non-nationals' entrance into healthcare facilities and service providers placing 'non-nationals' in a longer queue.[16–18,26] 'Non-nationals' are often unable to receive the best care available because of the presumption of an increased burden they place on the SA public healthcare system.[25,26,109]

Many cross-border migrant women do not have access to healthcare due to stigma, and are fearful of being asked for documentation and deportation.[25-27,109] The pandemic has added a layer to the pre-existent structural discrimination that has largely influenced health-seeking behaviours and social exclusion of both internal and cross-border migrant women within healthcare facilities.[20] Cross-border migrant women utilising PMTCT services face many of these barriers that disrupt their ability to adhere to medication and treatment for chronic diseases such as HIV, which requires long-term discipline.[94,109]

An increased HIV disease burden is occurring across the country, and its relationship with migrants is complex and contested.[35,99] Migration is a continuous, repeated process rather than a single event, and therefore, the timing of migration in relation to past migration is significant; the first time an individual migrates, for example, leaving a family home, is very different from subsequent migrations and may be linked to different HIV risk exposure.[22,35]

A migrant gap exists with policy and practices of PMTCT service provision and incorporation of highly mobile WLWH as users in SA, during the pandemic.[106]

8.1.2 Utilisation Experiences of PMTCT

Although the PMTCT cascade represents a complex system of sequential, interdependent steps that WLWH navigate as healthcare users to receive appropriate care and treatment for themselves and their newborns,

the National Department of Health's PMTCT guidelines do not address the complexities of mobility and healthcare access for these women in high mobility contexts.[3,20,55] The vulnerability must be acknowledged when looking at risk factors of acquiring HIV both as a highly mobile migrant and as a woman.[96,25] WLWH and their interactions with the healthcare system may very well differentiate from each other due to different variables (e.g. valid documentation, HIV status, place of residence, and/ or languages spoken).[94,96,25] It is crucial in understanding that this process does not allude to one story but many different processes and experiences for the individual.[9,35]

Studies on migration and health have focused mostly on defining migrants in the dichotomy of non-nationals versus nationals, where methodologies have used nationality and the ownership of citizenship and documentation to predetermine categories of migrants. [9,35,107] Research has shown that human behaviour commonly groups people into categories with the aim of making sense of the environment we live in.[35] However, the risk is that these 'groups', based on citizenship/documentation, become 'single stories' that give incomplete and simplistic understandings of the identities of others.[9,97,107] Instead, research to understand the influence of population movement on healthcare systems should consider the complexities of migration.[36]

It is important to recognise that mobile populations may be categorised into more nuanced typologies with different compositional, contextual, and collective characteristics that may contribute to their healthcare experiences.[9,16,35,107] For example, typologies may include nationals who are non-national permanent residents, where an individuals' place of birth is outside SA but they reside 5 or more years within SA, displaced individuals also known as someone who is forced to leave their home of habitual residence due to conflict but found safety internally in their own country of SA, and asylum seekers - defined as individuals who left their home country as a political refugee and is seeking asylum in SA.[16,22] Asylum seekers may have refugee status and are allowed to work in SA, and migrants with or without documentation such as no form of identification (ID), including a passport and/or ID card.[16,22] Research suggests that cross-border and internal migrants including interprovincial and intraregional sub-categories are relevant to the context of this research because of the vast movements that occur within the urban and peripheral areas of CoJ and Gauteng province.[16,35] However, by pre-determining typologies of migrants, it limits the ability to understand how migration and mobility patterns affect healthcare user experiences.

A literature gap exists, highlighting the need for a better understanding of different typologies of women and their experiences utilising healthcare in a high mobility context, the impacts of migrant status on their access to PMTCT healthcare, and their overall ability to adhere to lifelong care during the pandemic. This research aimed to qualitatively explore these experiences of different mobility typologies of migrant women

utilising PMTCT services at a public hospital in CoJ and how belonging to a specific typology might have affected the healthcare received and, their overall utilisation experience during the COVID-19 pandemic.

8.2 Methods

8.2.1 Study Site

Rahima Moosa Mother and Child Hospital (RMMCH) is a public hospital that provides PMTCT services in Coronationville and western Johannesburg catchment areas in Region B (Figure 1).[17,18] Region B is often associated with more developed areas and suburbs, but this is not the case in Coronationville, where vast patterns of migration occur.[17,18] In the early 1990s, Coronationville experienced rapid urbanisation, resulting in the establishment of informal settlements.[17,18] Coronationville has a population of 7348 people, comprised of 2500 people, of whom 60.8% are females living in informal settlements. [17,18] Forty-four percent of its entire population is unemployed, of whom 68% are internal migrants. [17,18]

In 2015, RMMCH was the first to implement PMTCT lifelong treatment. RMMCH is a site associated with high mobility and different migration patterns in Gauteng, where many WLWH use services outside of their districts/catchment areas and it informs the conditions for applicability to the broader migrant population in SA. Approximately 25 clinics refer patients to the ANC, no matter their nationality or legal status, and 87% of women using the ANC and post-natal care (PNC) are recorded as non-SA citizens. It is a busy maternal healthcare environment where HCWs see more than 36,000 outpatients and more than 12,000 births annually.[18] RMMCH had adopted the national guidelines for PMTCT lifelong treatment and was in its monitoring stage, providing a platform to analyse different mobility typologies and migrant experiences in the programme during the pandemic.

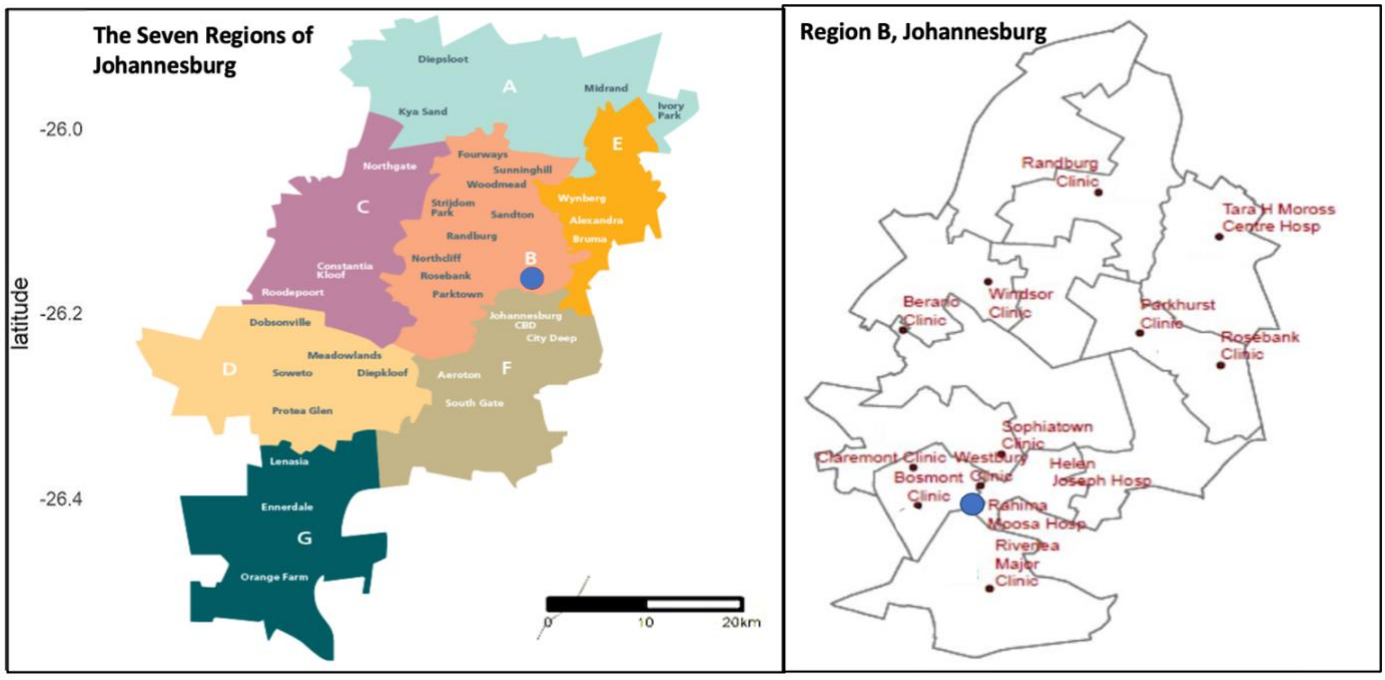


Figure 1. Regional map, Region B, Rahima Moosa Mother and Child Hospital

8.2.2 Study Design

Data were collected for 13 months (June 2020-June 2021) during the COVID-19 pandemic. This qualitative study consisted of 40 semi-structured interviews where data saturation was reached.[103] Interviews uncovered WLWH and their experiences utilising PMTCT services at RMMCH. Typologies were used to specifically analyse different migrant WLWH and their movement patterns, referred to as *mobility* typologies.[16] The different mobility typologies that surfaced and how belonging to a specific typology may have affected the healthcare received were examined. To avoid narrow conceptualisations of migrants, the wide range of typologies occurred was identified, where different classifications assigned to the participants based on socio-demographics, clinical characteristics, and their overall experiences shared in the utilisation of PMTCT services were used.

8.2.3 Study Recruitment

Study participants were recruited from the ANC. Participants had to be of the reproductive age of 18 years or older, HIV-positive, pregnant, newly delivered, or in post-natal follow-up. WLWH had to be enrolled in the PMTCT service and already initiated onto ART at RMMCH to be eligible for inclusion. Participants were not excluded based on language, and a translator was used on-site. WLWH were initially identified and asked by the nurse if they would like to participate in the study on a voluntary basis when conducting their follow-up assessments. If the individual woman agreed, they were referred to the research assistant/translator and PI in a private room within the ANC. The names and contact details of those who

agreed were then shared with the research team. Participants were provided the study information. Approximately 35 women were approached but declined, mainly due to the peak of the second wave of COVID-19. These individuals were concerned with staying longer at the hospital because of the risk of contracting SARS-CoV-2.

8.2.4 Data Collection and Management

A purposive sample approach was used to recruit patient participants on PMTCT at RMMCH.[103] Due to the hospital regulations and the implementation of COVID-19 protocols and procedures, data collection was delayed because of the lack of space to follow social distancing protocols in the hospital. A tent was set up outside the ANC to provide a ventilated area for patients to sit and wait until their number was called to enter the facility to receive their care. The recruitment of participants had to be adjusted for the first 2 months because potential participants would have to return outside or move to another area of the hospital to complete the interview process to maintain confidentiality.

Those who provided consent then completed an in-depth interview (IDI) in a private room. This research on sensitive migrant/WLWH participants ensured the protection of human subjects, and a distress protocol was followed for participants who became distressed by the nature of telling their story. An interview guide was informed by the conceptual framework and was used to collect data on 1) migrant status, 2) geography, 3) mobility history/temporality, 4) motivations/casual classifications, 5) socio-demographics, and 6) users clinical characteristics. [36,73,76,97,101,]

Interviews were audio-recorded and conducted in Tswana, Sotho, Zulu and Xhosa, Shona, Ndebele, Tumbuku, Changana, Chichewa, Afrikaans, and English and then were transcribed verbatim by one research assistant/translator and 1–2 interviewer(s). One counsellor who spoke Chichewa fluently only assisted the translator in Chichewa interviews if the participant struggled to communicate at times.

To ensure participant confidentiality and anonymity, all results were aggregated and assigned a unique identification number that only the PI had access to, to ensure that participant responses could not be linked to them.[103]

Demographic information, observations of participant behaviour, and journal memos were entered into NVivo 12.0 (QSR International Pty Ltd., 2018). To explore any preconceived notions from the research team, interviews used reflective journaling as an opportunity to engage with the data collected and daily journal entries more critically to enhance authenticity and learn from past experiences of the research process and findings.[76,103] Memos and journaling were used to maintain a process log, capture any

observations, and maintain a record of analytic decisions throughout data collection and analysis between the research team.[76,103]

8.2.5 Conceptual Framework for Exploring Utilisation of PMTCT Healthcare Services

The utilisation of PMTCT healthcare services conceptual framework (Figure 2) was developed to provide guidance in exploring utilisation experiences of PMTCT and migration in a high mobility context.[18,24, 73, 101]

McIntyre et al.'s Accessibility framework informed this framework, highlighting that by using 'access' as a concept, this would not include those migrants who have not accessed PMTCT services for comparison.[18,73] Utilisation is defined as the WLWH experiences/perceptions of their interactions with the PMTCT programme components and to the service providers within a high mobility context.[73] The framework was applied to explore accessibility and adherence barriers and facilitators in relation to PMTCT services and how the individual story of migration, and the mobility typology, has impacted their overall healthcare experience. The concept of utilisation is made up of 1) *adherence* issues to the programme and 2) *access* composed of four dimensions: *availability*, *affordability*, *acceptability*, and *adaptability*.[18,73] Adherence is conceptualised as the long-term ability of these different women to follow the PMTCT programme including taking medication routinely, not missing dosages and attending follow-up appointments. Accessibility refers to the equality and equity of PMTCT care in the healthcare facilities these women utilise, no matter their nationality and legal status.[18,73] Availability dissects the factors such as the range of maternal healthcare and PMTCT services relative to the need. This includes the hours of operation, ARV supply, and willingness of service provider to provide information in a demanding clinical environment.[18,73] Affordability refers to both the financial costs, which include transport, medicine charges, diagnostic tests, and childcare costs, and the opportunity costs, which refer to the time a woman can afford to take time from work to get to the hospital to receive PMTCT services.[18,73] Acceptability refers to whether the expectations of the women are met, including age, gender, race, ethnicity of provider, decision-making, and whether culturally appropriate services (e.g. multi- lingual counselling) are offered.[18,73] Acceptability also includes the woman's non-medical expectations of HCWs' treatment, dignity, and respect of their culture.[18,73] Adaptability refers to the sustainability and scalability of the PMTCT programme for all women, no matter their nationality and legal status.[18,73]

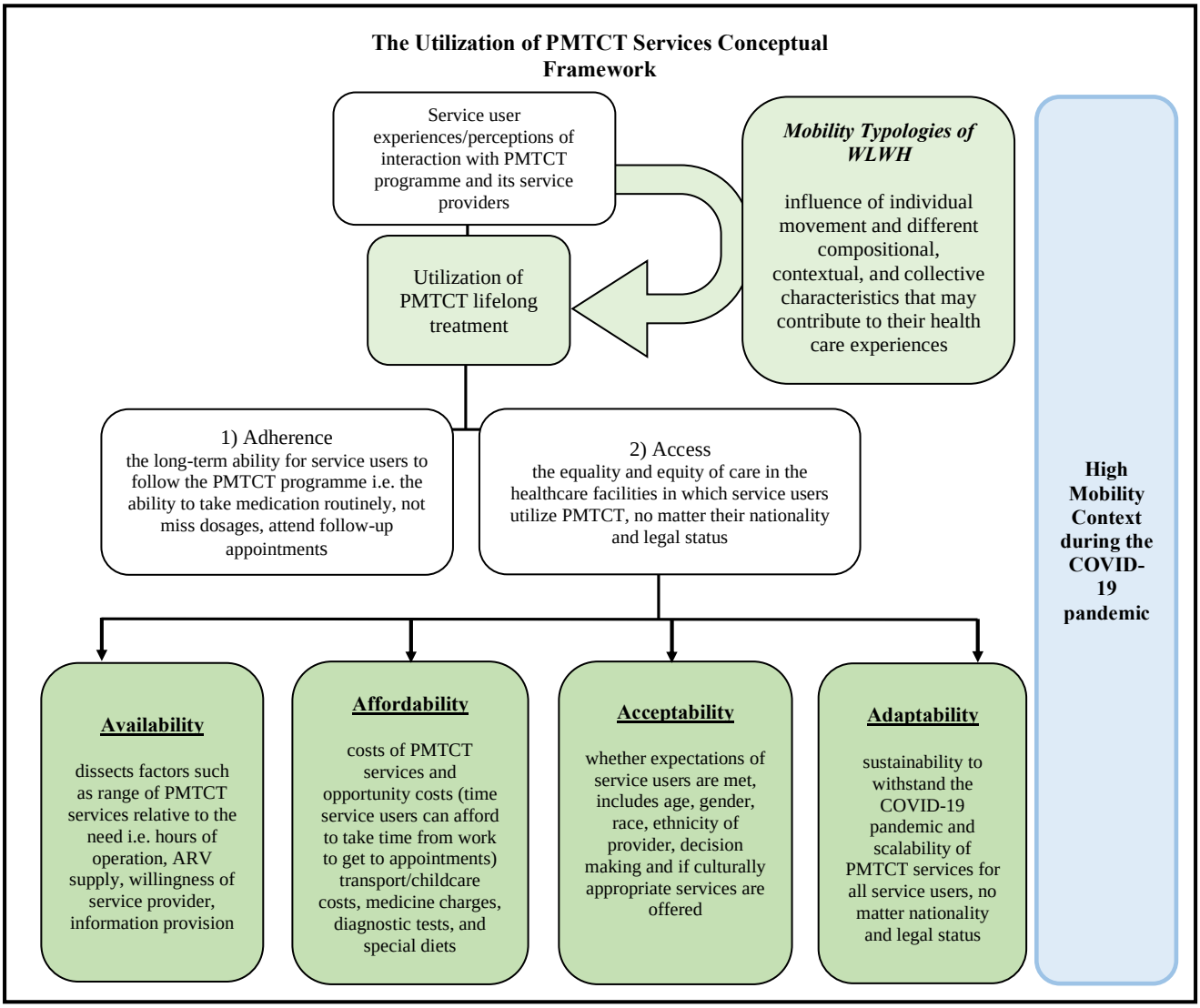


Figure 2. The utilisation of Prevention of Mother-to-Child Transmission Services conceptual framework

8.2.6 Analysis

Data were compared to draw similarities and differences amongst participants.[24,73,76,97,101,103] First, the dimensions of adherence and access were used to dissect and draw relationships to each of the participants' experiences. The typologies of migrants that surfaced were grouped based on their experiences that were similar or different. Second, the data on 1) migrant status, 2) geography, 3) mobility history/temporality, 4) motivations/casual classifications, 5) socio- demographics, and 6) users' clinical characteristics were analysed to help guide and categorise the different typologies that arose. Typologies are different classifications assigned to the participants based on the six categorical variables (Table 1) that provided a profile for the participant to draw further relations with the participants' utilisation experiences of PMTCT services.[36]

Table 1. Examples of the factors/variables involved in the development of migrant typologies

Categorical Area	Factors/Variables
Migrant Status	Nationality, documentation status, asylum seeker, refugee status, displaced persons, job-seeker, migrant-worker
Geography	Rural to urban migrants, intra-urban migration, inter-regional migration, internal migration, cross-border migration, return migration
Temporality	Time in transit, frequency of trips (weekly/monthly commuting), seasonal migration, contractual migration, short-term migration, location of facilities visited
Socio-demographic status	Age of patient, family structure, household income, employment status, and education level
Motivations/causal classifications	Job seeking, family reunification, asylum seeking, refugee resettlement, delivery of baby, studies
Clinical characteristics	Year of HIV diagnosis, attendance rate/number of healthcare facility visits, duration on PMTCT lifelong treatment, date of delivery, and outcome of baby (HIV status)

A thematic analysis was used to analyse the semi-structured interview transcripts to examine and identify common themes, topics, ideas, and patterns of meaning that were repetitive.[73, 76,97,101,103] Interviews were approximately 25–35 minutes.

The process of analysis began with open coding directly from the data.[73, 76,97,101,103] Codes were grouped into sub-themes that emerged from the data and then organised into the themes of adherence and the four dimensions of accessibility. Two researchers in the team coded individually. The consensus was reached at the third version of the coding scheme among three researchers in the team. The categories were reduced to identify key themes. Any commonalities and differences between utilisation experiences across WLWH were noted. Triangulation of data was used to ensure that different experiences of study participants were presented.[73, 76,97,101,103]

Descriptive statistics were reported for the demographics of the participants, including frequencies and proportions for categorical variables using Stata 14.[73, 76,97,101,103]

8.3 Results

8.3.1 Demographics and Characteristics

Forty interviews were conducted with WLWH, between 20 and 42 years old. Participants consisted of 22 cross-border and 18 internal migrants (11 interprovincial and 7 intraregional migrants). Of the 40 participants, 17 were non-national permanent residents, 2 sought asylum, 2 were without an address and displaced, and 4 women were without a valid passport or ID card (Table 2). The duration on ART ranged from 1 week to 20 years for participants, many of whom initiated ART at the clinic with the same-day initiation (SDI) policy. The duration of pregnancy ranged from 6 weeks to 8.5 months.

