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TREATMENT EXPERIENCES OF HIV POSITIVE TEMPORARY CROSS-BORDER MIGRANTS IN JOHANNESBURG: ACCESS, TREATMENT CONTINUITY AND SUPPORT NETWORKS

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A thesis submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in partial fulfilment of the degree of Master of Arts in Forced Migration Studies

Supervisors: Matthew Wilhelm-Solomon and Joanna Vearey

Johannesburg, 2013

DECLARATION

I declare that this dissertation is my own work. It is submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, for the degree of Master of Arts in Forced Migration studies. It has not been submitted for any other degree, or for examination in any other University.

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Roseline Hwati

22 March 2013

ABSTRACT

As the economic hub of South Africa, Johannesburg attracts cross-border migrants in search of improved livelihoods; over half the population of some of its inner-city suburbs are made up of cross border migrants. Globally as well as locally, foreigners have been blamed for the spread of diseases such as HIV. As a result, they have suffered challenges in accessing public healthcare, particularly antiretroviral treatment (ART) for HIV. Studies have shown that despite these challenges - foreigners experienced better ART outcomes than nationals. There is a need to explore the ways in which cross border migrants use to access and to stay on treatment, given the wide-range of challenges that they face during their stay in Johannesburg. Semi-structured interviews with five nurses and ten cross-border migrants currently receiving ART, along with non-participant observations, were used to collect data from two public clinics in inner-city Johannesburg. Analysis suggests that the family network in the country of origin remains critical, as cross border migrants are not disclosing their status in the city in which they live, but do so to their families in their countries of origin. Data shows that when it comes to accessing and staying on treatment, cross-border migrants go to the clinic every month as do nationals; ask for more treatment from nurses when going home temporarily; eat healthily; but hide when taking medication, and negotiate confidentiality and trust within their families in countries of origin. Some are found to access treatment in their countries of origin while staying in Johannesburg. Despite the lack of social networks in the inner city, this data suggests that cross-border migrants are successful in accessing and continuing with ART. There is need for future research to look at social networks for internal migrants, so as to compare results.

DEDICATION

To you, my ever supportive sister Daphne Mpofu, and my late father, Jokoniah Hwati.

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LIST OF ABBREVIATIONS

ART	Antiretroviral Therapy
HIV	Human Immune Virus
AIDS	Acquired Immune-Deficiency Syndrome
UNDP	United Nations Development Programme
IOM	International Organization for Migration
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
HPV	Human Papillomavirus
COJ	City of Johannesburg
DAAD	Deutscher Akademischer Austausch Dienst
SADC	Southern African Development Community
UNHCR	United Nations High Commissioner for Refugees
MSF	Medecins Sans Frontiers
CSVR	Centre for the Study of Violence and Reconciliation
JP	Joubert Park Clinic
AS	Albert Street clinic
TAC	Treatment Action campaign

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CHAPTER ONE: INTRODUCTION AND BACKGROUND TO THE STUDY

1. Introduction

The study explores the experiences of treatment access and continuity among HIV positive cross-border migrants, who are on antiretroviral therapy[1] (ART) in Johannesburg. This was done by looking at the way in which the issues of support and belonging influence how migrants living with HIV/AIDS access and stay on HIV treatment. It is a common assumption in the literature that people on treatment require support groups and that ART gives rise to new social relationships like support groups, but my study questions this showing that family networks remains the locus for temporary cross-border migrants on ART in the city of Johannesburg. Moreover, the study explores how their family networks shape their notions of belonging and home, given that treatment is a lifelong commitment, and may not be readily available in their areas of origin; the study looks at whether support and belonging will make them to want to stay in Johannesburg, or go back to their countries of origin. The study explores what cross-border migrants who are successful in complying with their treatment do in order to access and stay on HIV treatment, and examines the challenges faced by those that are not successful in this regard.

