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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

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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.