Table 2. Demographics of participants

Variable (number of responses)	**Sub-category**	**Frequency**
Mobility Typologies (40)	Cross-border	22
	Internal	18
	Interprovincial	11
	Intraregional	7
	Non-national permanent residents	17
	Asylum seeker	2
	Displaced individuals	2
	Individuals without (form of identification: passport, ID card)	4
Age years (40)	18-24	6
	25-35	23
	36-45	11
Highest level of education (40)	Primary to Grade 7	23
	Grade 8-10	3
	Grade 11	8
	Matric/Grade 12	3
	Higher education	2
	Certificate programme	1
Occupation (40)	Employed	14
	Self-employed	3
	Temporary employment	2
	Unemployed	20
	Missing	1
Marital status (40)	Married	14
	Engaged	1
	Single	5
	Co-dependent/living with partner	19
	Missing	1
Number of dependents (not including current pregnancy) (40)	0	11
	1	13
	2	11
	3	4
	>3	1
Place of birth (40)	Other province in SA	11
	In Johannesburg	4
	In Gauteng but outside Johannesburg	3
	Zimbabwe	19
	Malawi	2
	Mozambique	1
Residing (40)	With family in Johannesburg	4
	With partner in Johannesburg	33
	Single household	3

Most women (22) were from another country, including Zimbabwe, Malawi, and Mozambique, and spoke a beginner level of English. Eighteen of these participants preferred to conduct the interview in Shona, Ndebele, Sotho, and Chichewa. Interprovincial and intraregional participants primarily spoke Zulu. Three women presented with high-risk complications including blood pressure, previous miscarriages,

and/or ectopic pregnancy. The relationship a participant had with the ANC differentiated, ranging from first visits, follow- ups, and delivering a second/third child at RMMCH.

The utilisation of PMTCT framework included (1) adherence and (2) the four dimensions of access: availability, affordability, acceptability, and adaptability, which were used to organise subthemes derived from the IDIs (Table 3).

Table 3. Themes and subthemes

	Themes	**Subthemes**
Adherence	Facilitators and barriers for adherence to PMTCT services	Solely for health of baby
		Treatment interruption: Relocation Side effects
		Fear
Access		
Availability	Clinical environment for service users	Space
		PMTCT education and counselling
Affordability	Financial constraints and opportunity costs to receive PMTCT care	Job loss in lockdown
		Documentation
Acceptability	Interpersonal interactions (between healthcare users and PMTCT service providers)	Mistreatment
Adaptability	Services for different movement patterns	Same day initiation (SDI)
		Differentiated service delivery (DSD) -Individualised approach

8.3.2 Adherence: Facilitators and Barriers for Adherence to PMTCT Services

The adherence theme was composed of the sub-themes, ‘solely for health of the baby’, ‘treatment interruption: relocation and side effects’, and ‘fear’.

Solely for health of baby

All participants, no matter their nationality, were asked, ‘why do you take your treatment?’ All women responded that their main driving factor for adhering to ART was their concern solely over the outcome of their baby. Nothing else mattered in comparison to the babies’ health because they had lived with HIV so far and survived challenging life circumstances.

Most interprovincial migrants did not know about the PMTCT programme in great detail and under stood it as simply taking ARVs, to allow them to breastfeed their baby. A 26-year-old interprovincial migrant, who resided for nine years in Johannesburg, understood it as, "*If you're HIV positive, you have to take medication and do exclusive feeding. You shouldn't do breastfeeding because the child shouldn't be exposed to cracks. You are to give the child medication for a recommended period of at least six months"* [IDI 1].

A 42-year-old interprovincial migrant with primary-level education emphasised the need for practical education from adherence counsellors to become better informed that PMTCT went beyond just taking pills,

> *"They told me that I have four options, but they didn't tell me practically what that looked like . . . I need [to] not keep my struggle a secret knowing that somebody might help me if only I open up [. . .] I'm told that my body needs to acclimatise to taking the pills"* [IDI 21].

Geographic mobility and COVID-19 seemed to have a greater impact on adherence for cross-border migrant women. They were concerned with the risk of pregnancy complications because of the restrictions to enter borders and receive care during the lockdown.

Cross-border migrants who had previous births were aware of their HIV status and adhered to ARVs. However, most felt they were left in the dark, a Zimbabwean woman who travelled to and from SA for the past 6 years stated,

> *"You know when they do something, they just write on the paper. You go to the doctor and they write [something] down and when I get out, I then just see that they wrote something, but I don't know what it means. I want to know with these tablets that I am taking if the viral load going up or going down"* [IDI 28].

Interestingly, very few South African nationals who spoke local languages of Zulu and Sotho understood the high risk of the new-borns' exposure in comparison with cross-border migrants who received adherence counselling in another country outside SA. This indicated that more work needed to be done with the education component of the programme and supplying ARVs is not enough.

Treatment interruption: relocation and side effects

The commonest reasons for interruption of ART for cross-border migrants were relocation, running out of ARVs, and the adverse side effects of ARVs. A shy 20-year-old from Zimbabwe who arrived a year ago

found out about her status on the same day as her pregnancy. She expressed her concerns about running out of medication, *"I am five months pregnant now. I arrived in Johannesburg and live with my boyfriend [. . .] I have only been on treatment for four months and I just know I have to have enough to take mine all the time and [I] worry"* [IDI 22].

When compared to SA nationals, cross-border migrants reported more difficulty in understanding ARV side effects and medication dosages. A single 30-year-old from Zimbabwe on ART for 36 weeks explained, *"The one in a blue bottle doesn't make me sleep, it makes me have hallucinations. Sometimes when I sleep, I'll be having nightmares but I think it's because of the medication"* [IDI 40]. A nonnational permanent resident from Zimbabwe, married with two dependents in Zimbabwe, explained that she only understood dosages by speaking to a peer in her community of Zimbabwe, *"They* [HCWs] *just write and then I take it to the pharmacy [. . .] This lady told me that I have to drink them at night before I sleep. Then I ask[ed], how am I supposed to do that? She said, that's how it's supposed to be, you take them at 8 o'clock and then go to bed"* [IDI 29]. She was able to identify collectively with another WLWH from her country of origin and better understand the importance of adherence.

Cross-border migrants also relied on short message service (SMS) reminders and in mobile applications to improve their adherence to PMTCT care during COVID-19, *"On the phone, they put this app "MomConnect," which reminds us of if we have any hospital visits and how you should take care of yourself when the child is about to come"*[IDI 32].

Fear

Interprovincial migrants felt fear surrounding them in the healthcare environment. A 25-year-old from Mpumalanga explained,

> *"There are healthcare spaces where we are not permitted to enter because of the fear around COVID-19. I'm actually from a COVID-19 ward [. . .] I was discharged because my results said that I was negative. People are ill in that ward, some are pregnant [. . .] They don't mix them, the ones that are positive"* [IDI 6].

Many interprovincial migrants interrupted their adherence to ART and appointments because of their 'fear' of contracting COVID-19 when picking up their medication from the ANC. Fear was amplified by cross-border migrants receiving care. Specifically, these women expressed fear of contracting COVID-19 because of their distrust in the ability of the hospital to follow regulations. A non-national permanent resident from

Zimbabwe, married with six dependents, expressed her fear towards HCWs that were not following sanitary protocol measures when collecting her ARVs,

> *"To be honest, I'm not comfortable because I am checking for this Coronavirus when I'm coming in. They say I must be checked [and] put on a mask. I follow those instructions because I need the service from the hospital. But once I get in, I'll find some of the staff who are not following those regulations [. . .] They [nurses] were not even changing the linen. If someone just comes out, they will just take another patient in [. . .] to me I feel like I'm in a red-hot zone because I don't know how safe I am. It [COVID-19] doesn't affect other people and selects others"* [IDI 34].

She referred to being in a 'red-hot zone' as alarming and assessed these implications as a high risk for her to contract SARS-CoV-2, in what was supposed to be a safe hospital environment where precautionary measures are taken to provide the best possible care.

8.3.3 Availability: Clinical Environment for Service Users

Participants discussed the healthcare environment during COVID-19 including 'space' and 'PMTCT education and counselling'.

Space

There was a lack of consultation rooms because of social distancing and changes made to the hospital regulations. An intraregional migrant from CoJ was turned away from care,

> "*I gave them a call about my problem, and they replied by telling me that they don't have sufficient consultation rooms and that's caused this unfortunate situation. There's nothing I can do, it means whenever I have to go that side, I'll find that place as it is. Nothing is going to change"* [IDI 18].

Intraregional and interprovincial migrants were turned away from care and were unable to complete their appointments at local clinics because of a lack of equipment and human resources to do their follow-up testing during COVID-19. A 36-year-old interprovincial migrant from KwaZulu-Natal expressed her

frustration, *"clinics are small in size and do not have sufficient equipment and don't have doctors to cater for bigger needs"* [IDI 7].

Sanitary space was the main concern expressed by cross-border participants because if they were to contract COVID-19, the consequences would be more severe as a 'foreigner who could not be with their child' as the primary caregiver in Johannesburg.

Women who tested positive for COVID-19 were admitted to RMMCH if they have a high-risk complication,

> *"I had Coronavirus. I was admitted for two weeks due to my high blood pressure [. . .] they told me to continue getting medical [treatment] here. I think that's where many people with weak immune systems lose the battle against COVID-19. That's why you can't breathe because it chokes you. I'm pregnant and throwing up. I stay alone. I spent two weeks here and went to self-isolate for another two weeks"* [IDI 1].

Many cross-border, interprovincial, and displaced migrants were completely alone in Johannesburg and needed support, while their partner is working elsewhere or their families are back 'home'. *Home* was often associated with the location of their loved ones. Therefore, having a space and medical equipment available, which followed social distancing and sanitation guidelines, remained a crucial need for cross-border and displaced migrants- who have nowhere else to go. They depend heavily on the SA healthcare system to be able to withstand any pregnancy complications during COVID-19.

PMTCT education and counselling

All women, no matter their mobility history/temporality, suggested that the educational component of PMTCT could be improved. Many interprovincial and intraregional migrants were referred to RMMCH from clinics where they received most (if any) counselling and communicated that long waiting times could be taken as an opportunity to help educate women.

> *"The experience here is good in terms of checking the child since they have free sonars [. . .] but education wise they don't teach you anything. In Mpumalanga, when they give you medication like chronic tablets, they teach you how you should take it. Mind you a first-time pregnant woman will make mistakes because she doesn't know anything related to her medication. I wish that while we're waiting for the doctors to call us [. . .] there may be people who are designated to educate us about this programme, doing presentations. They should do it the whole day. Even if they do a repetition, it shouldn't be a problem because there are always new patients who come here"* [IDI 1].

Interprovincial migrants communicated that continuous education and knowledge sharing are ways to build their self-capacity and be able to prevent HIV transmission in their communities, *"Yes, I would like to know more so that I can inform another woman in the same situation as mine"* [IDI 10].

Some internal migrants received more information outside Johannesburg, *"I once did an auxiliary programme, I first heard about it there. I also heard about it during my first pregnancy at the clinic in Mpumalanga. Here, they never told me anything about this programme"* [IDI 19]. Emphasis was also placed on the distribution of PMTCT education to intraregional rural communities for those who do not have the same modes of availability as others who live in the city. A mother who arrived in CoJ seventeen years ago, and spent 5 months on ART, conveyed the importance of knowledge translation with COVID-19 and being immunocompromised,

> *"[. . .] because a lot of people who live in the rural areas are still behind in terms of access to information. Those living in Gauteng are better off because of some knowledge they receive from watching television. On the other hand, people living in rural areas do not have TVs, or radios, and do not have people who sit them down and educate them about the reality of this virus. A lot of people die out of ignorance"* [IDI 7].

Due to border closures, cross-border migrants seemed to have more difficulty in navigating the healthcare information received from both their country of origin and CoJ, *"When I had my first child I was scared. I didn't breastfeed so I want to know how I'm going to cope. Is it high risk or? I want to know because last time I didn't ask"* [IDI 30]. These WLWH needed to be equipped particularly with information on breastfeeding, which was a reoccurring topic. Breastfeeding created confusion with mixed messages received from different information sources such as healthcare professionals, media, and social networks.

However, two asylum seekers arrived in CoJ a few years ago and expressed a difference in opinion. They found that the information on PMTCT was very sufficient in comparison to the counselling they had received elsewhere, *"The information is 100% because even my first child is negative*" [IDI 16]. It is important to recognise that providing information can empower women in different life circumstances. Overall, PMTCT education and counselling were needed as a crucial component of PMTCT to support mothers of all journeys.

8.3.4 Affordability: Financial Constraints and Opportunity Costs to Receive PMTCT Care

Participants expressed financial constraints and opportunity costs including 'job loss in lockdown' and 'documentation' to receive care.

Job loss in lockdown

Interprovincial and intraregional migrants could not endure transport costs to the hospital because of losing their jobs during the pandemic. There were not enough taxis during lockdown for intraregional migrants to get to RMMCH, *"this place is far given the amount of money I pay to come here. I take two taxis for a single trip"* [IDI 11].

When investigating why some internal migrants migrated to CoJ, particular reasons included, "*to give birth*", "*receive better healthcare*" [IDI 34], and "*have better work opportunities*" to help support their families [IDI 20].

A self-employed woman from Zimbabwe explained, *"I came to SA to look for a job. My parents passed away when I was young so I grew up with my grandmother. I finished school at the age of 16 so I had to look for a way to survive"* [IDI 2]. Predominantly, cross-border migrants' main reason for moving to Johannesburg was employment opportunities.

Cross-border migrants significantly suffered from border closures. A Malawian participant and her boyfriend both lost their jobs and were "*left without an income due to lockdown*" [IDI 8]. The emotional toll was evident with financial stress for cross-border migrants. A displaced Zimbabwean migrant shared her very painful experience coming to Johannesburg to live with her sister, who was abusive and forced her to become a sex worker to put food on the table. She was distressed and expressed her inability to travel back to Malawi because of COVID-19,

> *"At first I felt ok, and everything was fine before I got raped. After that, I felt life was a struggle. I wished I could go back home. At the time, I didn't have the means to go back home. Later when I got some means, I travelled back home. I then came back to SA to try to make a living"* [IDI 17].

Although both internal and cross-border migrants needed financial support, cross-border migrants had to endure more opportunity costs to seek healthcare with border restrictions and very limited family support.

Documentation

Opportunity costs to use PMTCT services were amplified specifically for cross-border WLWH, where they could not attend appointments because of documentation issues. Cross-border and displaced migrants from Zimbabwe and Malawi expressed how the documentation was a major barrier to utilising services during the pandemic,

"It was very hard. We would travel on one bus and then step off to take another one. This occurred several times. Before we arrived at the border, we were arrested. When we arrived at the border we got arrested again. Even when we had passed through the border we still got arrested [. . .] My sister had identification, but I didn't. They thought she had kidnapped me" [IDI 17].

Documentation served as proof of a 'legal status' for cross-border migrants to enter SA to access healthcare and often crippled these WLWH who found themselves under difficult life circumstances. One woman from Malawi stated she was arrested multiple times and even stuck with an expired passport during the lockdown. She had to prove her story to staff constantly,

"They [nurses] said I don't have a permit and then I showed them my passport that I came here as [a] visitor then the lockdown closed me [on] this side of SA. Then my passport expired on the 31st of March. Then the second time, I ended up going to the nurse in charge and showed her my passport and I said if you check my pregnancy, it's for July and my passport expired in March when the pandemic started . . ." [IDI 34].

Implementation of the COVID-19 appointment booking system ultimately caused chaos for cross-border and interprovincial migrants who could not afford to take time off work (whether working in a different country/province of origin) to travel to the clinic because of border restrictions. A single 33- year-old Zimbabwean woman had contracted COVID-19 from a client at work and was stuck during the lockdown. She was booked for delivery and was trying to use an affidavit. She expressed her difficulty in attending her appointment because of her passport being robbed,

"It wasn't safe to pass through the passages. The phone they can take but the passport- because now when you are renewing, they must see the old one, that was my fear. It won't be a long process, I just won't get another one, that's the end of the story because they want to see it. I can't [use] my word of mouth, nor a photocopy, only the original" [IDI 33].

8.3.5 Acceptability: Interpersonal Interactions

Participants discussed 'mistreatment' regarding their interactions with HCWs during COVID-19.

Mistreatment

It was common for SA nationals to report they were never denied treatment at RMMCH. More SA nationals from Gauteng expressed they were comfortable when speaking with nurses, *"because when there's*

something I don't understand, I do ask questions and receive feedback" [IDI 14]. A 39-year-old intraregional migrant, employed, who regularly attended the hospital since relocating to Johannesburg, and was pregnant with her second child, thought otherwise. She stated there was a lot of "*negligence"* in the labour ward and *"the environment was not conducive. The treatment was the issue. Some patients were in pain, yet no one was attending to them. One of the patients gave birth in a toilet"* [IDI 18].

Interprovincial migrants expressed that treatment differentiated based on whom they interacted with and that the effort had to be made by both the provider and the user,

> *"The treatment you receive from the nurses is dependent on how you as a patient address them and how they're feeling at that time they assist you. They don't segregate in terms of background and status. For instance, [. . .] when another person comes to talk to me, my reaction will all depend on my mood at the time. I've never had problems of segregation here"* [IDI 7].

In contrast to SA nationals, many cross-border migrants spoke about their increased frustrations being separated from 'locals' and waiting in longer queues. Queues became more difficult with COVID-19 guidelines, *"I have a problem with long queues. Look at me now, I'm number forty-one despite the fact that I arrived at 6:30 a.m. We are a great number. It is cold, and we're in danger of contracting COVID-19"* [IDI 9].

Cross-border migrants reported poor behaviour and attitudes of nurses including being shouted at and called names such as 'defaulter' or 'foreigner' and were unaware of whom they could even speak/ report to,

> *"Some of the nurses, like when we go to the labour wards. Yoh! It's so terrible- but not all of them. I can't assume why they do that. Do they do that to the foreigners only or do they do that to everyone? Or they're just like that? They just don't have time. They just don't have the care. Because sometimes when you're in labour pain, you can't control yourself and that thing- you have no control over, but some [nurses] take it like it's their high time to abuse someone, to abuse patients"* [IDI 34].

Cross-border migrants, who newly arrived in SA, expressed that poor communication from nurses led to their distrust in the healthcare system. A non-national permanent resident from Zimbabwe reflected on how she feared having a caesarean section when she first arrived in SA ten years ago,

> *"I was scared because this was my first time, I was still young. I was also referred there from the clinic to go and do a caesarean birth [. . .] I spent a week in Johannesburg. I was crying every day and thinking of running away [. . .] I was being told that if I would have a caesarean birth, I would die. There*

are so many things that we are told about and hear, [. . .] even the sisters knew me as this girl who cries a lot and just wished that I would even go back home" [IDI 27].

Struggling with integration into a new space within the city was a common experience by many, whether from a different country, province, or moving from a rural area within Gauteng. Cross-border migrants had feelings of abandonment, wanting to belong, to be a part of the community, and not be left behind because of their HIV status or being a 'foreigner'.

8.3.6 Adaptability: Services for Different Movement Patterns

Participants were asked about areas to improve and better support their migration journey. Sub-themes included 'SDI' and 'differentiated service delivery' (DSD).

Same day initiation (SDI)

Women waited outside the counselling rooms and interacted with each other, laughing as they expressed that they did not see the point with testing when there was insufficient time for counselling to be conducted all in one day. A 35-year-old interprovincial migrant, on ART for 3 years stated, *"The only problem is that they don't give you all the information you need. They leave you ignorant"* [IDI 9].

Many participants from different mobility journeys only knew they have to take ARVs but lacked the answers as to why. The simple concise messaging that was provided lacked stressing the importance of long-term adherence post-delivery to patients.

There was a lack of ensuring confidentiality at all times during SDI, especially for cross-border migrants who remained the most vulnerable, without proper counselling or good education to conduct research on their own about HIV/PMTCT. A single and unemployed woman from Zimbabwe expressed, *"I desire to know about this programme but they don't have time to do counselling"* [IDI 12]. Time was a major factor for SDI to ensure that these vulnerable women had the information they need to really benefit from the programme.

Indirect disclosure occurred with SDI because of clinic flow, the constraints of space, the limited time spent with the counsellor, and the different queues that segregated women by their HIV status. Cross-border migrants compared RMMCH to other clinics they used, *"There is a difference. In Zimbabwe, people are segregated along the lines of languages. Some speak Shona, others speak Ndebele*" [IDI 3]. The language remained a large barrier for many cross-border participants (18) who expressed they were not as

comfortable speaking in English.

DSD: individualised approach

Participants spoke about different ways to help alleviate the challenges with their use of PMTCT services during COVID-19. Interprovincial and intraregional migrants recommended outreach services would be beneficial during the pandemic. A 35-year-old who had a stillborn stated, *"It would be a good idea for nurses to visit patients at their homes for check-ups to curb the long queues and the spread of the virus. We all have different challenges"* [IDI 13].

One common challenge expressed by participants was the need to access ART for a longer duration of time, also known as multi-month dispensing (MMD).