Cross-border migrants are those people who have crossed national borders, residing outside their countries of origins UNDP (cited in IOM, 2010; Martin, 2001). The study mainly focused on temporary cross border-migrants, who are those individuals with no permanent residence permit, as well as undocumented cross-border migrants. For the purpose of this study, temporary cross border migrants will be defined as those people that, according to the South African immigration amendment Act No. 13 of 2011 (section 10, (a) to (l)), are those in possession of temporary residence permit, including asylum seekers. Undocumented cross-

[1] ART from herein after.

border migrants are those individuals with no documentation allowing them to legally stay in the host country (Director for Social and Human Development and Special Programs, 2009). This study excluded documented refugees, as they fall into the category of foreign nationals with permanent residence, who as a result are afforded the same rights as citizens, as set out in the Refugees Act No. 130 of 1998 (section 5, (g)). The category of the cross-border migrants focused on in this study was not those on transit or those who go to their countries of origin and come to South Africa every month, but on those that stay in the city of Johannesburg indefinitely. This is because temporary cross-border migrants face challenges of documentation which might be either going to get them stamped all the time or not having them which might pose them challenges of getting secure jobs. For the purpose of this study, the terminology temporary cross-border migrants and cross-border migrants will be used interchangeably, to refer to the above category. This research is based on cross-border migrants accessing HIV treatment from Albert Street and Joubert Park clinic in the Johannesburg. These are primary healthcare clinics run by the city of Johannesburg, and they are in Region F of the inner-city of Johannesburg (COJ, 2013). In this study, self-reported stories of different experiences of what temporary cross-border migrants do to access and to stay on HIV treatment were used. Given the risks that accompany migration generally, and cross-border migration in particular – such as threats of deportation (Vearey & Wilhelm-Solomon, 2011), high physical mobility, change of residence (Vearey, 2008), language barriers, xenophobic attitudes in South African society (Landau & Freemantle, 2010) and problems of documentation and police harassment (Muanamoha, Maharaj and Preston-Whyte, 2010) – it is important to find out what cross-border migrants do to access and to stay on HIV treatment, and to ascertain how these experiences shape their health identities. Whyte (2009, p. 6) notes that, “The formation of identity and subjectivity in relation to health is a fundamental issue in social science”. Considering that people are required to stay on treatment in order to remain healthy (Vervoort, Borleffs, Hoepelman and Grypdonck, 2007),this research undertakes to understand the different strategies used by cross-border migrants in order to access and to stay on treatment in the face of various challenges.

The study drew upon the literature on access and adherence to ART, access to healthcare, migration and the lived experiences of migrants in Johannesburg, migration and belonging, and the literature on health identities, drawing on perspectives from public health, migration studies and medical anthropology. These studies are given further dimension in the way in which the study attempts to understand what cross-border migrants on ART do to access and

remain on treatment in the city of Johannesburg. The rest of this introduction chapter will discuss the statement of the problem, the research question; aim, objectives and justification of the study.

1.1 Statement of the Problem

Cross-border migrants face the challenges associated with migration, for example poor housing (Fennely, 2005), language barriers (UNHCR, 2010), xenophobic sentiments (Landau & Freemantle, 2010), and even access to healthcare (Vearey, 2011) when they are in South Africa, and particularly when in Johannesburg. It is however, significantly more challenging for those on ART, since they have to continue with regular treatment in order to stay healthy. It is important to find out what cross-border migrants on ART do to access and negotiate continuity of treatment, since it is lifelong. This is because internationally, migrants face challenges in accessing treatment, which might have an impact on their continued access and continuity of ART showing that there is something that HIV positive cross-border migrants on ART in Johannesburg are doing in order to access and to continue with treatment, which can best be understood from the HIV positive cross-border migrants on treatment, and the healthcare workers that provide treatment to them.

1.2Research Questions

This study aims to answer the following empirical questions:

(1) What do cross-border migrants receiving HIV treatment do to access and stay on antiretroviral treatment?

(2)Are there cross-national support groups in the diaspora community and how do you access these networks?

In responding to the above empirical questions, the study also addressed the sub-questions in Appendix E.

1.3 Aim

The study's aim was to understand experiences and responses of cross-border migrants in accessing and staying on HIV treatment. The study also sought to understand how support networks and belonging shape what they do, in order to ensure continuity of treatment, given the potential challenges that are associated with mobility and migration, for example when it comes to temporary cross-border migrants. More so, looking at the fact that treatment might require them to stay in Johannesburg, in the event that ART might not be readily available in their countries of origin.