All women were referred from local clinics to RMMCH because of high-risk complications and nurses required a referral letter. Two cross-border participants were waiting on permanent residency and struggled without letters or asylum-seeking papers to utilise healthcare in Gauteng.

RMMCH remained reputable amongst different mobility typologies utilising PMTCT services, who expressed they were not turned away like other clinics when they did not have documents or speak the local languages.

A woman born in Mozambique, who spoke little English, arrived from Maputo a few months ago. She commented that she found RMMCH to have better services to offer than back home, *"Because I didn't get tested in Mozambique. I really don't know what they are doing there. RMMCH helped me choose the time for drinking the pills"* [IDI 15]. This presented a contrasting case, where a cross-border migrant found the PMTCT information received more useful than her country of origin. The fact that translation services were available to her through a counsellor at the clinic who spoke Changana and provided information in a language she could understand proved it was beneficial to her as a new arrival in CoJ. This indicated two crucial elements, a willing service provider to take the time to provide information and translation services for individuals who do not speak any of the local languages, to better understand and benefit from the information provided.

8.4 Discussion

This research qualitatively explored the individual experiences of WLWH from different mobility typologies, using public healthcare services in the high mobility context in CoJ. It is a contribution to

knowledge by both identifying mobility typologies, using cross-border, asylum seekers, displaced individuals, interprovincial, intraregional, and non- national permanent residents of women who surfaced from the data and the similarities and differences between their utilisation experiences of PMTCT services. This study extended literature beyond predefined labels for migrants that tend to limit descriptions to the dichotomy of nationals versus non-nationals and allowed for more tailored strategies responsive to the service needs of highly mobile women.[36,97]

Most women (57%) had a primary to grade 7 level education, were between 25 and 35 years old, had one or two dependents, were unemployed, and were co- dependent. Fifteen women had taken ART for less than one year, 12 of whom were cross-border migrants, 4–8 months pregnant, and had initiated ART for the first time at RMMCH. This remains an alarming concern for many cross-border migrants who are newly diagnosed only when accessing available PMTCT care at a state hospital for the first time.

The utilisation of HIV/PMTCT was restricted during the pandemic due to lockdown periods that limited the capacity and movement of migrants.[99] Findings contributed to an explicit narrative to help address the challenges with the HIV health system response for these mobility typologies and consider the individualised experiences of these women when developing strategies to prevent future interruption of PMTCT care.[107-110]

The following was derived from the conceptual framework, which was valuable in providing a better understanding of the adversities faced by different mobility typologies in both adherence and the dimensions of access, to help determine a way forward to address these challenges.

Cross-border migrants

Geographic mobility and COVID-19 seemed to have a greater impact on adherence for cross-border migrant WLWH because of the lockdown restrictions. The commonest reasons for interruption of ART were relocation, running out of ARVs, and the side effects of ARVs. There was a heavy reliance on SMS reminders, which could strengthen retention to the programme.

The dimension of availability indicated that although all women, no matter their nationality, struggled to understand the importance of adherence to ART post-delivery, cross-border migrants had significant challenges with navigating PMTCT information received because of poor communication by HCWs.[18] It is important to target key messages on breastfeeding while on ART in various languages and at a primary education level that many in the catchment area will understand. Health talks should be conducted both in-person and virtually, taking advantage of long waiting times to provide PMTCT education and adherence

counselling. This will build the self-capacity of patients, through the empowerment of information, made available in different languages.

Affordability highlighted that it was common for these women to be the primary caregiver without a support system physically present and undergo financial burden during the lockdown. Documentation remained a significant opportunity cost for asylum seekers and displaced individuals. They could not attend appointments because of difficult life circumstances including job loss and stolen/lost documentation. DSD could combat this by offering a unified pathway for migrants and healthcare providers across the care continuum.[103,104] DSD can provide a verifiable standardisation of care and a lifelong longitudinal digital patient health record for cross-border migrants and different mobility typologies.[103,104]

The dimension of acceptability revealed more fear and reluctance of cross-border migrants to utilise services because of their distrust in the ability of the hospital to follow regulations. Briefing sessions should be executed weekly/monthly (depending on the frequency of changes that occur) to better inform HCWs on the updated protocol and procedures during the pandemic.

Mistreatment and discrimination were existent towards these individuals from some HCWs. They were often placed in longer queues, segregated by language, called names, and lacked confidentiality from staff. Language should not be a gateway or equivalent to whether the patient is 'enough' to receive a service.[36,107-111] Service providers should be trained on language sensitivity and behaviour by conducting value clarification workshops. HCWs should be provided psychosocial support to assist in managing poor behaviours and xenophobic attitudes towards cross-border migrants.[16–18,32] It is important for providers to better understand that an individual's place of birth or where they reside does not solely define them.

Interprovincial migrants

Availability highlighted that some interprovincial migrants craved practical education when receiving adherence counselling, and demonstrations should be conducted by HCWs.

Most experienced fair treatment depending on the HCWs they interacted with in general. However, there was not enough time to have thorough counselling conducted and indirect disclosure occurred due to segregating patients by HIV status.[18] A rotation schedule should be implemented to allocate time for counsellors. Precautionary measures need to be taken by management to ensure that privacy is available for patients with any space made available.

Acceptability revealed that some individuals were turned away from clinics and unable to complete appointments because of the lack of human and structural resources. Research has indicated that the impact of the COVID-19 lockdown significantly reduced ART services by 46% in 65 South African primary care clinics.[34,112]

Adaptability indicated the provision of PMTCT during COVID-19 should include bundling services in the same visit and providing services outside the facilities including at-home visits or pop-up clinics. This could reduce the risk of exposure to COVID-19 where vulnerabilities are amplified for individuals who are often turned away at facilities.[34,112]

Intraregional migrants

Challenges stood out in the availability of space with COVID-19 protocols and the resources to complete patient appointments. The healthcare system should enable migrants to access the chosen services through multiple channels and touch points with as little friction as possible to reduce the burden on patients and healthcare systems.[34] Flexible ART collection and pick-up point dates/times strongly influence long-term engagement in HIV care.[34,112]

Affordability revealed more intraregional migrants, and non-national permanent residents appeared to gain access to and utilise services easily when compared to other WLWH crossing international borders, asylum seekers, or migrants without documentation. However, most intraregional migrants were unable to take time off work or have transport to the hospital because of the limited number of taxis during lockdown. The overburdened clinical environment and COVID-19 impacted the availability of services, especially WLWH in rural areas with limited access to the clinic.

Non-national permanent residents

Findings demonstrated that some non-national participants can have permanent residency in SA and still strongly identify with different compositional, contextual, and collective characteristics which are fluid due to their mobility.[35] There is a 'biosociality' that 'arises from belonging and identifying with a biological condition and shared therapeutic practice'.[39] By looking at the unique journey with mobility, migration, and HIV at an individual level, channels of support should be embedded into the programme delivery.[38,39]

Struggling with integration into a new space within the city was a common experience by many, whether from a different country, province, or rural area. For service responsiveness to better integrate PMTCT care

on a larger scale, adherence support groups should be available in different languages where mothers can connect with a community they identify with.[34–38,112]

Migration and health are not static, and the policy and programme actors need to take action this research and review the healthcare system in SA. The healthcare accessibility rights of these individuals should be advocated for by key stakeholders to provide the best care possible and not discriminate against or exclude migrants, especially highly mobile WLWH who remain vulnerable and are already at a disadvantage.

In 2018, the SA Human Rights Commission reported on public hospitals in Gauteng province denying migrants healthcare services linked to their nationality and/or legal status.[32,112]There is a failure to ensure access to preventative and treatment interventions for all in SA, undermining any single nation's sovereign response to both HIV and COVID-19 care.[16,27,32,101,112] A call to action in SA is needed for the inclusion of migrants and mobile populations to help strengthen the healthcare response nationally and form 'regional harmonisation and operate inclusive healthcare systems' going forward, especially for vulnerable populations like migrant WLWH.[3,16, 27,32,101,112]

Adaptability revealed that RMMCH echoed many of these issues with the severity of disruption and was able to rebound with COVID-19 planning. The hospital's decisions to continue to tailor specific PMTCT services are embedded in a larger healthcare referral system.[32,39,111,112] Healthcare system challenges remain which include service cutbacks for provision of counselling and support and retention in care for WLWH. An increased risk of loss to follow-up (LTFU) remains because of the lack of unity between healthcare systems to trace mobile women attending different facilities with a unique ID number.

In light of COVID-19, studies suggest a DSD integrated approach to patient care that focuses on individualised needs and the different lived experiences of HIV, to prevent future treatment interruptions.[34,56,113,114] One common challenge expressed by participants is the need to access ART for a longer duration of time during the pandemic. A person-directed care approach could supply healthcare services on a virtual platform, including language-sensitive information, educational materials with visuals for communication and MMD for long-term supply of ART, to reduce the number of visits for highly mobile migrants.[103] This could help build the service users' capacity to be in ultimate charge of choosing health services in line with their values, beliefs, and needs.[32,34,56,114]

8.4.1 Strengths and Limitations

Self-reporting allowed participants to describe their own utilisation experiences with PMTCT in-depth and provides insights to help strengthen service provision. Self-reporting bias may be a limitation with

participants reporting on adherence to ART. Some interviews conducted in Chichewa could have self-reporting bias with the assistance of a fluent speaking counsellor. People who utilised PMTCT are not representative of those who remain inaccessible, and we cannot know how their experiences may differentiate from those still absent from PMTCT care.

The vast typologies showcased by the 40 participants sampled and study results have broader applicability in mobility contexts outside Johannesburg.[16,17] Furthermore, the mobility typologies identified are not exhaustive of all typologies that exist. However, the transferability of using the methodology in identifying typologies for future research in migration and health is broadly applicable both in the SA population where movement between provinces and regions of the city occur. There is an opportunity for broader applicability to other countries that experience resource-constrained healthcare settings. However, limitations may be sampling in rural remote areas where limited population movement may occur when compared to urban areas.

By allowing the data to determine the typologies, rather than defining the typologies *a priori*, the study aimed to avoid the pitfalls of previous studies that assume solely that these typologies are limited to a dichotomy of citizen versus migrant.[36]

Conducting qualitative field research under the COVID-19 conditions was challenging, and attempts to move interviews online proved not to be feasible to capture the nuances, body language, and observation of the participants, important in understanding participants‘ stories.

8.5 Conclusion

The COVID-19 pandemic has shone a light on the pre-existent healthcare system challenges. Future healthcare system and pandemic preparedness emphasise the importance of adapting to the ever-changing healthcare climate in response to the needs of highly mobile WLWH.

Future research studies in migration and health should utilise the methods of not predetermining typologies *a priori* to identify and address specific challenges at both patient and healthcare system levels. RMMCH provided insight into the mobility typologies within SA utilising PMTCT programming, emphasising the importance to look at patients more holistically to better incorporate their needs and inform decision-making that occurs in government and within healthcare facilities.

To address the migrant gap in healthcare service provision, more collaboration between research, policy, and programming spaces is needed to continuously develop strategies and strengthen service provision for the inclusion of highly mobile migrant WLWH.

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Disclosure statement

The data are owned and governed by the Human Research Ethics Committee at the University of Witwatersrand, Johannesburg, South Africa. All data are stored in the central research team repository. Data consist of interview transcripts that contain human identifying information and cannot be shared publicly for confidentiality reasons. Requests for further data may be sent to melaniebisnauth@gmail.com.

Ethics and consent

Ethical approval for the study was granted by the Human Research Ethics Committee (HREC) at the University of Witwatersrand, South Africa (approval number M190816 MED19-07-084). Provincial clearance was obtained by Gauteng Province and The National Health Research Database (NHRD No: GP_201912_003) and City of Johannesburg. Written consent was obtained for interviews.

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Competing interests

The authors declare that no competing interests exist.

Paper context

The sustainability of HIV services was a global challenge during the COVID-19 pandemic. The utilisation of PMTCT treatment and care has become more difficult for highly mobile populations due to border closures and lockdown, documentation, and xenophobic attitudes from service providers. Exploring utilisation experiences between different typologies of women allowed for tailored strategies responsive to their service needs. Differentiated service delivery models could assist in alleviating the burden on the healthcare system and patients.

LINKAGE

Linking Notes between Chapters 6, 7, 8 and 9 (Papers 1, 2, 3 and 4)

This section contains information to clarify the link between Chapters 6, 7 and 8 (Papers 1, 2 and 3) to Chapter 9 (Paper 4). In depth discussions in findings of individual papers are in the discussion sections of each paper, while an overall discussion follows in Chapter 9 (a working draft for Paper 4).

Chapter 6 (Paper 1) looked retrospectively at the Option B+ policy and programming impact on PMTCT in 2015, this allowed for a better understanding of the roll-out of the guidelines and the impact on both patients and HCWs. While, Chapter 7 explored further in-depth, the perspective of HCWs solely and their provision of PMTCT services to the large number of migrant women that utilise treatment and care at RMMCH, a high mobility context.

Chapter 7 and 8 (Paper 2 and 3) data collection occurred during the COVID-19 pandemic, and it inevitably had an impact on the PMTCT programme and its service provision by HCWs and its utilisation by WLWH. Therefore, the PMTCT service provision and utilisation involves the aspects of both mobility and migrant typologies, as well as the COVID-19 impact on the provision and use of these services.

Chapter 8 (Paper 3) explored the perspective of WLWH and investigated the different mobility typologies that surfaced. Chapter 8 (Objective 3) identified the various mobility typologies of women utilising the PMTCT services at RMMCH. Paper 3 also addressed Objective 4, to qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.

Paper 4 serves as a future policy piece, drawn from Chapter 9, which addresses the need for responsiveness from SA government and NDoH. Chapter 9 brings together collectively the previous papers 1,2, and 3 and draws overall conclusions, recommendations, and a way forward for both policy and programme implementation. Chapter 9 provides the principal findings of the overall thesis and in relation to other studies in the field, as well as implication for policy practice and research. This chapter concludes with the recommendations for future research regarding WLWH, mobility typologies, service provision of PMTCT and future pandemic preparedness, and the vision for the South African PMTCT programme.

CHAPTER NINE: PAPER FOUR

Paper 4: Bisnauth MA, Coovadia A, Kawonga M, Vearey J. (2022) Challenges and lessons learned in Prevention of Mother to Child Transmission (PMTCT) services for migrant women living with HIV during the COVID-19 pandemic: a qualitative study in South Africa, *BMC Public Health* (working draft paper for submission)

At the time of this thesis submission, Paper 4 is currently a draft paper that will be pulled from the discussion chapter for submission to the *BMC Public Health* as an original article. For the purposes of this thesis, figures and tables as well as their captions have been placed in the appropriate places within the text of the article and general formatting is aligned with the requirements of the specific journal.

Chapter 9: General Discussion, Recommendations and Way Forward

9.1 General Discussion

The papers that were presented in Chapter 6, 7 and 8, each contributed to the objectives outlined in the thesis. It is important to understand that each paper has built towards reaching the overall aim, to both identify and explore the differences and similarities between different mobility typologies for utilisation of the PMTCT programme, during the COVID-19 pandemic. The qualitative research investigated these WLWH utilisation experiences of the PMTCT programme at RMMCH as healthcare users, HCWs perceptions as service providers of PMTCT, and perceptions of key stakeholders in policy and programming at city, provincial, and national levels regarding PMTCT utilisation in the high mobility context of RMMCH.

In this section, the previous three chapters (Paper 1, 2, and 3) are discussed, bringing together each paper's critical discussion points and recommendations. These points are in the scope of policy and programming, to help pave a way forward for future research and the vision of the South African PMTCT programme.

In Paper 1 (Chapter 6) titled, '*Option B+ Program for the Prevention of Vertical Transmission of HIV: a Case Study in Johannesburg, South Africa'*, WLWH experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH were explored. This research looked retrospectively at the Option B+ policy and programming impact on PMTCT in 2015, which allowed for a better understanding of the roll-out of the guidelines and the impact on both patients and healthcare professionals.

This research identified that there were existing challenges with the national guidelines, that major challenges were present within the public hospital, and within the broader healthcare system (including referral clinics).[18,107,115] These challenges affected the policies and procedures at RMMCH both at the clinical and management levels.[2,18,107] Chapter 6 highlighted that research studies tend to focus on quick rollout the PMTCT programme without considering the users' perspective before implementation occurs.[18] This is a missed opportunity where the end user could inform how the components of the programme could be widely adapted and made more sustainable.[18] The accessibility framework in Paper 1 provides us with the additional component of 'adaptability' and was used in the following chapters (7

and 8) to help inform and better understand the patients' perception about going on ART for life to better understand strategies in implementing an adaptable approach for adherence.[2,18,107,115]

In Paper 2 (Chapter 7) titled, '*Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers*' investigated the experiences of HCWs providing PMTCT at RMMCH and, the perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial, and national levels, regarding PMTCT access and migration in a high mobility context during the COVID-19 pandemic.[107]

Lastly in Paper 3 (Chapter 8) titled, '*Addressing the Migrant Gap: Maternal Healthcare Perspectives on Utilising Prevention of Mother to Child Transmission (PMTCT) services during the COVID-19 pandemic, South Africa*' the experiences of WLWH are explored.[115] Paper 3 investigated the different mobility typologies that surfaced from data and identified the various mobility typologies of women utilising the PMTCT services at RMMCH.[115] Paper 3 qualitatively explored the differences and similarities in utilisation experiences between different typologies (in relation to mobility) of WLWH on the PMTCT lifelong treatment programme during the COVID-19 pandemic.[115]

Both Papers 2 and 3 (Chapter 7 and 8) data collection occurred during the COVID-19 pandemic, and it inevitably had an impact on the PMTCT programme, its service provision by HCWs and, its utilisation by WLWH. More severe consequences arose from the data, specifically for cross-border migrants.[107,115]

9.2 Principal Findings

The following principal findings have been provided from Chapters 6,7, and 8 (Papers 1, 2 and 3). In Chapter 6 (Paper 1), women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH were explored. The research demonstrated (pre-COVID pandemic) that work had become very challenging to manage for the HCWs because of the; '(1) need for strengthening indicators to decrease loss-to-follow-up; (2) inconsistency in delivery of counselling and support services and; (3) lack of compassion and understanding by service providers.'[18] The difficulty of managing care within the healthcare environment had affected overall views and experiences of these women going on ART-for-life.[18] There was a need for education, counselling and clarity in messaging, as this was emphasised by all 55 patient participants that responded, 'they chose to take the FDC pill to protect the baby's health and believed lifelong ART could be stopped after delivery, unaware of the long-term benefits.'[18] Interestingly, this research highlighted that adaptability was a concept that needed to be explored,

especially because ‘non-national’ WLWH perspectives were presented. There was a gap where the perspectives of migrant women utilising PMTCT treatment and care at RMMCH were not represented and that their voices should be heard, to strengthen PMTCT for migrant typologies.[18,107,115]

In Chapter 7 (Paper 2), this research explored the pandemic and the barriers it created for healthcare staff providing PMTCT services and the perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels, to understand what strategies could be implemented with COVID-19 and address challenges with ART adherence for the highly mobile population to better manage the programme.[107]

Cross-border migrant women were reported to undergo many healthcare user challenges compared to internal migrants for PMTCT during COVID-19 because of ‘the documentation required to access care and navigate a more complex healthcare system, now amplified by lockdown and border closures’.[107] Multiple appointments booked for patients during the first wave of COVID-19 pandemic, negatively impacted migrants and their mobility, making it nearly impossible for these individuals to utilise PMTCT services routinely and access care.[107,115] Many cross-border and internal migrants were unable to afford opportunity costs to travel from their origin country/province because of border closures.[96,107]

Multi-month medication dispensing and long-term medication supply was a severe need during the pandemic, especially for patients on the move.[107,115] ‘COVID-19 added an extra layer to an already overburdened healthcare facility and highlighted the existing gaps of a network of referral clinics across Gauteng province’.[107,115]

HCWs need more time to build rapport with patients, this could help strengthen the WLWH self-capacity.[107] For this to occur, structural and organisational changes need to be actioned immediately. There needs to be trust in the healthcare system from both users and providers, reassured through alleviating stressors (i.e. asylum papers). Providing clear communication that stresses the importance of adherence to ART when breastfeeding and post-delivery can help aid in the disjointed understandings of PMTCT programming.[96,107] Language diversity of IEC materials should be made available to help serve individuals who do not speak the local languages to better understand of the importance of adherence and risks of non-adherence.[97,107,115]

RMMCH has provided PMTCT for a large number (40%) of highly mobile women outside their catchment area while enduring the pandemic.[96,107,115] COVID-19 added extra burden to the limited resources that were not available and led to poor staff attitudes.[96,107,115] Service providers did not spend enough time with these WLWH, counselling and building rapport, especially with cross-border migrants who needed specific attention and more time due to the language barrier.[107] HCWs reported the increase in the risk of LTFU with cross-border migrants.[107] 'Stigma and mistreatment still exists with some healthcare providers toward the migrant HIV population', often left vulnerable and in fear of falling ill from COVID-19.[97,107] These WLWH were unable to receive support at the facility due to capacity restrictions.[97,107]