1.4 Objectives

The objectives of the study were to:

- Determine whether migrants have future plans for staying on treatment if they move back home forever, during short holidays, or if unplanned movement takes place.
- Identify their sense of belonging and their experiences of staying on treatment
- Explore the strategies that cross-border migrants use in accessing and staying on treatment.
- Explore how they access support systems.
- Determine the health identities that are formed due to their experiences of accessing and staying on treatment.

1.5 Justification

There is a gap in terms of the literature on access and treatment continuity in South Africa when it comes to cross-border migrants. There are studies that have looked at the concerns around how cross-border migrants have been deported, and this poses risks for their continuity of treatment, as states fail to protect their rights (Human Rights Watch, 2009a;

Human Rights Watch, 2009b). Some studies have focused on migrants and their access to treatment, which raises questions of stigma and treatment continuity (Vearey, 2008; Vearey, 2011; Vearey and Wilhelm-Solomon, 2011). Other studies have looked at the challenges faced by migrants living in South Africa and their difficulties in accessing follow-up treatment (Bygrave et al., 2010). However, there is a need to understand more about the different obstacles that HIV positive cross-border migrants are facing, as well as what they do to access and stay on treatment. Many may choose to change abode, which is a common and regular phenomenon in Johannesburg. Temporary, permanent, planned and unplanned mobility is taking place and people are moving back home. There is a need to look at their perceptions as well as to examine what they intend to do to access and to continue with treatment. The research wanted to have an influence in the following interventions:

(1) To contribute to policy debates around migrant access to healthcare.

(2) To add to literature on access and continuity of ART among cross-border migrants.

(3) To see whether cross-border migrants in need of ART are getting it.

1.6 Conclusion

In conclusion, cross-border migrants in general and HIV positive cross-border migrants in particular, face different challenges globally, regionally and nationally. It is important to understand what they do to access and stay on treatment, given the different challenges that they face when they are in the city of Johannesburg. This is due to the fact that for them to stay healthy, they need to stay on ART, whether in the city of Johannesburg, or in their countries of origin.

CHAPTER TWO:

LITERATURE REVIEW

2. Introduction

The literature relevant to this study has been reviewed from various disciplines on public health, medical anthropology and migration studies, and will deal with the following themes: migration in the context of Southern Africa, South Africa and Johannesburg; provide a background of HIV and AIDS and ART globally, nationally and in Johannesburg in particular; and provide a brief history of the public healthcare system and the history of migration and access to health services in Johannesburg and the South African context; access to health services; access to HIV treatment among migrants; studies on continuity of HIV treatment; HIV and deportation; and health identities and belonging. This literature is from studies done globally, regionally and nationally. These discussions aim to give a contextual background to this study.

2.1 Migration in Southern Africa and the South African Context

Economic differences between countries are said to influence migration in Africa (Arango cited in Adepoju, 2006). Internal and international migrations in Southern Africa are complementary in this respect, because they are both caused by economic and social factors which lead people to migrate (Adepoju, 2006). Adepoju argues that migration in Africa is characterised by labour migration in Western and Central Africa, refugee flows in Eastern Africa and labour migration from Eastern and Southern African countries to South Africa. There is increasing migration due to political, economic and social pressures across Africa as a continent, as well as elsewhere in the world. IOM (2010) defines internal migration as the movement of people within the country. There are two types of cross-border migration, and these are voluntary and forced migrations (Martin, 2001; Director for Social and Human Development and Special Programs, 2009). Voluntary migrants are those that leave their

countries of origin, travelling to other countries to seek improved livelihoods, while forced migrants are those that leave their countries of origin due to conflict, human rights abuses and political suppression (Martin, 2001). Cross-border migration in South Africa comprises both documented and undocumented migrants. Landau and Wa Kabwe-Segatti (cited in IOM, 2010) argue that it is challenging to provide the exact figure of undocumented migrants in South Africa. However, undocumented migrants in South Africa are estimated to be around 8-10 million (FMSP and Musina Legal Advice Office; Landau & Wa Kabwe-Segatti as cited in IOM, 2010). Statssa (2012) note that international migration of approximately 1.4 million people has taken place in South Africa amongst the black population since 1996, with emigration of 447 000 members of the white population. A small but important number of these migrants are refugees and asylum-seekers (Vearey, 2008). Hawley (2008) notes that there is no exact figure of foreign-born nationals now living in South Africa, but that the Institute of Race Relations believes it is between three and five million. According to IOM (2010) 1.6 million cross-border migrants currently reside in South Africa. Statssa (2012) argues that migration is important when looking at the population in Gauteng, because it is a process that has shaped its population. The economy in Gauteng is high, and attracts many migrants who come in search of jobs (Statssa, 2011). Recent data from the 2011 census shows that there are 12.2 million people residing in Gauteng and that this has increased from the population in 2001, mainly because of migration (Statssa, 2012). While it had 566 760 internal migrants in 2001, it had 901 622 internal migrants in 2011 (Statssa, 2011). Landau and Wa Kabwe-Segatti (cited in IOM, 2010) argues that 18 per cent of Gauteng's population moved to the province since 2001.