PMTCT lifelong treatment management for patients remains difficult because of inconsistent delivery across clinical departments of counselling and support services for SDI.[18,98,99,107,115] Therefore, the success of the PMTCT programme is critical for prevention of maternal and child mortality and morbidity across the nation.[98,99,107,115] The programme is capable of building health awareness to empower women to take control of their health decision-making.[18,98,99,115]

Chapter 8 (Paper 3) explored WLWH and their individual experiences of using public healthcare services in the high mobility context of Johannesburg.[115] This specifically is a major contribution to knowledge by *identifying typologies* of women utilising PMTCT care.[115] This paper extends literature beyond predefined migration categories that tend to limit descriptions to the dichotomy of citizen versus migrant.[115] This research allowed for identification of similarities and differences in the utilisation experiences between these different typologies of women that arose from the data that included; cross-border; interprovincial; intraregional; non-national permanent residents; WLWH who sought asylum; displaced individuals; and migrants with or without documentation, thus allowing for more nuanced and tailored strategies responsive to the service needs of mobile women'. [115]

Findings revealed that some 'non-national' participants can have permanent residency in SA and still strongly identify to different compositional, contextual and collective characteristics that are fluid because of their mobility. [115] We stressed the importance on the need to look at the individuals' unique journey with mobility, migration, and HIV (at an individual level) to draw similarities and differences when comparing their experience to others. This helped to provide recommendations to PMTCT service responsiveness to all WLWH on a larger scale.[115] There needs to be an explicit narrative that addresses the challenges with HIV health system response for all different mobility typologies of women and, that

considers the individualised experiences of these women when developing strategies to prevent interruption of PMTCT care.[7,96,115] Adherence support groups should be available in different languages where mothers can connect with a community they identify with, for service responsiveness to all WLWH on a larger scale.[115]

Interprovincial migrants 'craved practical education when receiving adherence counselling, demonstrations should be conducted during health talks by HCWs'. Fear was also present when using healthcare services.[107,115] Some were turned away from clinics and unable to complete appointments because of the lack of human and structural resources available.[107,115] Provision of PMTCT during COVID-19 should include bundling services in the same visit and providing services outside the facilities (e.g., at home visits or pop-up clinics).[115] This could reduce risk exposure to COVID-19 where vulnerabilities are amplified for individuals that are often turned away at facilities.[115]

Most interprovincial migrants experienced fair treatment depending on the HCWs they interacted with, but indicated there was not enough time to have thorough counselling conducted and that indirect disclosure occurred because they were segregated by HIV status.[115] This is unacceptable, precautionary measures need to be taken by management to ensure that privacy is available for patients with the limited space, through a rotation schedule to allocate time to counsellors.[115]

Intraregional migrants were unable to take time off work or have transport to the hospital because of the limited number of taxis during lockdown.[115] The overburdened clinical environment as a result of the pandemic had impacted the availability of services, especially for WLWH in rural areas with limited access to the clinic.[115] Challenges stood out in the availability of space with COVID-19 protocols and the resources to complete their appointments.[115] 'The healthcare system should enable migrants to access the chosen services through multiple channels and touch points with as little friction as possible for reducing burden for patients and health systems.[115] Having flexible ART collection and pick-up point dates and times strongly influenced long-term engagement in HIV care.[107,115]

9.3 The Conceptual Framework: Different Typologies of Women

The utilisation of PMTCT services conceptual framework allowed us to better understand that all women no matter their nationality, struggled to understand the importance of adherence to ART after the birth of their baby.[107,115] WLWH that were moving more frequently between provinces and countries

experienced significant challenges with receiving and understanding PMTCT information. These women reported more side effects which led to disruption of adherence to their ARVs, grappling with being on the move and balancing different life circumstances.[96,115]

The following findings were derived from the conceptual framework throughout stages of the research. The adaptability component (Paper 1) was added and the healthcare provider and key stakeholder perspectives and mobility typology components (Paper 2 and 3). Overall, utilisation of PMTCT and HIV support services became challenging, especially with the COVID-19 pandemic lockdown and capacity restrictions, limiting the movement of people.[7,115]

Availability

The overburdened clinical environment due to COVID-19 impacted the services made available, including space and counselling to educate women on breastfeeding.[18,115] Almost all women, no matter their mobility typology (which included cross-border; interprovincial; intraregional; non-national permanent residents; WLWH who sought asylum; displaced individuals; and migrants with or without documentation) expressed their desire to learn more about PMTCT programming and felt that there was more work to be done with educational components of the PMTCT programme.[115] Though, a few interprovincial and cross-border participants reported that the education they received elsewhere was more substantial than RMMCH.[115] Service providers should take advantage of any and every opportunity to educate all women (when in long queues or sitting in the waiting room) on PMTCT and HIV, including topics such as breastfeeding.[107,115]

Affordability

Findings revealed financial constraints and opportunity costs that were amplified for specifically cross-border migrants due to the barriers of documentation, border closures and lockdown, overall disrupting their PMTCT care.[107,115] Provincial border restrictions impacted both interprovincial and intraregional migrants, echoing similarities with restrictions of movement and utilisation of PMTCT healthcare services.[115] More intraregional migrants and non-national permanent residents appeared to gain access and utilise services easily when compared to other WLWH crossing international borders, asylum seekers, or migrants without documentation.[115] In addition, participants that were displaced and

undergoing difficult life circumstances (i.e., forced sexual labour) faced barriers of documentation, such as sourcing a valid passport to travel back to their country of origin.[115]

Acceptability

Highly mobile women in cross-border migration patterns relied on SMS reminders to adhere to ART when moving around. While some cross-border migrant WLWH expressed fear and reluctancy to utilise health services because of the risk of becoming infected.[107,115] Mistreatment and discrimination were existent towards these specific individuals from some service providers, especially towards participants without documentation and asylum seekers compared to intraregional migrants.[107,115] Interestingly, a woman who is a non-national permanent resident did not always identify as a South African and felt she didn't 'belong' ,but attached her identity to her country of origin or where her loved ones resided 'back home'.[94,115]

Adaptability

Research has indicated that the impact of the COVID-19 lockdown significantly reduced ART services by 46% in 65 South African primary care clinics.[107,112,115] Providing PMTCT during COVID-19 should include bundling services in the same visit and providing services outside of facilities (i.e., at home visits or pop-up clinics) to the extent possible to reduce risk exposure to COVID-19 where vulnerabilities are amplified, in this case cross-border migrants or individuals without documentation, and displaced individuals that are often turned away at facilities.[94,107,115]

RMMCH echoes many of these issues, especially the severity of disruption. The hospital was able to rebound with COVID-19 planning and its decisions to continue or tailor specific PMTCT services and embed these changes in a larger healthcare referral system.[107,112]

9.4 Findings in Relation to Other Studies in the Field

There are limited empirical studies to elicit the real impact of COVID-19 on migration and the well-being of migrant WLWH.[104,110,116] The IOM reported that most female migrants negatively report on their well-being due to COVID-19 and are less likely to return to their country of residence, despite the pandemic. [104,110,116]

PMTCT studies have emphasised that the integration of lifelong ART can be feasible and acceptable, shifting the healthcare provider and service user relationship, finding 'common ground' with components such as infant feeding, and decreasing stigma surrounding clinical visits.[65,104,116]

PMTCT service users have reported that improvements to the programme included that the services delivered by the same HCW, strengthened the relationship of receiving care. This built rapport and trust between the WLWH and healthcare provider, no matter their nationality or status.[65,77,112,116] Furthermore, studies have shown that mothers reported increased engagement from the father and support from family when male involvement was integrated into the PMTCT programme, allowing for co-parenting engagement.[65,117] There is still a gap when analysing a migrant WLWH on the move, who resides alone. This can become challenging but remains an important opportunity for PMTCT programmes at healthcare facilities, much like RMMCH to further integrate men as part of the family planning component.[18,115]

Furthermore, strong evidence argues that counselling and support group sessions for WLWH can lead to improvement in health care engagement, HIV treatment adherence and, overall retention- contributing to improved maternal, mental health, and child outcomes, for PMTCT programmes.[118,119]

Transport issues remain a logistical barrier for affordability and availability of services in many PMTCT programmes in other countries much like SA.[64,65,69] For example Malawi has worked on decentralising services, bringing care to the community, and overall removing transportation to the clinic as a barrier.[64,65,69]

Integration is crucial in providing a 'holistic focus on the woman's well-being and motivating her', by not only providing the information, but 'sharing information of interest to her' to help benefit the health of her and her child.[64,65,69]

Long-term sustainability should be the focus of PMTCT programming in SA and not just temporarily fill gaps to support delivery and provision of PMTCT services. Research has suggested there needs to be better understanding of the role that contextual factors play, these include; staff shortages, barriers of transportation, infrastructure and lack of space, stock-outs, large patient populations, and service provision in both rural and metropolitan areas.[64,69] Findings from this study have suggested that contextual factors much like the ones listed prior, can become a challenge with communication pathways

between the service provider and user.[18,107,115] For example, in Papers 2 and 3, the lack of space in the pandemic created challenges resulting in disclosure issues for some patients.[107,115] Studies highlight the need to empower those working at the healthcare facilities across SA to help determine the most effective and efficient ways for implementation, continuously monitoring and strengthening the programme and overall evaluation for the end users.[64,69]

9.5 Implications for Policy, Practice, and Research

There is a need for 'policy objectives to establish a secure, strategic, and integrated approach' for highly mobile WLWH migrants 'into healthcare communities as a constitutional right to basic needs' and PMTCT healthcare.[5,52,120] Meanwhile, SADC migration policy aimed to be open to intra-regional movement, it still presents challenges with cross-border migration that is 'less securitised' as we saw with border closures and documentation requests during the COVID-19 lockdown period.[120]

Many highly mobile WLWH remain (some with no legal identity in SA) and continue to face the challenges of PMTCT utilisations due to the barriers of documentation, missing reports of VLs, and PCR test results.[120,121] There is no doubt that this has called for a synchronised plan with the South African government and the NDoH.[120,121]

According to STATS SA (2018), SA was estimated to receive a net immigration of 1.02 million people between 2016 and 2021 and Gauteng province has the highest population of non-South Africans at 7.4% of the entire provinces' population.[3] "*South African doctors have a legal duty to report illegal immigrants to the authority*" which emphasises a need for discussion of policies within the broader context of SA, given reports of cases where migrants were denied healthcare, based on their nationality and legal status, and echoed in some of the healthcare provider attitudes towards some of the highly mobile WLWH in Chapter 7 (Paper 2).[21,38,122] This is an ethical problem and a larger health systems issue at play that highlights the need for value clarification workshops and further training to help get to the underlying issues such as xenophobic attitudes and discrimination that exist in the some of the healthcare settings. This includes public hospitals like RMMCH and from service user reports of these highly mobile WLWH, there are negative attitudes and discrimination that exist amongst some of the referral clinics too across SA.[21,38,122] We cannot generalise that all healthcare settings have denied or continue to deny migrants access to healthcare services but these stories and lived experiences should not be ignored when it comes to improving the healthcare system as a whole.[38] For buy-in, HCWs not only

need to understand the importance of equal and equitable healthcare for all in SA but also 'be able to advocate' for it.[38,123]

Hospital settings and the clinical work environments need to encourage positive behaviour, however, as we saw burnout, this can contribute to negativity in a workplace that is already overburdened.[4,123] It is important to make use of the resources available and RMMCH, such as adherence support groups. It would be useful to integrate support for the issues that different migrant typologies face into these adherence groups. This takes on a more inclusive approach by not singling out the WLWH that are highly mobile.

SA faces a major challenge with achieving 'structural and behavioural change' and 'its government must not be complacent in its influence to spread information and drive social change' for ART adherence and support, 'leaving no one behind'.[96,120,121] The South African government is called on to 'scale-up and supply funds for campaigns' (i.e. Treatment Action Campaigns (TAC)) to promote health awareness but become more involved in the interventions for migrant populations. This is needed in Gauteng province, where negative climates towards these individuals exist.[120,121] There remain major repercussions in the failure to do so, resulting in poor delivery of HIV testing, PMTCT and ART service coverage, inaccessibility, poor quality and coordination of care and patient tracking, lack of support and medical management, which undermined the efforts to eliminate HIV infections in new infants and mothers by 2020.[69,123,124]

The costs of service provision remain a detrimental barrier to migrant WLWH. There appears to have been insufficient communication to HCWs in costs of service provision to migrants.[52,125]

"In Gauteng province, refugees, asylum seekers and other non-citizens are being classified as 'private patients' and charged as such under the amendment of Regulation 1958 in June 2020. This ordinance regulates the classification of patients and payments of fees. According to the Uniformed Patient Fees Schedule (UPFS), provincial governments are empowered to regulate health care tariffs for admission and fees paid to the hospital. According to the UPFS, all citizens, refugees, asylum seekers and non-citizens from SADC should be means tested to determine how much they are charged for non-primary healthcare. However, under the amendment, refugees and asylum seekers are treated as private patients and charged disproportionately. For some new mothers, this has meant a R7 000 bill for a natural birth or R15 000 bill for a C-section, with birth certificates reportedly being

withheld until payment has been made and hospital administrators refusing to provide sufficient information for patients to approach DHA and ask for clarification around their documents to be issued".[125]

Often agenda-setting and policy processes engage key actors and partners in government and political roles but fail to involve the voices of those impacted by the PMTCT policy and programming implementation (including the migrant WLWH and their loved ones) hindering the acceptance of the PMTCT lifelong treatment with poor yield for targeted outcomes of the programme.[33]

In addition, policy overlap can occur where different policies, guidelines and components are implemented at different healthcare facilities due to inconsideration of health system requirements to implement changes.[33]

Moving forward, we must ask 'what the relationships around technical assistance and support are, readiness to fund policies, resources available, and the key actors that drive' the PMTCT programming and policy implementation and monitoring on the ground, 'allowing time to evaluate before rapid changes occur to help minimise health system gaps'.[33]

Internal migration is a complex process and largely contributes to the movement patterns in Gauteng, by examining this more closely with research, it can help direct policy and practices in providing comprehensive healthcare services, including PMTCT care to the migrant population overtime.[70] This can be beneficial in critical planning and preparedness for when a pandemic arises much like COVID-19.[70]

Research is needed to help provide both quantitative and qualitative data on population movements and address the persistent gaps in migration statistics, with integration from small and big data sources as well as key actors (including non-governmental organisations (NGOs), institutions like WHO, and the IOM).[70] Research on PMTCT utilisation and migrant typologies in relation to their movement patterns/mobility could help continuously guide policymakers.[70] Furthermore, this can inform ways of innovation to help address challenges faced by the migrant populations, and address those who do not have limited access or no access at all.[70]

9.6 Overall Strengths and Limitations

In Chapter 6, the emphasis was placed on how the PMTCT programme and Option B+ policy (before solely named lifelong ART) often excludes the voices of those that are most impacted by its implementation. The strength of this study was its ability to provide a platform for many pregnant HIV-positive women to share their lived experiences with lifelong ART.[18,115] The study was able to explore the perceptions of HCWs from both clinical and management levels and how their work is impacted by the national consolidated guidelines as a way to inform Option B+ PMTCT programming.[18,107] Qualitative research develops concepts that can provide better understanding and speak to the concerns of those who provide healthcare and the interaction with their recipients.[18,88,107,115,126]

The use of triangulation strengthened the validation of the data in the study. In addition, because of the study's diverse and large sample, the study findings may be transferrable to other settings that are implementing this programme.[18,88,107,115,126,127] Though the study was conducted six months after introduction to the Option B+ programme, the study had delineated many issues earlier on that could be considered in shaping the programme aspects, for example peer group support and knowledge transfer/education for HIV positive women.[18,107]

In Chapter 7, this research explored qualitatively healthcare provider experiences of PMTCT in the high mobility context of Johannesburg during COVID-19.[107] Qualitative interviews were conducted with different cadres of staff, this sample is a strength because, despite the small sample size, it has transferability and broad applicability with the results.[88,107]

By allowing the data to determine the typologies, rather than defining the typologies *a priori*, the study aimed to avoid the pitfalls of previous studies that assume solely these typologies are limited to a dichotomy of citizen versus migrant.[88,107,126] The use of finer-grained migrant typologies is a significant improvement from this national versus non-national dichotomy and goes beyond the reproduction of a 'single story'.[9]

However, the limitations of this research recognises the use of body language of the investigator may have affected the results through moderator bias. Therefore, acknowledgment and disclosure of the PI's perspective enhances the credibility of the study.[18,88,107,115,126]

This study focused on one hospital system in Johannesburg, SA, which may limit the ability to make assumptions about the findings beyond the local context in which this study was conducted. However, this site served many individuals with different movement patterns, and provided insights through first-person accounts on the myriad issues, examining competing propositions or similarities on different aspects of the programme, informing the greater healthcare system, and public health policies and practices.[107] This thesis research makes a contribution to global public health by adding knowledge about the role of migration. The analytical focus is on PMTCT of HIV, but there are likely to be applications that go beyond.[115] The work is augmented by the effort to identify the disruptive impact of the COVID-19 pandemic on health-seeking behaviour in SA, arguably the country most impacted by the HIV epidemic.[107,115]

Additionally, a convenience sample of HCWs (Chapter 6, Paper 1) was selected for qualitative interviews based on recommendations from the head of the department of Paediatrics and Child Health at RMMCH.[18,128] In order to mitigate the limitation of biased selection of the HCWs, a purposive sampling method was then used (Chapter 7 and 8, Paper 2 and 3) to increase credibility of the study.[107,115] To gain a maximum representation of views, ensuring that patients were not subjected to selection bias based on their ability to speak English, can increase the validity of the research.[107,115]

In Chapter 7 and 8, self-reporting bias may be a limitation with participants reporting on adherence to ART.[2,3] The strength of self-reporting allowed participants to describe their own utilisation experiences with PMTCT in depth and provide insights to take one step towards strengthening service provision.[107,115] People who utilised PMTCT are not representative of those who remain inaccessible, and we cannot know how their experiences may differ from those still absent from PMTCT care. It also needs to be considered that the study group consisted only of patients that were able to access the hospital.[115]

The vast typologies showcased by the 40 participants sampled and study results have broader applicability in mobility contexts outside Johannesburg.[115] Furthermore, the mobility typologies identified are not exhaustive of all typologies that exist.[115]

Empirical evidence is provided throughout this thesis. Specifically in Chapter 8, the strength in provision of first-person accounts of migrant WLWH, allowed us to examine competing propositions and similarities amongst participants.[115] The factors and variables that were incorporated in determining

the different typologies that surfaced from the data collection of participants, included *clinical characteristics,* bringing together the intersections of both migration and health.[115] Chapter 8 also illuminates the added challenges with adherence and access related to the COVID-19 pandemic and underlines the importance of the availability of preparedness plans targeting this heterogeneous group.[115]

Conducting qualitative field work research under the COVID-19 conditions was challenging, attempts to move interviews online proved to not be feasible to capture the nuances, body language and observation of the participants which was important in understanding their stories.[18,88,107,115,126]

Reporter bias is recognised as a further limitation with underreporting of access to care problems by the participants, despite our best efforts to build rapport and ensure confidentiality during the interview process.[88,126] There could be many reasons for underreporting issues relating to access to care, including fear of prosecution, deportation, ostracisation, or discrimination in terms of medical care.[38,89]

9.7 Recommendations for Policy, Programme Implementation and Future Research

Research in the field of migration should be actioned, based on the following principles;

1) 'Power imbalances' do exist and can 'influence the priorities in research', 'greater transparency' is needed '' in funding, agenda-setting, in decision-making and evaluation processes need to be fostered, diversity and inclusive of voices' that are impacted by policy and programme changes, to help avoid the pitfall of the single story (i.e. incorporate different mobility typologies of migrant WLWH);

2) Recognise the 'value in longitudinal research', often rapid changes to programmes due to policy implementation has caused healthcare facilities to 'organically come up with strategies' to address components of the PMTCT programme that are not captured and become missed opportunities for key lessons learned;

3) 'Innovate, collaborative (interdisciplinary research) and adaptation of multilingual approaches for production and the distribution of knowledge';

4) Create an 'enabling environment and safe space' for sharing and to learn from each other, allow for 'self-reflection', this can 'enrich experiences of migrants and researchers' and;

5) Write in ways that are inclusive and speak to different audiences, break away from rhetoric language like ‘citizen’, ‘migrant’, ‘other’ and address these complexities however many times , challenge the terminology used in the field.[38]

As indicated in Chapter 6, for lifelong treatment programming to function and be successful in other settings for HIV-positive pregnant women, certain components need to be addressed to ensure adaptability which includes (but is not limited to) by providing continuous counselling and support services for women with SDI.[18]

Furthermore, RMMCH needs to improve their internal communication and collaboration amongst HCWs across all units to develop consistency for the use of indicators for the programme and understanding of individual roles in delivering consistent messages and services to mothers.[18] Communication is essential in helping patients build trust in service delivery, decreasing the LTFU and can alter the patient perception on long-term adherence.[18, 107,115] Most importantly, an HIV-positive pregnant woman needs to understand the long-term benefits of FDC for both herself and her baby.[18,107,115] This would help build trust in services utilised by these pregnant women and alter their perceptions on medication adherence holistically after delivery of the baby.[18, 107,115] A recommendation is for collaborative sessions that are feasible for HCWs with existent training sessions which can be managed with a rotation schedule for workers to come together and give their input.[18, 107,115]

A challenge for HCWs was the ability to express sympathy for the patient.[18,107] In highly constrained resource settings, a recommendation is to have support workshops for HCWs engaged in this work to manage and cope better.[18,107] It is important to maintain the health of RMMCH?s staff. Support workshops can allow HCWs to come together and build closer relations to each other, understanding that they are all undergoing changes in their work.[96,18,107,115] The work load increased for HCWs with COVID-19 demands and staff shortages were a result of being booked off sick.[96]

Limited information is provided from the education that nurses give in the antenatal clinic. It is recommended that instead of delivering education and information in a lecture style format, it should be conducted as interactive sessions to stimulate the patients and keep them engaged. Interactive sessions allow pregnant HIV-positive women to build mentorship and a network where they can form healthy relationships which can improve their adherence to ART.[96,18]

HIV is a life changing diagnosis with major social implications and treatment approaches have become lost and often motivated by reaching targets, driven by stakeholders (funders). The individual is more than just a number and this has serious consequences on people's lives. The life-long requirement for treatment has major consequences to ensure that the initial messaging communicated to patients is sound, concise, understandable, and very clear.

Women's' perceptions of their partners' approval of their HIV status have been identified as a strong predictor of willingness for women to return to the antenatal clinic.[96,115] RMMCH provides women with counselling but often males are not allowed into the facility which acts as a barrier to uptake.[97]A recommendation is to provide additional support groups where the male partners can attend to increase open communication by including the male in child spacing and family planning methods.[97]

Maintaining open communication and working on compassion and patience would make workers more aware that their attitude and behaviour toward patients can impact the quality of care the patient receives. It is recommended that training workshops be held for frontline nurses and physicians.

It is crucial to understand the barriers to the short and long-term sustainability of the Option B+ programme. Understanding the environment in which a PMTCT programme operates can address policy implementation and programme issues and hence inform how adaptable Option B+ programming is on a larger scale. The national guidelines have been developed but adaptability remained problematic to successful roll out of the Option B+ programme outside of RMMCH.[38,,97,128]

In Chapter 6, the implications of this part of the research indicates the need to address changes within the healthcare system at both clinical and management levels.[18] Emphasising that it is crucial to incorporate the perspective of patients and frontline HCWs in policy implementation; uptake and adherence are key indicators in informing if the Option B+ PMTCT programme is adopted into state hospitals effectively.[18] This can help address issues before policy implementation is executed. Often, stakeholders and policymakers come together to create a policy to do what they see may be best from a top down approach.[92,42] However, by using a community based approach, implementation plans can take place as a discussion by including the patient and HCWs at the table and spark open dialogue between the key actors and those impacted by the implementation.[42] Community based approaches can empower

individuals, such as these HIV-positive pregnant women to acknowledge expectations about themselves, their behaviour and potential.[92,42] The involvement of the patient living with the illness in the community can provide insight as to how Option B+ could be integrated and adapted to meet the unique needs and values of the surrounding community at healthcare facilities undergoing high resource constraints.[18,42]

Chapter 6, suggests that extensive research needs to be executed on how to strengthen indicators for long term sustainability of the programme in conducting a longitudinal study comparing system planning between healthcare facilities and state hospitals.[18] Collaboration across the departments of RMMCH and can provide perspective and insight as to what indicators need to be strengthened for the Option B+ PMTCT programme.[18] This can be executed through interdisciplinary department meetings and training may encourage dialogue between staff internally and report any issues and concerns they may be experiencing with the programme to upper management.[18,107] RMMCH had at the time, existent clinical training sessions specifically with frontline nurses (pre-COVID). By including the physicians and counsellors that work within the departments, this can overall strengthen the communication between HCWs.[18,96,107] Remember all HCWs can provide feedback as to how their work environment is managing these indicators, which may be entirely different depending on which department they work in.[2,96,18] Future evaluations need to address if interdisciplinary collaboration within hospitals can improve the management and understanding of Option B+.[18,96,107]

Chapter 7 stressed that the NDoH PMTCT guidelines do not address the complexities of mobility and healthcare access in high mobility contexts.[107] Better education and understanding could alleviate challenges of MTCT rate in highly mobile WLWH to less than 5%.[107] Particularly for non-national women who are seen as a politically weak group that has not gained visibility on SA's health policy agenda, and are at an elevated risk of facing inequalities and unfair treatment by healthcare providers when utilising PMTCT healthcare services across Johannesburg.[92,107] There is a lack of understanding about how provision of PMTCT care in the healthcare environment can be strengthened for migrant women to better support their individualised needs.[97]

By restructuring the booking system of patients due to COVID-19, this alleviated over 200 deliveries in six months for RMMCH.[2] Strategies to strengthen the PMTCT programme gaps with service provision include an integrated electronic database of records or travel book that cross-border migrants could carry with them.[2] These can provide access to patient history within different regions, between provinces, or in another SADC country and possibly combat lost PCR tests/records, address pharmacy

scripts for dispensing and pick-up of ARVs, reduce duplication of appointments and costs for patients to travel, and the demand of healthcare providers.[97,107]

COVID-19 changed the way staff worked and demonstrated that immense changes could be implemented through technology to alleviate issues with patient demands which included, chatgroups and SMS reminders. Constant and consistent quality improvement to the database at the hospital should be ongoing to reduce LTFU and poor adherence.[97,107]

To address poor healthcare provider behaviour and attitudes, mental health support through Employee Assistance programming should be provided which includes, training, values clarification workshops, and team building exercises that can be conducted by a third party to mediate management and frontline healthcare providers.[96,107] There are larger systemic issues at play with xenophobia in the SA healthcare system that need to be addressed through mentoring and interdisciplinary training.[8,42-45,107]

In comparison to five years ago, a gap for structured counselling remains with PMTCT programming at RMMCH.[56,107,115] The clinical flow with counsellors must allocate time for patients, especially with the implementation of SDI.[8,107,112] Many women are initiated onto ART but there still remains a lack of understanding of the importance of adherence after the birth of the baby, especially during the course of breastfeeding.[18,25,56,107,115]

A shuttle or transport service with different pick-up points could be provided by the NDoH and RMMCH for highly mobile patients to ease the financial costs of traveling that was amplified for migrants, specifically those with multiple appointments during the pandemic.[8,46,56,97,103]

Health education was delivered primarily in English, which acted as a double-sword, providers felt that foreigners who do not speak the language, lose out on education. Language shouldn't be an excuse to discriminate against any individual, there is a potential to translate and distribute information, education, and communicative (IEC) materials to the larger migrant population attending RMMCH and its referral healthcare facilities.[18,25,107,115]

In the closing of Chapter 7, we recommended further studies are needed that explore the patient perspective to better understand if and how the mobility profiles of women who are on the PMTCT programme may have an impact on their utilisation experiences, including their overall ability to adhere

to lifelong care.[107] Furthermore, the major task for healthcare providers was to reinstate service delivery of PMTCT without putting themselves or patients at risk of COVID-19 infection, and the use of technology to alleviate the high burden of patient demand.[107] It is important to take what was learned during the pandemic and integrate it into routine service delivery, which includes long term medication supply to reduce multiple visits to the hospital and overall risk of COVID-19 transmission for HIV pregnant women.[107,115] Healthcare policies that work toward inclusion and sustainability for migrants are needed to improve the integration of safer and practical methods of PMTCT provision into health systems.[42,107]

In Chapter 8, through the exploration of patient perspectives at first-hand, it is revealed that COVID-19 amplified existing challenges, especially for cross-border migrant women that are highly mobile to utilise PMTCT services.[115]

Furthermore, training service providers on language sensitivity within the clinical environment, conducting value clarification workshops and, providing mental health support, could assist in managing poor behaviours and xenophobic attitudes towards cross-border migrants.[42,56,96,107] It is important for providers to better understand that an individuals' place of birth or where they reside does not solely define them.[115]

In light of COVID-19, a DSD integrated approach is recommended for patient care which focuses on individualised needs and the different lived experiences of HIV to prevent future treatment interruptions.[97,107,115] This person directed care approach can supply healthcare services on a virtual platform, including language sensitive information, and educational materials with visuals for communication, and MMD for long term supply of ART and reduce the number of visits for those highly mobile migrants.[5,107,115] This would help build the service users' self-capacity to be in ultimate charge of choosing health services in line with their values, beliefs and needs.[42,97,107,115] The healthcare system should enable her to access the chosen services through multiple channels and touch points with as little friction as possible for reducing burden for patients and health systems.[42,97,107,115] Flexible ART collection and pick-up point dates/times strongly influenced long term engagement in HIV care.[42,97,112,115] DSD can offer a unified pathway for migrants (no matter their mobility typology) and health care providers across the care continuum, a verifiable standardisation of care, and a lifelong longitudinal digital patient health record for different mobility typologies.[103,104,115]

The failure for SA to address the needs to strengthen migration and health approaches both before and during the pandemic has exacerbated risks for these migrant WLWH on the move, including existing tensions.[129] Moving forward, we stress the importance to continuously share the lessons learned nationwide and internationally.[129,130]

Future pandemic preparedness should be addressed with DSD models which include tailored strategies responsive to the service needs of mobile women such as MMD of ARVs, virtual educational care and language sensitive information, to assist in alleviating the burden on the healthcare system and women of all mobility typologies.[107,115] Further research studies are recommended to investigate how healthcare systematic changes can address the gaps within programming and policy spaces for inclusion of highly mobile women.[107,115]

9.8 Vision for the South African PMTCT Programme

Migration governance in SA and its responses to the HIV epidemic, the COVID-19 pandemic and PMTCT service provision need to be inclusive in its programming.[129,130] There needs to be greater efforts made to combat the healthcare risks at an individual level.[42, 56] The PMTCT programme was used as a lens in this research to provide insight as to how we can strengthen healthcare system response for vulnerable populations of highly mobile WLWH.

The COVID-19 pandemic has taken the world by storm over the past few years. SA, like many other countries experienced significant constraints to its movement patterns due to restrictions with lockdown and border closures.[129,130] This global pandemic should be taken as a learning opportunity in how to close existing gaps within healthcare, including its infrastructure, and lack of both human and medical resources, to provide the best possible care for the mother-infant pair.[116]

SA still needs to take on a more ‘pragmatic approach’, ‘the government should take note of the healthcare climate before imposing high levels of lockdowns and restrictions’.[129,130] Despite all the severe lockdowns, SA has a total number of 97 955 COVID-19 deaths (a mortality rate of 481 per 100,000).[3] It is advised that public health officials and policy actors take into account the life circumstances of many migrants in the province of Gauteng who are on the move when implementing restrictions and regulations, considering its impact on their healthcare outcomes in the near future.[129] The country and its healthcare institutions need to prepare in order to resume a new normalcy.[129] There are

detrimental effects on the SA society and public health as a result of restrictions that were placed on the movement of people.[129,130]

Strengthening the healthcare systems response to ensure optimal treatment for as many patients as possible, both those with COVID-19 and with other chronic illnesses like HIV should be made a priority.[129] There needs to be migration-aware and 'mobility-competent healthcare systems' in place that speak to the realities and life circumstances of migrant WLWH in SA.[42,48,129,130] This includes the 'reorientating of healthcare systems response to focus on mobility typologies', future pandemic preparedness, and the epidemic of HIV, with focus on providing routine PMTCT healthcare services for all women.[123,131]

DSD strategies can prove to be beneficial when providing PMTCT services which include technology, use of remote registration, helplines, online scripts, tracking, and test results in real time.[48,104] This allows migrant WLWH on the move to transcend borders without the concerns of physical barriers of care with border control and travel bans and remain engaged in care.[48,104] By using a virtual platform, healthcare services can be integrated with educational resources that are language sensitive for mother-infant pairs.[2-3] Ultimately, this integrated virtual platform will provide relief to many with the financial burden (job loss and transport), while traveling throughout the pandemic and relying on access to ART from healthcare facilities in their country of origin or in SA.[104]

For the first time, international migration is included and linked in the 2030 universal sustainable development goals (SDGs) and targets, addressing the need for safe migration and is inclusive of the impact of migrants on economic and social life needs.[129,131] 'The principle of "leave no one behind" urges government to consider in policy and programming migrants and sub-groups that are vulnerable', including migrant WLWH and their infant pair.[129-131]Although limited data exists on how this has affected migrant and mobile populations, 'particularly the ways in which it intersects with health seeking behaviour', more migration data will be needed on WLWH 'who are disproportionately impacted' across SA when it comes to PMTCT healthcare utilisation.[131]

It remains a concern that there are many reports of non-nationals with expired documents being denied routine HIV healthcare services in SA.[104,125]HCWs have reported concerns about migrants giving incorrect information and moving between healthcare facilities to access care, including chronic treatment, over fears of being tracked and deported.[115,125] All healthcare staff, including informal

gatekeepers such as security guards and administration clerks, need to be reminded regularly that non-citizens are not turned away from healthcare facilities as per the DHA.[104,125] The DoH guidance needs to be adapted to manage these patients with the appropriate level of skill and resources for the primary reason they seek healthcare access, feeling welcomed. [48,107,125]

Often, the development of complex public health strategies take a top-down approach where key stakeholders which include government and the state develop policies without involvement of those delivering (street level bureaucrats i.e. healthcare providers) or receiving (PMTCT users) the public health services.[32,48,96,107] This has been 'obstructive 'to the way healthcare services such as PMTCT are delivered and how it is received by service users. [32,48,96,107] Resulting in a 'call to action' to provide platforms where the voices and experiences of both WLWH, from different movement patterns and mobility typologies and, healthcare providers from city and provincial levels can help inform policy and decision-making processes, to overall strengthen PMTCT programming and the overall healthcare provision, especially 'under strenuous conditions that we saw and are still seeing with the global pandemic of COVID-19'.[96,107,130,131]

9.9 Conclusions

In conclusion, this research emphasised the importance of exploring migrant typologies and going beyond simplistic understandings and labels to group these individuals, based on their citizenship/nationality or status often used in literature.[115] Moving forward in PMTCT policy and healthcare programming in South Africa, it is crucial to look at individuals more holistically to better incorporate their needs and inform decision making that occurs at government and on the ground in healthcare facilities. To help close the gap of healthcare service provision to highly mobile individuals, more collaboration between research, policy and programming spaces are needed to continuously develop strategies and strengthen healthcare service provision for these different healthcare users on the move.[115]

'Migration and health are not static', and the policy and programme actors need to action this research and review the healthcare system in SA.[97] It is crucial to reconsider the structural and organisational barriers that perpetuate poor frontline healthcare worker attitudes and the challenges created for PMTCT healthcare service provision.[96] The healthcare accessibility rights of these individuals should be

advocated for by key stakeholders to provide the best care possible and not discriminate or exclude migrants, especially highly mobile WLWH who remain vulnerable and at a disadvantage.

Future research studies in migration and health should utilise the methods of not predetermining typologies a priori, to understand their service users and key challenges to better address specific barriers at both patient and healthcare system levels.[115]

Moreover, the COVID-19 pandemic has shone light to the pre-existent healthcare system challenges, emphasising the importance of adapting with the everchanging healthcare climate.[107] The key lessons learned from the COVID-19 pandemic and specifically DSD when it comes to HIV service provision to individuals on the move, should be actioned immediately to help alleviate burden on both patients and the healthcare system.[107,115]

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CHAPTER ELEVEN: APPENDICES

Appendix A:
Ethics Clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms M Bisnauth

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M190816

NAME: (Principal Investigator)	Ms M Bisnauth
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	*Exploring healthcare user perspectives on utilisation of prevention of mother to child transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa*
DATE CONSIDERED:	2019/08/30
DECISION:	Approved unconditionally
CONDITIONS:	Phase 1 approved 2019/12/18 Phase 2 approved 2021/03/05
SUPERVISOR:	Professor J Vearey
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2019/12/18

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

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 submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **«Missing mail merge field»** and therefore reports and re-certification will be due in the month of **«Missing mail merge field»** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Melanie Bisnauth
Signature of Principal Investigator

5 MAR 2021
Date

Appendix A:
Ethics Clearance RMMCH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

Enquiries : Karen Marshall
Tel : (011) 470 9284
Fax : 086 553 4623
Email : Karen.Marshall@wits.ac.za

TITLE OF RESEARCH PROJECT:
"EXPLORING HEALTHCARE USER PRESPECTIVE ON UTILISATION OF PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) SERVICES IN HIGH-MOBILITY CONTEXT IN JOHANNESBURG, SOUTH AFRICA"

NAME OF RESEARCHER:
Ms. Melanie Bisnauth
School of Public Health
University of the Witwatersrand

NHRD REF NO: GP_201912_003

Dear Ms. Bisnauth,

Permission is granted for you to conduct the research as indicated in the title above.

The terms under which this permission is granted is contained in the Researcher Declaration form that you have signed. Failure to comply with these conditions will result in the withdrawal of such permission.

It is crucial for you to inform the Research Coordinator, Karen Marshall of the actual start and end dates of your study. This could be done by e-mail.

Should the study commence more than 12 months after receipt of this approval letter you will have to go through the process of applying again.

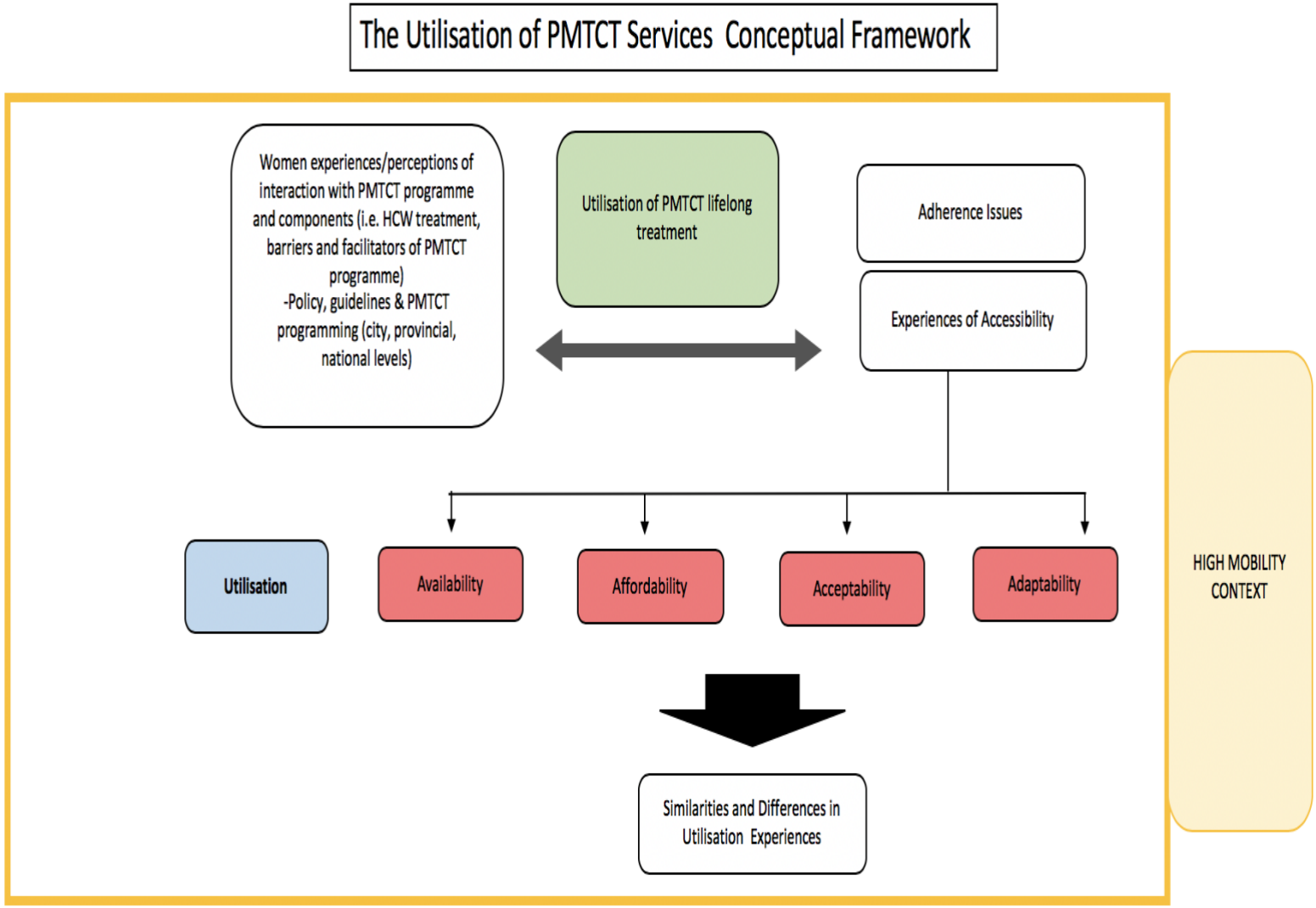
You are strongly advised to keep a signed copy of the declaration form so as to ensure that the terms of this agreement are complied with at all times.