Closely related to the above, Johannesburg is the largest city in South Africa, and a majority of the migrants appear to come from poorer countries (Berger, 2008). Some neighbouring countries like Zimbabwe and the Democratic Republic of Congo have experienced a political crisis which has led to cross-border migration and lack of enough job opportunities, which have forced many to escape to South Africa (Berger, 2008). Berger (2008, p. 2) points to the fact that Johannesburg is an economic hub in the region, acting as a major contributor to the national economy, and that it is within easy reach of neighbouring countries like Botswana, Mozambique, and Zimbabwe. Jacobsen (cited in IOM, 2010) argues that almost a quarter of the Johannesburg inner-city population are cross-border migrants. Recent data by Landau; Vearey, Palmary and Nunez et al., (cited in IOM, 2010) argues that in some inner-city suburbs, over half of the population in Johannesburg inner-city are cross-border migrants.

Different migrant groups are governed by different legislations and have different rights. Martin (2001) argues that states have different responsibilities towards different types of migrants and 130 countries have signed the UN Convention relating to the status of refugees, in which they are not supposed to return them to circumstances in which they might reasonably fear persecution, and therefore they have an obligation to protect the refugees that they would have admitted. South Africa is amongst the countries that abide by this; with the same law applying to refugees internationally also applies to refugees in South Africa as stated in the Refugees Act No. 130 of 1998. There is no other legal obligation that extends beyond the UN convention relating to the status of refugees when it comes to international migrants; however there is the international human rights law, national laws and international labour organisation conventions that protect the recruitment and employment rights in host countries (Martin, 2001). Johannesburg is a good and exceptional case study to explore migrants' access to ART because of the density of migrants given the fact that they are now accessing health care at state health services.

2.2 History of HIV and AIDS

AIDS[2] was first discovered in 1981 and is caused by HIV-1, and though HIV-2 causes AIDS, it is less aggressive as an illness and is predominantly found in West Africa (Lewthwaite & Wilkins, 2009). A high level of HIV in the body leads to the destruction of the CD4 cells[3] (Lewthwaite & Wilkins, 2009). According to UNAIDS (2011), 34 million people in the world were living with HIV, and 5.6 million were from South Africa at the end of 2010. In relation to this, UNAIDS (2009) notes that the challenges of HIV are that over 500,000 new infections in adults are happening annually, and that AIDS results in 1,000 deaths every year. Vadiee (2011) argues that 27 million people have died from AIDS, and more than 60 million people are infected worldwide, hence the HIV epidemic is entering into its 3rd decade of prevalence. Some authorities have also shown that South Africa is one of the countries with the highest number of people living with HIV (Johnson, 2012; UNAIDS, 2011; Stein, Lewin and Fairall, 2007). According to Statssa (2012), the estimated overall HIV prevalence rate of the total population in South Africa is approximately 10.6%, and it is estimated that 5.38 million people of the South African population were HIV positive in 2011.