Yours sincerely,

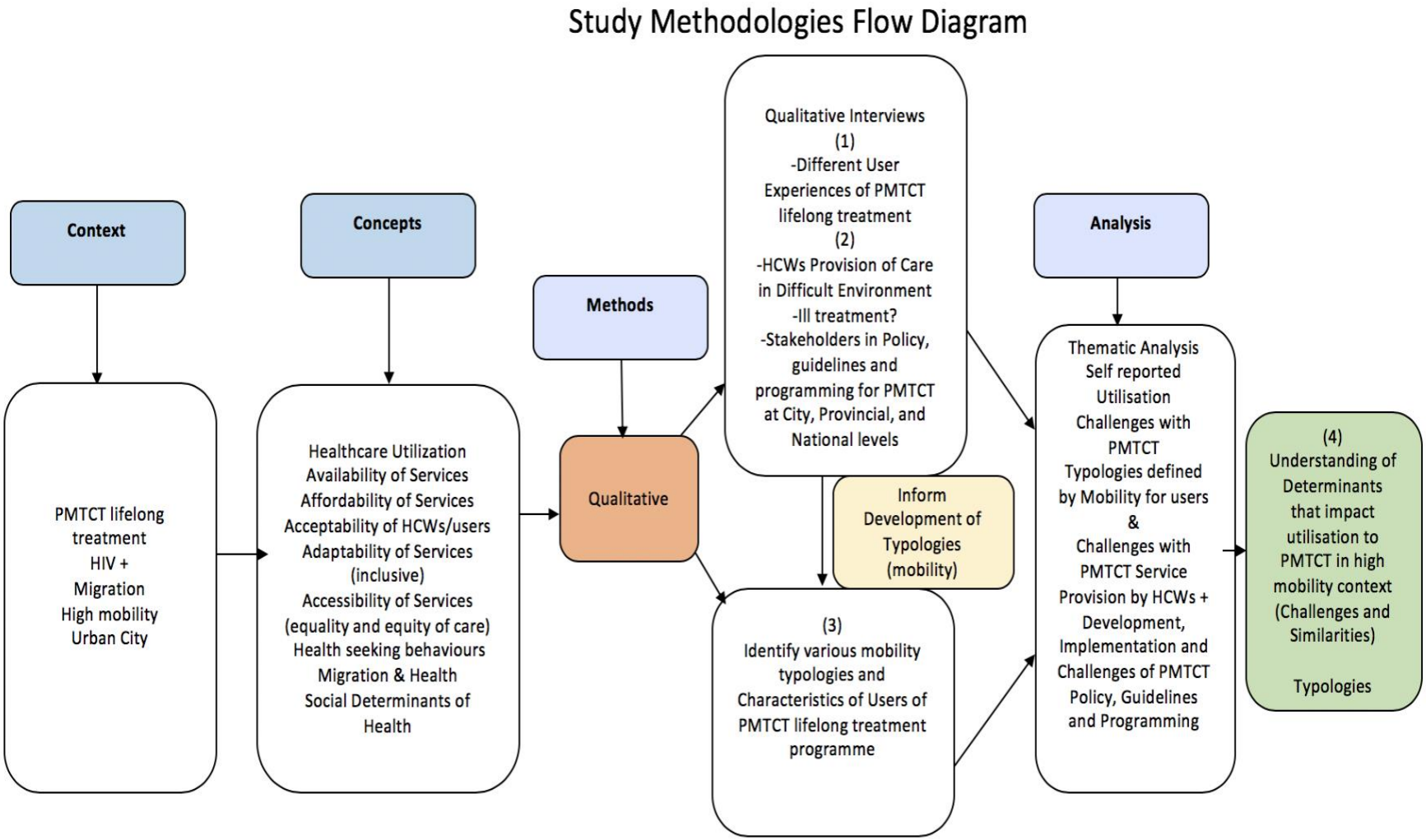
DR FREW BENSON
ACTING CHIEF EXECUTIVE OFFICER
2019:12:04

ADDRESS: Cnr FUEL & OUDSTHOORN STREET CORONATIONVILLE 2093 / PRIVATE BAG X20 NEWCLARE 2112 JHB

Appendix B:
The Utilisation of PMTCT Healthcare Services Conceptual Framework



Appendix C:
Study Methodologies Flow Diagram



Appendix D:
Table: Objectives, Data Collection Tools, Description of Data, and Method of Analysis

Objectives	Data Collection Tool	Description of Actual Data (Qualitative)	Method of Analysis
Objective 1 To explore all women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH	• Stage 1b-2a: Qualitative in-depth interviews (until data saturation reached) with 1a purposive sample of women • Interview Guide • The utilisation of PMTCT healthcare services framework • Interview audio recordings • Journaling	• Qualitative interviews (ANC, PNC) guided by The utilisation of PMTCT healthcare services framework with Sample 1a all women on PMTCT (40 Semi-structured interviews) explored experiences of utilising PMTCT and mobile histories from patient users (healthcare user experiences and perceptions of their interaction with the PMTCT programme and components (i.e. HCW treatment, interactions with any hospital staff from point of entry, barriers, and facilitators to PMTCT services) • Journal notes of behaviour throughout interviews	• Thematic analysis for qualitative semi-structured interviews with women and utilising The utilisation of PMTCT healthcare services conceptual framework to help guide the identification of domains that emerged from all transcribed data and audio recordings with the help of QSR NVivo 11 software • Transcribed data analysed in two-steps; 1) audio recording and note taking completed simultaneously throughout the interview process and 2) audio recording was replayed, • Secondary check completed by the translator to improve validity of the transcribed interviews. • Acknowledged bias and personal assumptions use triangulation to ensure rigor

			• Cross-checking with interview transcripts, journal notes • NVivo coding for interviews
Objective 2 To investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic	• Stage 1a: Qualitative semi-structured interviews (until data saturation reached) with purposive sample of healthcare workers and key stakeholders for PMTCT policy, guidelines, and programming at city, provincial and national levels guided by The utilisation of PMTCT services conceptual framework • Interview audio recordings • Journaling • Policy and procedure documents from hospital protocol (rules and regulations), regional and national practices of PMTCT may be referred to help determine provision of MNCH at RMMCH	• Qualitative interviews with (10 semi structured interviews) with key stakeholders for PMTCT policy, guidelines, and programming at city, provincial and national levels • HCWs (10 semi-structured interviews) involved with PMTCT at RMMCH working at facility (e.g. hospital clerks, linkage officers, nurses, physicians from Paediatrics/OBGYN and PMTCT programme manager) guided by The utilisation of PMTCT healthcare services framework 1b healthcare workers (10 semi-structured interviews) to explore provider perspectives for PMTCT in a high mobility context until data saturation. • Issues with PMTCT healthcare provision and treatment of patients discussed with HCWs (e.g. 'What could you do to better improve the services made available for PMTCT at RMMCH?	• Thematic analysis for qualitative semi-structured interviews with key stakeholders and HCWs and utilising The utilisation of PMTCT healthcare services conceptual framework to help guide the identification of domains that emerged from all transcribed data and audio recordings with the help of QSR NVivo 11 software • Transcribed data analysed in two-steps; 1) audio recording and note taking was done simultaneously throughout the interview process and 2) audio recording was replayed, • Coding for gaps to suggest ways to do better to address challenges with provision of PMTCT in high mobility context • Acknowledged bias and personal assumptions use

		How do you treat your patients?) • Development, implementation, and challenges of PMTCT policy, guidelines and programming was explored with key stakeholders at city, national, and provincial levels were asked, *'Please describe your successes and challenges with PMTCT policy in South Africa? Gauteng? Johannesburg? Can you elaborate on this specifically for the migrant and mobile populations?* Journal notes of behaviour throughout interviews • PMTCT Guidelines implementation at RMMCH • WHO and NDoH protocol that RMMCH follows	triangulation to ensure rigor • Cross-checking with interview transcripts, journal notes • NVivo coding for interviews
Objective 3 To identify the various mobility typologies of women utilising the PMTCT services at RMMCH	• 40 semi-structured interviews Qualitative interviews from (Obj. 1a) were analysed to describe mobility • Semi-structured interviews analysed factors (i.e. ill-treatment) influence patients utilisation of care with PMTCT for different categories of women .	• Patient data on users' socio-demographic characteristics from qualitative interviews, duration on lifelong treatment, missed dosages of ARVs, trust of healthcare workers and any obstacles with accessibility and adherence issues as a measure of the dimensions of the utilisation of PMTCT healthcare services conceptual framework that may overall impact	• Patient data on users' six factors/variables: migrant status, geography, temporality, socio-demographic status, motivations/causal classifications, and clinical characteristics analysed from qualitative interviews

		utilisation (i.e. ill treatment by HCWs, family obligations, difficult working hours, understanding the healthcare worker, etc).	
Objective 4 To qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic	• Stage 2a: Qualitatively (40 semi-structured interviews) to assess for similarities/differences in the utilisation experience across typologies of women	• Self- reported accessibility and adherence captured from qualitative semi-structured interviews • Analyse for similarities/differences of utilisation experiences across typologies of women - participants rate of different variables (e.g. dependents, work, etc) to PMTCT lifelong treatment.	• Thematic Analysis for significant differences in rating of experiences across typologies of women. • Characteristics: Patient data such as nationality, age of patient, year of HIV diagnosis, date of delivery and six factors/variables analysed from qualitative interview responses determine if the typologies impact utilisation on the PMTCT lifelong treatment programme

Appendix E:
Interview Guide for Patients

Qualitative ***To explore women's experiences of utilisation of the PMTCT programme in the high mobility context of RMMCH.***
Interview code number: _____
Interviewer: Melanie Bisnauth

Location:_____

Date: _____

Length in (hour/mins): _____

The following for the first part of the interview is structured, collecting data on socio-demographic and clinical factors. The latter are guided questions. Domains of interest are bolded. P= probes.

Demographic Data

1. What is your age?
2. What is your sex?
3. What is your date of birth?
4. Where were you born? If RSA, where? If outside RSA, what countries did you travel through en-route to South Africa? [Write down province/country of birth below. Please include information about countries that you may have travelled through/spent time in en-route to South Africa]
5. When did you arrive in South Africa? How long have you been here in Johannesburg? (less than 1 year, 1-5 years, 5 years or more)? Where in JHB do they live? Where were they before that, for how long? And before that?
6. What documents do you currently hold? (Undocumented (no valid permit documents from the South African Department of Home Affairs), Asylum Seeker Permit (Section 22), Refugee Status (Section 24), Rejected refugee currently undocumented (no valid documents from the South African Department of Home Affairs), Temporary Resident Permit: Visas: [visitors, student, work permit, exceptional skills permit], permanent resident with RSA ID, permanent resident without RSA ID, citizen with RSA ID, citizen without RSA ID, passport from country other than SA, SA passport, other specify, unknown, refuse to disclose)
7. What language(s) do you speak? (English, Afrikaans, Ndebele, Northern Sotho, Sotho, SiSwati, Tsonga, Tswana, Venda, Xhosa, Zulu, Farsi, Other)
8. What is your highest level of education?

Mobility History

9. If from South Africa but outside of Johannesburg, where are you from? how do you view yourself in Johannesburg, how do you identify now with South Africa? Johannesburg?
10. If outside RSA, what countries did you travel through en-route to South Africa? When did you arrive in SA? Where are you currently living?

11. When did you arrive in current town/city? Why? Can you explain why you relocated?
12. If non- South African, why did you come to South Africa? (Find employment? To join your family? To access healthcare? Seeking asylum? To escape political persecution/violence? Other?)

Stage of Pregnancy and Family Obligations

13. Are you currently pregnant and expected to deliver? Did you newly deliver a baby? How long ago?
14. Are you married? Do you have a partner/spouse? If yes, how did the healthcare system here at RMMCH accommodate your partner? Did they attend RMMCH with you for healthcare or go somewhere else? P: Why?
15. Do you have children/dependents and how old are they?
16. Where does the income in the household come from? (spouse contribution, immediate family contribution, government assistance, financial subsidies, housing subsidy, other)

Decision to attend RMMCH

17. Is this your first visit to RMMCH? If not, how many times have you been to RMMCH before?
18. Have you attended any other public health facilities in South Africa before? If yes, where?
19. Did you choose to come to RMMCH? If yes, why? If no, which clinic were you attending? How long have you been coming to the clinic?

Background Experience

20. Do you know about PMTCT? (initially say prevention of mother to child transmission, then if they do not know probe to maternal and child healthcare services) If yes, what do you know about it? P: Who told you about it?
21. Have you experienced any difficulties/challenges with PMTCT/MCH services in/out RMMCH? What were/are they?
22. Please describe your experience with the PMTCT/MCH services you access at RMMCH?
23. What successes have you experienced with using these services?
24. What do you/don't like about the services here at RMMCH?

Understanding of PMTCT, Education and Source of Information

25. Do you think it is working? Please tell me more about why do you think that?

Commitment with PMTCT programme at RMMCH and ARVs

26. Is there anything that has changed with your ability to take the HIV medication/treatment? P: Please tell me more about why you think that?
27. Do you miss any dosages? P: Why? What has made it more difficult?

Utilisation Experiences (with COVID-19)

28. Have you had a good or bad experience here at RMMCH? P: Could you tell me more why you think that?
29. Has COVID-19 changed your experience and your ability to access the healthcare facilities? How was it then and how is it now?
30. How do you feel about coming in the hospital under these conditions? Do you think that you are high risk?
31. Have you missed any of your appointments due to COVID-19? Has it impacted your taking your medication? Why?
32. Who did you deal with in the health care setting? What was your response?

33. How did they help you? P: What did you do after that?
34. How do you feel about your interactions with HCWs here at RMMCH?
35. Do you feel that these services are available at good times for you?
36. How do you get to RMMCH to access these services?
37. Do you have any concerns? Do you ever express your concerns to the HCWs here? Tell me about it OR why not?
38. Do you feel like the PMTCT services here are what you can receive anywhere else?

Strategies Women Use to Combat Challenges with PMTCT at RMMCH

39. Have you ever been denied treatment? P: What do you do? Have you experienced this at RMMCH? What happened in the end?

Availability

40. What would you like to have with the PMTCT programme? Would you like to know more about the PMTCT programme?
41. What can RMMCH do to make it easier for you?
42. Are you happy with the services RMMCH make available to you?
43. Do you find the education that nurses provide about PMTCT useful? Why or why not?

Affordability

44. Have you ever been charged a fee for using PMTCT services, either here or elsewhere? If yes, where/what/how much/did you pay/did you get treatment?
45. Where, what service, how much, did you pay for it? If you failed to pay, did you get treatment?

First Interaction with PMTCT Lifelong Treatment Programme

46. Please tell me how long you have been on the PMTCT lifelong treatment programme?
47. Where did learn about the PMTCT lifelong treatment programme? (Treatment Action campaign or ad, HCW at RMMCH, HCW outside RMMCH, family and friends, other?)

Other Medical Conditions May Impact Adherence to PMTCT programme and ARVs

48. Do you have other medical conditions? If so, what are they?
49. How does this affect your ability to take your medication for HIV?

Acceptability, Disclosure and Stigma

50. Have you disclosed to anyone? How did you feel? If disclosed, how did disclosing make you feel about taking your HIV medication (ARVs)?

Accessibility

51. What are the major differences between the healthcare system here than back home? Have you ever returned home for healthcare? Why so?
52. Have you had to relocate to be able to use mom and baby/HIV services? If yes, why?
53. How would you say it is in terms of easiness to get to the hospital? What is your method of transportation to RMMCH?
54. Do you these PMTCT services in different locations? P: With ease?
55. Do you attend other clinics as well as this one at RMMCH?
56. What is different about the services you use?

Relationship with HCWs

56. What was your experience with the healthcare worker when told you that you would have to take this medication/treatment for life? Did you get sufficient counselling?
57. Do you feel comfortable to express yourself to your healthcare worker? What about your concerns? What doesn't make you feel comfortable with your healthcare worker here at RMMCH?
58. Have you ever felt mistreated by a healthcare worker? Why?
59. What services have you received at RMMCH? Were you happy/not happy with the services received? Why or why not?
60. Do you feel you have the same care/treatment as other women here at RMMCH? What is different?
61. If you have questions, do you feel you get enough help from a healthcare worker at RMMCH? Why or why not?

Appendix F:
Interview Guide for Healthcare Workers

Interview Questions- Healthcare Workers

Exploring healthcare user perspectives on utilisation of Prevention of Mother to Child Transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa.

Melanie Bisnauth, (PhD School of Public Health)
(Faculty of Health Sciences – University of Witwatersrand)

Information about these interview questions: This gives you an idea what I would like to learn about your experience with the PMTCT treatment programme at Rahima Moosa Hospital. Interviews will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: "*So, you are saying that …?*), to get more information ("*Please tell me more?"),* or to learn what you think or feel about something ("*Why do you think that is…?").*

Interview code number: _____
Interviewer: Melanie Bisnauth

Location:_____

Date: _____

Length in (hour/mins): _____

The following for the first part of the interview is structured, collecting data on socio-demographic and clinical factors. The latter are guided questions. Domains of interest are bolded. P= probes.

Experience in Department and Work

1) What is your age?
2) Gender?
3) Title?
4) How long have you worked at RMMCH? In which department(s)?
5) How do you feel providing PMTCT and HIV care at RMMCH?

Work Environment, Mobility and Difficulty

6) How would you describe this work environment? P: How is the workflow? Communication? Can you describe the changes with COVID-19?

Types of Patients

7) Where would you say most of the patients you see on the PMTCT lifelong treatment programme are from?

8) What are some of the reasons that you have believe patients attend the PMTCT lifelong treatment programme here at RMMCH? P: What have you heard/seen as some of those reasons?
9) How long have your patients on the PMTCT lifelong treatment programme attended RMMCH? Have you ever experienced challenges in providing PMTCT services to them here at RMMCH? Maternal? Child health?
10) What documents do you these women need have to use PMTCT services at RMMCH? If she is RSA? If she is a non-national? (i.e. ANC card requirements? temporary resident permit, RSA ID, etc.). What changes may have occurred with COVID-19 (regulations, standard operating procedures (SOPs) and/or practices)
11) What services are available overall at the hospital for to patients? P: Are there any differences? RSA national? Non-national patient coming from a different country? What services are available with COVID-19?
12) Are there differences in service provision at RMMCH with the PMTCT lifelong treatment programme? with COVID-19?
13) Do you feel the hospital is experiencing any challenges in provision of PMTCT? If so, what are some of the reasons for this? P: Do you feel RMMCH has enough resources to provide PMTCT services? Exhausted? If so, what are some of the reasons for this? What about with COVID-19?
14) How many referrals vs. walk-ins do you see?
15) What are some of the reasons for patients for PMTCT lifelong treatment programme come to see you?

Programmatic Routines

16) Please tell me about your daily routine (if there is one). What tasks does this include specifically for the PMTCT lifelong treatment programme?

Utilisation with Women who have Access to PMTCT

17) Where did you learn about the PMTCT lifelong treatment programme?
18) Where do you think your patients get their information about the PMTCT lifelong treatment programme?
19) Who are the women that you see at RMMCH accessing PMTCT?
20) Do you think your patients have any challenges using PMTCT services? P: What are some of those utilisation issues? with COVID-19?

Adaptability

21) Do you think that the PMTCT lifelong treatment programme is effective? P: Why
22) What strategies would you implement at RMMCH to improve PMTCT use? P: Anything specifically for certain patient populations you see? Mobile populations? What about with COVID-19?

Mobility and Uptake/Adherence

23) How are you finding your patients medication uptake/adherence? Is it increasing or decreasing in general? Are they missing dosages more frequently? P: Please tell me more about why you think that? What about with COVID-19?
24) What are some of the reasons you think adherence declines? P: Do you think after these pregnant women give birth adherence declines? Why or why not?
25) What are some of the reasons women move in and out of RMMCH? P: Do you think mobility has an effect on a women's uptake/adherence with the PMTCT lifelong treatment programme? Why? What about with COVID-19?

Mobility and PMTCT Healthcare Availability

26) What do you think of the PMTCT services here at RMMCH? (Good/Bad)

27) What ways would you improve the services made available for PMTCT at RMMCH? Specifically for mobile populations? What about with COVID-19?

Identifying Barriers for Patients in Implementation of PMTCT lifelong treatment programming

28) What are some challenges that you are finding that your patients face with the PMTCT lifelong treatment programme/policy? P: How is it impacting their ability to comply with medication (i.e. accessibility, transportation, time, missed work)?
29) Are there any other challenges that you hear from your patients? P: maybe patients voice complaints on getting to the facility etc.?
30) How do you feel towards your patients? On most days? Are there some patients/groups that you may have challenges with? If so, please explain. Have you or any other healthcare worker ever mistreated a patient?

Compassion of Healthcare Professional

31) How do you feel when you have to tell her she is going on lifelong treatment?
32) Do you think/feel that your patients have a choice with this PMTCT lifelong treatment programme? Why or why not?
33) Do you feel you understand your patients?

Resources for Education/Educational Barriers

34) What have found with the education component of the PMTCT lifelong treatment programme at RMMCH? Do you think it is useful? Any issues?

Assessment of the Current Policies and Processes in RMMCH

35) If your patient has questions, do you think they feel comfortable enough to come to you for follow up or more information? If so, how do you ensure they feel comfortable?

Barriers in Communication

36) Does language pose a barrier at times, how do you overcome this?

Respect for Patient and Alternative Practices and Ability to Manage Role as Healthcare Professional

37) What initiatives do you take to make sure you are providing your patient with the best possible care? (stigma, respect individual privacy…)
38) How do you involve the patient in decision making around alternative treatment options?

Appendix G:
Interview Guide for Key Stakeholders involved in PMTCT Policy, Guidelines and Programming

Interview Questions- Key Stakeholders (City/Provincial/National) Levels

Exploring healthcare user perspectives on utilisation of Prevention of Mother to Child Transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa.

Melanie Bisnauth, (PhD School of Public Health)
(Faculty of Health Sciences – University of Witwatersrand)

Information about these interview questions: This gives you an idea what I would like to learn about your experience with the PMTCT lifelong treatment programme at Rahima Moosa Hospital. Interviews will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: "*So, you are saying that …?*), to get more information ("*Please tell me more?"),* or to learn what you think or feel about something ("*Why do you think that is…?").*

Interview code number: _____
Interviewer: Melanie Bisnauth

Location:_____

Date: _____

Length in (hour/mins): _____

The following for the first part of the interview is structured, collecting data on socio-demographic and clinical factors. The latter are guided questions. Domains of interest are bolded. P= probes.

Experience in Department and Work

1. What is your title?
2. Your role?
3. How long have you been working in PMTCT? In what scope? At which level (city, provincial, national?)
4. How does your role impact PMTCT? Please elaborate.

Work Environment: High Mobility, Difficulty

5. Do you think there are gaps, issues or problems related to HCWs for PMTCT or not? If so, what do you think are the most important gaps, issues, or problems for PMTCT?
6. How would you address the abovementioned challenges with PMTCT?
7. Johannesburg inner city is reported to have high numbers of mobile and migrant populations. What in your view constitutes a migrant?

8. What is your experience in working with the mobile population? Migrants? What typologies?
9. Would you say high mobility and migration has any impact on PMTCT delivery? Why? How?
10. How do you view your role in the provision of services to migrants?
11. In your experience, what solutions/interventions have already been tried to resolve any challenges with this mobile population when it comes to PMTCT service delivery?
    P: Setting up district management teams? Moving components of PMTCT care from local government to Ministry of Health? Performance based reward system?
12. Did the solutions work? Why or why not?
13. What interventions would make the biggest difference to improve PMTCT access for migrant / mobile populations?
14. Can you tell me what kind of ethically or morally challenging issues you had to tackle in your function for PMTCT? P: Allocation of resources? Transfer of HCWs? Why is it difficult? What was the outcome of this decision? Did it improve anything with PMTCT?

Types of Patients

15. Where would you say most of the patients for PMTCT lifelong treatment programme are from?
16. What are some of the reasons that you believe patients attend the PMTCT lifelong treatment programme here in SA? Gauteng? Johannesburg? Inner-city?
    P: What have you heard/seen as some of those reasons?
17. What documents do you these women need have to use PMTCT services in SA? Gauteng? Johannesburg? Inner-city? If she is RSA? If she is a non-national? (i.e. ANC card requirements? temporary resident permit, RSA ID, etc.).
18. What PMTCT services/ components are available overall for patients? P: Are there any differences? RSA national? Non-national patient coming from a different country?

Routines

19. How do your routine tasks impact the PMTCT programme? (If there is one).

Utilisation with Women who have Access to PMTCT

20. Where do you think you and your colleagues get their information about the PMTCT lifelong treatment programme?
21. Do you think patients have any challenges using PMTCT services? P: What are some of those utilisation issues ? Do you think challenges differ by nationality, migration status, other?

Adaptability

22. What strategies would you implement at city/province/national level to improve PMTCT use for mobile populations? P: Anything specifically for certain patient populations you see? Mobile populations?

Mobility and Uptake/Adherence

23. How are you finding PMTCT medication uptake/adherence? Is it increasing or decreasing in general? P: Please tell me more about why you think that?
24. Do you think after these pregnant women give birth adherence declines? Why or why not?
25. Do you think mobility has an effect on a women's uptake/adherence with the PMTCT lifelong treatment programme? Why?

Identifying Barriers for Patients in Implementation of PMTCT lifelong treatment programming

26. How do you feel about mobile populations? Migrants? Do you believe PMTCT treatment is available for all who need it? Access same quality of care for PMTCT across the country? province? city? Why or why not?

Understanding of Mobile Populations

27. Do you feel you understand what they experience when influencing policy, guidelines, or programmes for PMTCT? Please explain.
28. What perspectives do you incorporate when developing policy, guidelines, programmes for PMTCT? Please explain. Do you consider issues for migrant populations?

Resources for Education/Educational Barriers

29. What have you found with the education component of the PMTCT lifelong treatment programme? Do you think it is useful? Any issues?

Assessment of the Current Policies and Processes in RMMCH

30. What is your approach towards policy, guidelines, programming for PMTCT? Do you think about the patient centered approach? If so, how do you ensure patient perspective is included?

Barriers in Communication

31. Does language pose a barrier at times, how do you overcome this?

Alternative Practices and Ability to Manage Role as Healthcare Stakeholder

32. How do you involve the patient in decision making around alternative treatment options when making these policies, guidelines?

Appendix H:
Audio Recording Consent Form

PARTICIPANT INFORMATION SHEET AND CONSENT FORM FOR AUDIO RECORDING

A Study of/about:
Exploring healthcare user perspectives on utilisation of Prevention of Mother to Child Transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa.

Student Investigator:
Melanie Bisnauth
School of Public Health
University of Witwatersrand
Johannesburg, South Africa
(XXX) XXX-XXXX ext. XXXXX
E-mail: melaniebisnauth@gmail.com

What am I trying to discover?
To explore the experiences and challenges of healthcare users of all women in utilisation of PMTCT lifelong treatment programme in a high mobility context. The study will investigate the experience of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels, and healthcare workers as well in providing PMTCT and HIV care in such a complex environment at RMMCH. Moreover, it will reveal who the various types of women are, navigating their way through the complex healthcare system, what factors affect their experiences and how their accessibility challenges and adherence issues impact their utilisation experience on the programme.

Research Question
For HIV-positive women, aged 18 and older attending Rahima Moosa Mother and Child Hospital, what are their healthcare user experiences with PMTCT lifelong treatment? What are some of the challenges faced with using the services? Have these challenges influenced taking medication? What are the similarities and differences of women user experiences when looking at HIV and adherence? How has mobility and movement influenced their experience?

You are invited to take part in this study because it involves healthcare workers or females like yourself that are pregnant or have delivered, HIV-positive and in the PMTCT lifelong treatment programme. I want to give you a chance to express your feelings about the programme. I am hoping to learn more about ways Rahima Moosa Mother and Child Hospital can help women have better healthcare experiences, take medication and what they can change to do so. I am doing this research for a PhD thesis for part of my program in Public Health.

What will happen during the study?
If you decide that you want to be part of this study, first you will be asked to fill out this consent form. Second, I will ask you to participate in an interview in a separate room in Rahima Moosa Hospital. With your permission, this interview will be audio recorded and handwritten notes will be taken. This all should take about 1 hour. While doing these things, if you do not know what to say or do next, you can say 'I do not know'. Please feel free to ask any questions throughout the study. If you do not understand some of the words or concepts, I will take time to explain them to you as we go along. I am going to talk about things like your feelings about the programme and using PMTCT services and treatment at Rahima Moosa Hospital. I will be asking you questions about your personal journey and experience with maternal care. I will also ask you for some demographic/background information like your nationality, age, and education. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Are there any risks to doing this study?
It is not likely that there will be any harms, discomforts, inconveniences, or risks associated with this study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy. However, if you do feel discomfort or stress, we can pause or stop the study at your request.

Are there any benefits to doing this study?
The research will not benefit you directly. I hope to learn more about how healthcare workers or women healthcare experiences with the programme. I hope that what is learned as a result of this study will help Rahima Moosa Mother and Child Hospital to better understand what factors may act as barriers for women as healthcare users` and ways to improve treatment at healthcare facilities and taking your medication.

Who will know what I said or did in the study?
You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one will know whether you were in the study. Every effort will be made to protect your confidentiality and privacy. The information/data you provide will be kept in a locked desk where only I will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, an archive of the data, without identifying information, will be maintained for 10 years.

What if I change my mind about being in the study?
Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can withdraw from the study for whatever reason, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided in the interview process will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

You will still receive all the services that you usually do, and it will not have any bearing on your job. If the interview takes place, the person cannot 'stop participation' but request that the information by them not be used in the research study. Once you have interviewed, your responses will remain anonymous: your answers will be put into a database and will not be identifiable to you. This means that once you have submitted your interview responses cannot be withdrawn from the study because I will not be able to identify which responses are yours.

How do I find out what was learned in this study?
I expect to have this study completed by approximately Month-Day-Year. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study:
If you have questions or need more information about the study itself, please contact me at:

Melanie Bisnauth
Rahima Moosa Mother and Child Hospital
Department of Paediatrics and Child Health
Phone # will be provided

This study has been reviewed by the University of Witwatersrand Human Research Ethics Committee (HREC) and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the Chairperson of this Committee, who is Professor Clement Penny, and who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

CONSENT

- I have read the information presented in the information letter about a study being conducted by Melanie Bisnauth of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time.
- I have been given a signed copy of this form.
- I agree to participate in the study

I hereby give my consent to participate in the study:

Signature: _____ Date: _____

1. With your permission, we would also like to audio record the interview. Please sign below if you agree to be audio recorded during the interview.

I hereby give my consent for audio recording:

Signature: _____ Date: _____

2. …Yes, I would like to receive a summary of the study's results.
(If the organisation agrees to disseminate results to participants, the summary will be provided at Rahima Moosa Hospital, Department of Paediatrics and Children Health)

… No, I do not want to receive a summary of the study's results.
… Yes.

If yes, please provide your contact details:

Phone Number: _____

Email: _____

… No.

Signature: _____
Date: _____

Name of Participant (Printed) _____
***two copies of the form will be provided 1) researchers file 2) participant to keep

Appendix I:
Distress Protocol

Distress Protocol

The following is provided as a means of preparation should a participant become distressed during the interview and data collection/analysis phases of this study.

Prior to the commencement of any interview, information regarding the counselling available at Rahima Moosa Mother and Child Hospital (RMMCH) and in the community, should it be required will be provided to all prospective and actual study participants. This information will be made available at three points during the study:

1) Prior to a participant consenting to take part in the study;
2) In the introduction information sheet provided to the participant;
3) To the participant prior to the interview commencing.

An additional notification of this information will also be given to those participants should they become distressed during the actual interview.

Strategies to assist those distressed during an interview.

Should a participant become uncomfortable or distressed while discussing their experience. RMMCH will execute the potential strategies to address their needs during the interview, the following actions will be taken by the interviewer:

1. The interviewer will suggest that it is appropriate that the interview be terminated.
2. If the participant wishes this to happen, the interview will be completed.
3. Time will be spent with the participant and assistance provided, within the scope of interviewers' abilities, to discuss their concerns and support them, if appropriate.
4. The participant will be recommended to speak to a RMMCH health professional to discuss their concerns.
5. A follow-up phone call will be made by the interviewer the following day to ensure that the participant is alright. During this time, the information previously provided regarding counselling services in the community and at RMMCH will be, once again, provided.

Contact details provided to participants

Details of the RMMCH counsellor and community counselling services will be sent to all prospective and study participants. These details will include:

1. A list of phone number of Johannesburg Department of Health funded and delivered counselling responses as outlined in the City of Johannesburg, Department of Health Counselling Services Report.
2. Details of the organisation. This will include the following information:
    a. Goal of the organisation
    b. Information that they, the participant, will be required to provide to the health personnel manning the service.
    c. Details of the likely assistance that they may receive from contacting the service.

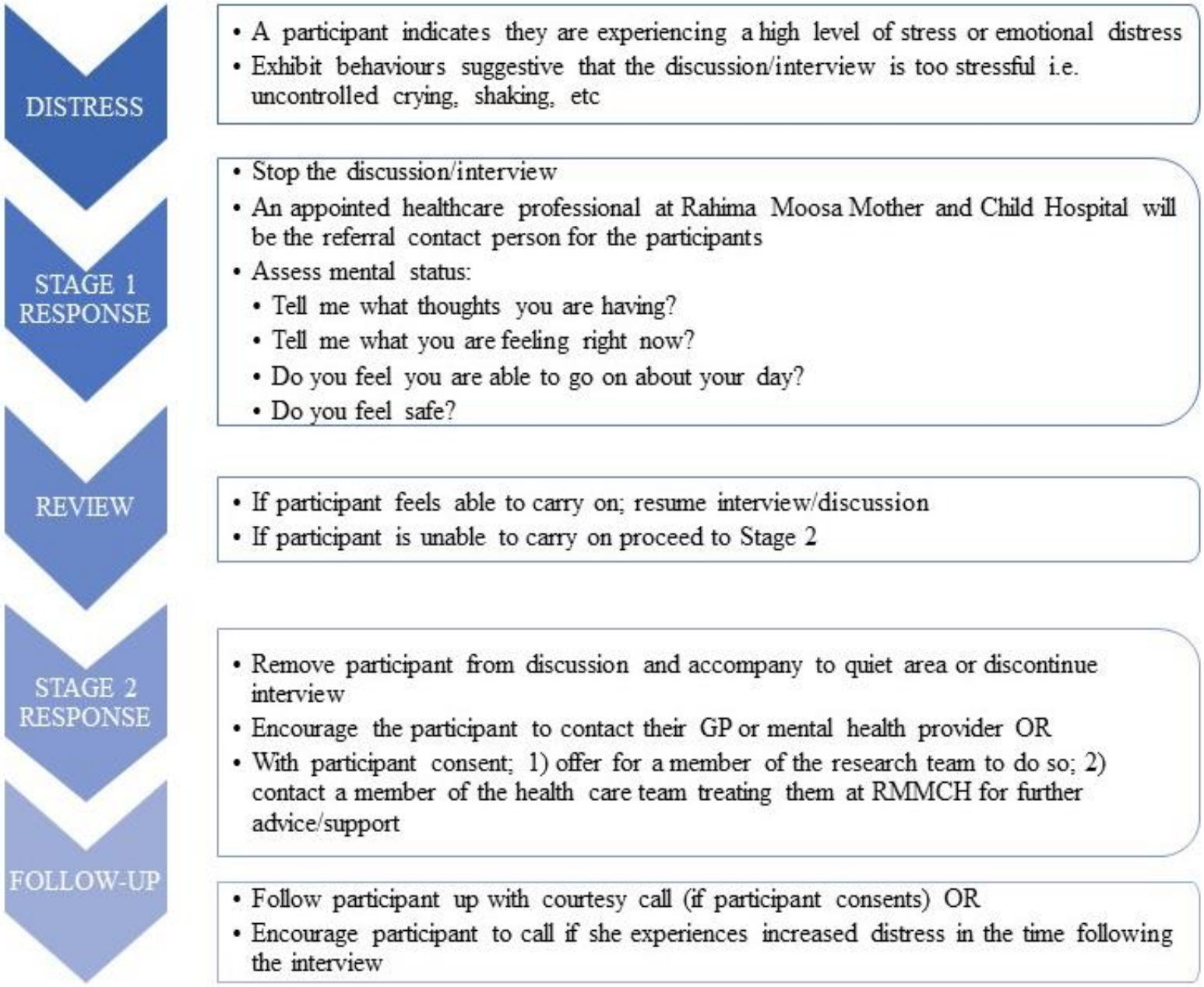
Conclusion

Although it is unlikely that these interviews will result in a distressing result for the participant, it is the interviewer's duty of care to the participant that these strategies are put in place prior to commencing the interviews.

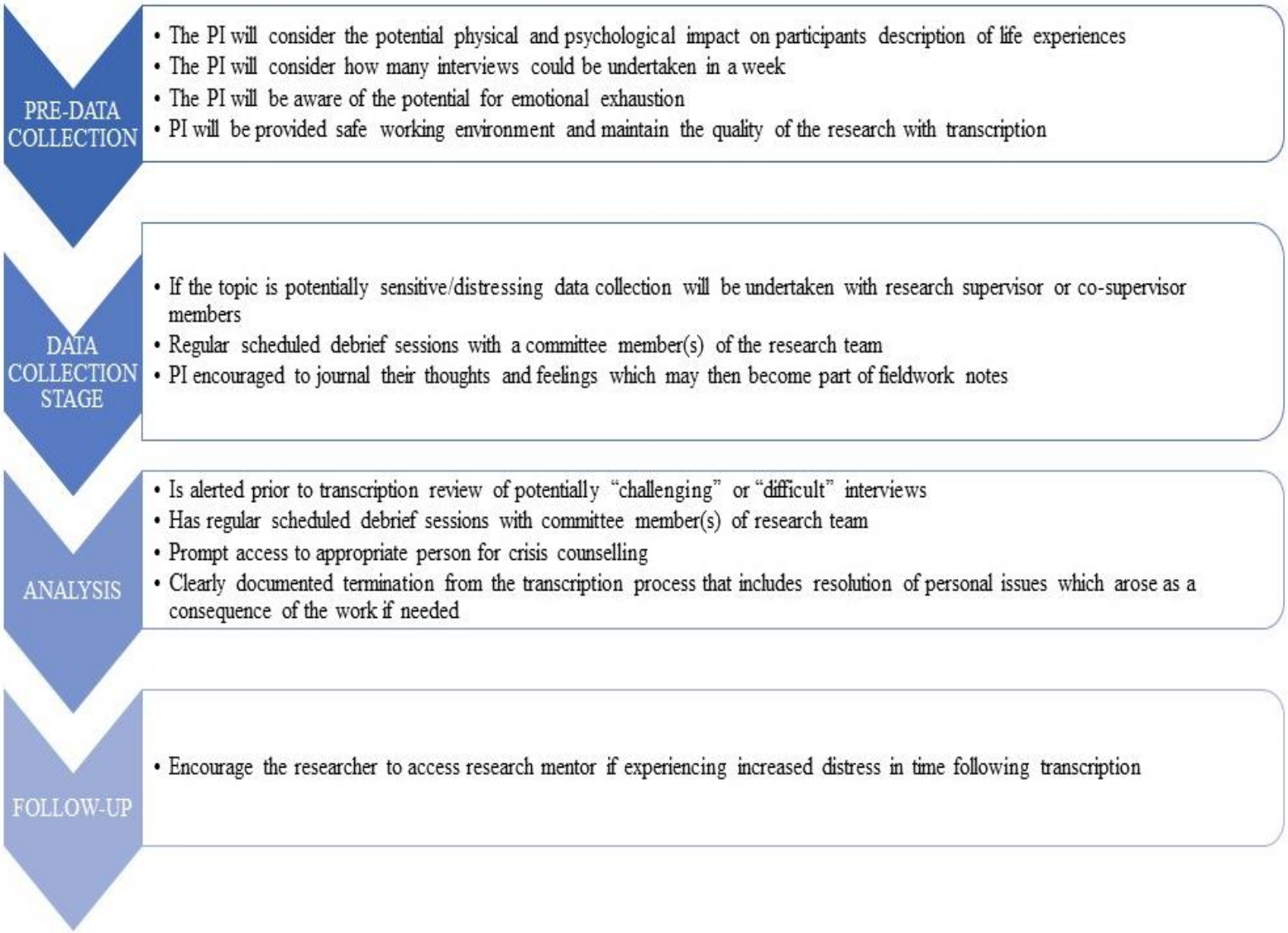
Distress Protocol 1- Diagram 1: The protocol for managing distress in the context of a research interviews (Modified from: Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Distress Protocol 2-Diagram 2: The protocol for managing distress in the context of a research interview management/transcription in data collection and data analysis phases (McCosker, H Barnard, A Gerber, R (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All. Forum: Qualitative Social Research, 2(1)' and Gregory, D Russell, C Phillips, L (1997). Beyond textual perfection: transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.)

Appendix I:
Distress Protocol 1- Diagram 1



Appendix I:
Distress Protocol 2- Diagram 2



Appendix J:
Oral Consent Form

Appendix J

Exploring healthcare user perspectives of PMTCT services in a high-mobility context: women living with HIV at Rahima Moosa Mother and Child Hospital, Johannesburg, South Africa.

Researcher: Melanie Bisnauth

Oral Consent Script

Introduction:

Hello. I'm Melanie Bisnauth. I am conducting interviews about the PMTCT lifelong treatment programme for the prevention of mother to child transmission of HIV at Rahima Moosa Hospital. I'm conducting this as part of research for my thesis at University of Witwatersrand, PhD in Public Health program in Johannesburg, Gauteng, South Africa.

What am I trying to discover?
To explore the experiences and challenges of healthcare users of all women in utilisation of PMTCT lifelong treatment programme in a high mobility context. The study will investigate the experience of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and, national levels, and healthcare workers as well in providing PMTCT and HIV care in such a complex environment at RMMCH. Moreover, it will reveal who the various types of women are, navigating their way through the complex healthcare system, what factors affect their experiences and how their accessibility challenges and adherence issues impact their utilisation experience on the programme.

What will happen during the study?
If you decide that you want to be part of this study, first you will be asked to fill out this consent form. Second, I will ask you to participate in an interview in a separate room in Rahima Moosa Hospital. With your permission, this interview will be audio recorded and handwritten notes will be taken. This all should take about 1 hour. While doing these things, if you do not know what to say or do next, you can say 'I do not know'. Please feel free to ask any questions throughout the study. If you do not understand some of the words or concepts, I will take time to explain them to you as we go along. I am going to talk about things like your feelings about the programme and using PMTCT services and treatment at Rahima Moosa Hospital. I will be asking you questions about your personal journey and experience with maternal care. I will also ask you for some demographic/background information like your nationality, age, and education. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Are there any risks to doing this study?
It is not likely that there will be any harms, discomforts, inconveniences, or risks associated with this study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy.

Are there any benefits to doing this study?
The research will not benefit you directly. I hope to learn more about how healthcare workers or women healthcare experiences with the programme. I hope that what is learned as a result of this study will help Rahima Moosa Mother and Child Hospital to better understand what factors may act as barriers for women as healthcare users` and ways to improve treatment at healthcare facilities and taking your medication.

I will keep the information you tell me during the interview confidential. Information I put in my report that could identify you will not be published or shared beyond the research team unless we have your permission. Any data from this research which will be shared or published will be the combined data of all participants. That means it will be reported for the whole group not for individual persons.

Who will know what I said or did in the study?
You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one will know whether you were in the study. Every effort will be made to protect your confidentiality and privacy. The information/data you provide will be kept in a locked desk where only I will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, an archive of the data, without identifying information, will be maintained for 10 years.

Voluntary participation:
- Your participation in this study is voluntary.
- You can decide to stop at any time, even part-way through the interview for whatever reason.
- If you decide to stop participating, there will be no consequences to you.
- If you decide to stop we will ask you how you would like us to handle the data collected up to that point.
- This can include; data can be destroyed it or using the data collected up to that point.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- If you have any questions about this study or would like more information you can call or email Melanie Bisnauth at **(number will be provided for office)**

You will still receive all the services that you usually do and it will not have any bearing on your job. If the interview takes place, the person cannot 'stop participation' but request that the information by them not be used in the research study. Once you have submitted your responses for this anonymous interview: your answers will be put into a database and will not be identifiable to you. This means that once you have submitted your responses cannot be withdrawn from the study because I will not be able to identify which responses are yours.

This study has been reviewed by the University of Witwatersrand Human Research Ethics Committee (HREC) and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Please let me know if you would like a summary and what would be the best way to get this to you.

Consent questions:
- Do you have any questions or would like any additional details?
  [Answer questions.]

- Do you agree to participate in this study knowing that you can withdraw at any point with no consequences to you?
  [If yes, begin the interview.]
  [If no, thank the participant for his/her time.]

Read aloud:
- I have read the information presented in the information letter about a study being conducted by **Melanie Bisnauth** of University of Witwatersrand.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time.
- I have been given a copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.
… Yes.
… No.

2. …Yes, I would like to receive a summary of the study's results.
(If the organisation agrees to disseminate results to participants, the summary will be provided at Rahima Moosa Hospital, Department of Paediatrics and Children Health)

… No, I do not want to receive a summary of the study's results.

If yes, please provide your contact details:

Phone Number: _____

Email: _____

… No.

Signature: _____ Date: _____

Name of Participant (Printed) _____

***two copies of the form will be provided 1) researchers file 2) participant to keep

Appendix K:
Study Information Sheet and Written Consent Form

STUDY INFORMATION SHEET AND WRITTEN CONSENT FORM

A Study of: *Exploring healthcare user perspectives on utilisation of Prevention of Mother to Child Transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa.*

Student Investigator:
Melanie Bisnauth
School of Public Health
University of Witwatersrand
Johannesburg, South Africa
(XXX) XXX-XXXX ext. XXXXX
E-mail: melanie@gmail.com

Purpose of the Study:
To explore the experiences and challenges of healthcare users of all women in utilisation of PMTCT lifelong treatment programme in a high mobility context. The study will investigate the experience of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and, national levels, and healthcare workers as well in providing PMTCT and HIV care in such a complex environment at RMMCH. Moreover, it will reveal who the various types of women are, navigating their way through the complex healthcare system, what factors affect their experiences and how their accessibility challenges and adherence issues impact their utilisation experience on the programme.

Research Question
For HIV-positive women, aged 18 and older attending Rahima Moosa Mother and Child Hospital, what are their healthcare user experiences with PMTCT lifelong treatment? What are some of the challenges faced with using the services? Have these challenges influenced taking medication? What are the similarities and differences between these women user experiences when looking at HIV and adherence? How has mobility and movement influenced their experiences?

You are invited to take part in this study because it involves key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels, healthcare workers or women like yourself that are pregnant or have delivered, HIV-positive and in the PMTCT lifelong treatment programme. I want to give you a chance to express your experience using PMTCT services at Rahima Moosa Hospital. I am hoping to learn more about ways Rahima Moosa Mother and Child Hospital can help women have better healthcare experiences, take medication and what they can change to do so. I am doing this research for a PhD thesis for part of my programme in Public Health.

What will happen during the study?
If you decide that you want to be part of this study, first you will be asked to fill out this consent form. Second, I will ask you to participate in an interview in a separate room in Rahima Moosa Hospital. With your permission, this interview will be audio recorded and handwritten notes will be taken. This all should take about 1 hour. While doing these things, if you do not know what to say or do next, you can say 'I do not know'. Please feel free to ask any questions throughout the study. If you do not understand some of the words or concepts, I will take time to explain them to you as we go along. I am going to talk about things like your feelings about the programme and using PMTCT services and treatment at Rahima Moosa Hospital. I will be asking you questions about your personal journey and experience with maternal care. I will also ask you for some demographic/background information like your nationality, age, and education. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Are there any risks to doing this study?
It is not likely that there will be any harms, discomforts, inconveniences, or risks associated with this study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. I describe below the steps I am taking to protect your privacy. However, if you do feel discomfort or stress, we can pause or stop the study at your request.

Are there any benefits to doing this study?
The research will not benefit you directly. I hope to learn more about how healthcare workers or women healthcare experiences with the programme. I hope that what is learned as a result of this study will help Rahima Moosa Mother and Child Hospital to better understand what factors may act as barriers for women as healthcare users` and ways to improve treatment at healthcare facilities and taking your medication.

Who will know what I said or did in the study?
You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one will know whether you were in the study. Every effort will be made to protect your confidentiality and privacy. The information/data you provide will be kept in a locked desk where only I will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, an archive of the data, without identifying information, will be maintained for 10 years.

What if I change my mind about being in the study?
Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can withdraw from the study for whatever reason, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided in the interview process will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

You will still receive all the services that you usually do and it will not have any bearing on your job. If the interview takes place, the person cannot 'stop participation' but request that the information by them not be used in the research study. *Once* you have submitted your responses for this anonymous interview, your answers will be put into a database and will not be identifiable to you. This means that once you have submitted, your responses cannot be withdrawn from the study because I will not be able to identify which responses are yours.

How do I find out what was learned in this study?
I expect to have this study completed by approximately **Month-Day-Year**. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study:
If you have questions or need more information about the study itself, please contact me at:

Melanie Bisnauth
Rahima Moosa Mother and Child Hospital
Department of Paediatrics and Child Health
Phone # will be provided

This study has been reviewed by the University of Witwatersrand Human Research Ethics Committee (HREC) and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Refer to next page for Consent Form*

CONSENT

- I have read the information presented in the information letter about a study being conducted by **Melanie Bisnauth** of University of Witwatersrand.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time.
- I have been given a copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.
… Yes.
… No.

2. …Yes, I would like to receive a summary of the study's results.
(If the organisation agrees to disseminate results to participants, the summary will be provided at Rahima Moosa Hospital, Department of Paediatrics and Children Health)

… No, I do not want to receive a summary of the study's results.

If yes, please provide your contact details:

Phone Number: _____

Email: _____

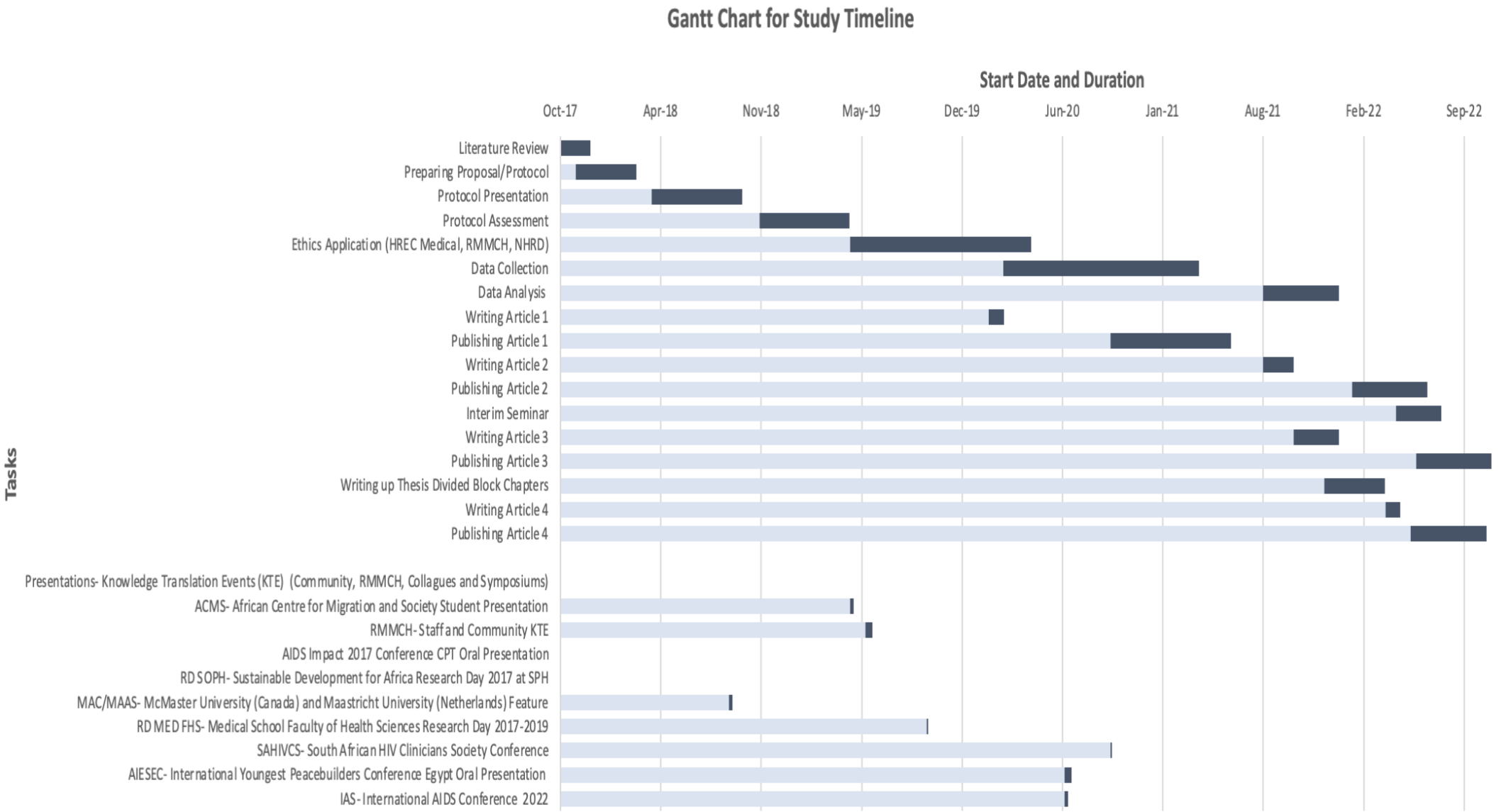
… No.

Signature: _____ Date: _____

Name of Participant (Printed) _____

ID Number _____
***two copies of the form will be provided 1) researchers file 2) participant to keep

Appendix L:
Gantt Chart for Study Timeline



Appendix M:
Funding and Budget

NB: The study was funded until February 2021 by Life in the City, School of Governance, University of Witwatersrand.

Research Project Detail	**Projected Cost**	**Total Cost**
Recruitment Costs		
Refreshments (participants partaking in 1-hour qualitative interviews)	3750 ZAR	
Printing (information sheets, consent forms, translated IEC material, protocol, thesis)	15 800 ZAR	**19 550 ZAR**
Transport Costs		
Travel expenditure to/from Rahima Moosa Hospital	5 500 ZAR	
Data Collection & Analysis		
Translator/Transcription (for 1-hour qualitative interviews with participants)	15 000 ZAR	
Software License for NVivo Q12 (Qualitative)	27 000 ZAR (Quote Full License)	
STATA		
RedCap Training		
Tablet and Phone, Headphones for Research Assistant (COVID-19)	3 000 ZAR	**50 500 ZAR**
		70 050 ZAR
Knowledge Translation Events (KTE)		
(presentations and brochures for Rahima Moosa Hospital Staff, Community Event, ACMS, School of Public Health) opportunities to disseminate findings to key audiences	10 000 ZAR	
Presentations (AIDS Impact Jul 2017, PHASA, AIESEC Egypt Jul 2018, Wits 2019, SAHIVCS Oct 2020, IAS 2022, Fast Track Cities 2022)	39 600 ZAR	
Publications (International incl.)	181 400 ZAR	***231 000 ZAR***
Total		***301, 050 ZAR***

Appendix N:
Table of Publications

Objective	Themes	Papers	Journal	Publication Status & Date
1) To explore all women's experiences of utilisation of the PMTCT lifelong treatment programme at RMMCH.	PMTCT Health Policy, Guidelines and Programming: Exploring Adaptability Patient centered care for PMTCT utilisation	Option B+ Program for the Prevention of Vertical Transmission of HIV: a Case Study in Johannesburg, South Africa	Frontiers Journal of Public Health	Published October 2020
2) To investigate the experiences of HCWs providing PMTCT at RMMCH and perceptions of key stakeholders in PMTCT policy, guidelines and programming at city, provincial and national levels regarding PMTCT accessibility and migration in a high mobility context during the COVID-19 pandemic.	Challenges of PMTCT service provision to migrants utilising maternal care in South Africa	Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers	SAGE Health Services Insights Journal	Published January 2022

3) To identify the various mobility typologies of women utilising the PMTCT services at RMMCH and; **4)** To qualitatively explore differences and similarities in utilisation experiences between different typologies (in relation to mobility) of women on the PMTCT lifelong treatment programme during the COVID-19 pandemic.	Challenges for migrants accessing maternal care in high mobility context, South Africa Typologies of Mobility and Challenges that impact utilisation for PMTCT Ill-treatment in healthcare settings	Addressing the Migrant Gap: Maternal Healthcare Perspectives on Utilising Prevention of Mother to Child Transmission (PMTCT) services during the COVID-19 pandemic, South Africa	Taylor & Francis Global Health Action	Published August 2022
*Additional paper	Policy and practice gaps in PMTCT services for migrant – a way forward	Challenges and lessons learned in Prevention of Mother to Child Transmission (PMTCT) services for migrant women living with HIV during the COVID-19 pandemic: a qualitative study in South Africa	BMC Public Health	Chapter 9- TBD

Appendix O:
Declaration of Students Contribution to Articles

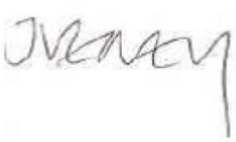
Declaration**:**

Student's contribution to article(s) and agreement of co-author(s)

I, Melanie Ann Bisnauth, student number 1589334, declare that this Thesis is my own work and that I contributed adequately towards research findings published in the articles stated below which are included in my Thesis.

Signature of Student … 
Date…24/05/2022

Name of Primary Supervisor…Dr. Jo Vearey

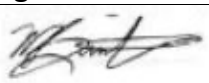


Signature of Primary Supervisor … **Date** 20 June 2022

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Thesis. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for his/her degree purposes.

Article 1: Title: Option B+ program for the prevention of vertical transmission of HIV: a case study in Johannesburg, South Africa

- **Journal name, year, volume and page numbers:** Frontiers International: Public Health Journal. doi: https://doi.org/10.3389/fpubh.2020.533534, October 2020, Volume 8, Article 533534, p. 1-14

Authors	Name	Signature	Date
1st author	M.A. Bisnauth		24 May 2022
2nd author	A. Coovadia		20 June 2022
3rd author	L. Mbuagbaw		
4th author	M.G. Wilson		
5th author	S. Birch		

Comments by primary supervisor:

……

Article 2: Title: Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers

Journal name, year, volume and page numbers: SAGE *Health Services Insights*, UK, https://doi.org/10.1177/11786329211073386, January 2022, Volume 15, p. 1-11

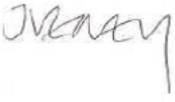
Authors	Name	Signature	Date
1st author	M.A Bisnauth		24 May 2022
2nd author	A. Coovadia		20 June 2022
3rd author	M. Kawonga		1 July 2022
4th author	J. Vearey		20 June 2022

Comments by primary supervisor:

……

Article 3: Title: Addressing the Migrant Gap: Maternal Healthcare Perspectives on Utilising Prevention of Mother to Child Transmission (PMTCT) services during the COVID-19 pandemic, South Africa

- **Journal name, year, volume and page numbers:** Global Health Action, Sweden, Under Final Review for Publication, July 2022

Authors	Name	Signature	Date
1st author	M.A Bisnauth		24 May 2022
2nd author	A. Coovadia		20 June 2022
3rd author	M. Kawonga		1 July 2022
4th author	J. Vearey		20 June 2022

Comments by primary supervisor:

……

Appendix P:
Turn It In Report

ORIGINALITY REPORT

21%	20%	16%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.ncbi.nlm.nih.gov Internet Source	7%
2	Macsphere.mcmaster.ca Internet Source	5%
3	www.frontiersin.org Internet Source	2%
4	journals.lww.com Internet Source	1%
5	Melanie A Bisnauth, Ashraf Coovadia, Mary Kawonga, Jo Vearey. "Providing HIV Prevention of Mother to Child Transmission (PMTCT) Services to Migrants During the COVID-19 Pandemic in South Africa: Insights of Healthcare Providers", Health Services Insights, 2022 Publication	<1%
6	doaj.org Internet Source	<1%

Appendix Q:
Closing Report HREC Letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

2022/10/25

Ms M Bisnauth
School of Public Health
Medical School
University

Sent by e-mail to: melanie_bisnauth@live.com

Dear Ms Bisnauth

Re: **Protocol Ref No:** M190816
Protocol Title: *Exploring healthcare user perspectives on utilisation of prevention of mother to child transmission (PMTCT) services in a high-mobility context in Johannesburg, South Africa*
Principal Investigators: Ms M Bisnauth

Thank you for your letter of 2022/10/21.

We note your closing report and an impressive publications output, especially given the obstacles placed in your way by the recent Covid-19 pandemic.

Thank you for keeping us informed.

Yours Sincerely

J. Burns
.....
Mr I Burns
For the Human Research Ethics Committee (Medical)

CB Penny
.....
Dr CB Penny, Chairperson, Human Research Ethics Committee (Medical)