[2] Acquired Immune deficiency Syndrome

[3] Key immune effector cell or CD4 lymphocyte

2.3 History of Anti-retroviral Therapy

In response to the global HIV epidemic, the World Health Organization (WHO) recommended a public health approach to ART, which has been widely implemented (Gupta et al., 2012). At the end of 2011, more than 8 million people were receiving ART in low-income and middle-income countries, which was 26 times higher than the number in December 2003 (Gupta et al., 2012). In South Africa, better-resourced provinces started the ART rollout as early as 2001, regardless of the lack of national direction (Coetzee et al. cited in Stein et al., 2007). However, some poorer and some rural provinces lacking resources started the ART rollout in May 2004 (Stein et al., 2007). According to Statssa (2012), in 2005 in South Africa, in the overall population aged 15 years and older, of those who were in need of ART only 101 416 were receiving ART and among children of the overall population, only 11 959 of those who were in need of ART were receiving ART. In 2010, among the overall population of the ages 15 years and older, of those who were in need of ART, 1 058 399 adults were receiving ART, whilst among children of the overall population – of those in need of ART – 105 123 were receiving ART (Statssa, 2012). UNAIDS (2011) notes that as a result of the HIV testing and counselling campaign and treatment expansion that took place in South Africa from April 2010 to June 2011, the number of public health facilities initiating ART increased from 495 to 2 948. They also state that ART rollout continues to be successful, noting that among the 1.4 million people initiated onto ART, 1.1 million remain on ART (UNAIDS, 2011). The improvement of ART access in South Africa was also a result of the pressure of civil society groups like the Treatment Action Campaign (TAC) (Robins & von Lieres, 2004). Statsa (2012) argues that those who become infected with HIV do not need ART immediately, because there is an asymptomatic time during which the body's immune system controls the HIV infection, but that after some time and as the virus increases in the body, the patient will be in need of ART, as the body will be overwhelmed. Stein (2007) argues that ART has offered hope to patients.

HIV can be managed if patients continue to take their treatment. Vervoort et al. (2007), Persson et al. & Pierret (cited in Gilbert & Walker, 2009) note that Highly Active Anti-Retroviral Therapy (HAART) has reduced HIV and AIDS-related mortality and that the lifelong treatment has turned HIV from a terminal infection into a chronic disease. Adherence

of 90% to 95% or more is required to suppress the virus (Hammami et al., 2004; Davies et al., 2008). UNAIDS (2012) also argues that globally, people who adhered 95% to the treatment were healthy and could live longer. Osterberg and Blaschke (2005) define adherence to medication as the degree to which patients take their medication as required. From this it is clear that adherence to HIV treatment is a lifelong medical issue, that all patients already on ART have to strictly follow in order to remain healthy. Effective treatment will help with undetectable viral load, as well as with reducing the risk of transmission. While this is not an adherence study as such I explore the strategies people use in adhering to treatment and how this has implications for long term treatment and social relationships.

2.4 History of the public healthcare system in the South African context and Johannesburg

The history of South Africa has had effects on the health policies and the health services that are in existence today (Coovadia et al., 2009). This is because, during apartheid, the society was structured according to race, with the result that health services for blacks were not well funded in comparison to services for whites, and this had an effect on access to health services (Coovadia et al., 2009; Kleinert & Horton, 2009). The post apatheid constitution binds the state to work towards the right to healthcare, but there are still experiences of inequality when it comes to healthcare services (Coovadia et al., 2009). The ANC's health plan of the post-apartheid era focused on primary healthcare and the public healthcare system was transformed so as to address the inequalities of the apartheid era (Coovadia et al., 2009). While post-apartheid policies have brought some improvements in public healthcare, there were also some challenges experienced, especially during Thabo Mbeki's presidency, due to the fact that he was reluctant to acknowledge the need for HIV treatment. This together with the approach by the former minister Manto Tshabalala-Msimang, had an impact on prevention of HIV and availability of ART (Kleinert & Horton, 2009), which gave rise to strong civil society movements around HIV like the TAC. The new government under President Jacob Zuma has made huge improvements in healthcare (Kleinert & Horton, 2009). However, while there are improvements, there is shortage of doctors and health workers which has an impact on the healthcare system (Coovadia et al., 2009; Kleinert & Horton, 2009).

Closely related to the above in Johannesburg, the public hospitals are run by the Gauteng Provincial Administration, while the clinics are the responsibility of the City and are

responsible for public health issues such as immunisation, maternal and child health, as well as AIDS education and prevention (COJ, 2013). The history of healthcare service delivery in Johannesburg has been characterised with poor quality care, but they have moved from that to have a vision of equal access, wich emphasises on primary healthcare through the district health system (COJ, 2013). Primary health clinics in Johannesburg provide curative care, maternal and child health, health promotion activities, community outreach, as well as services offered between eight to ten hours a day (COJ, 2013). In the primary health care clinics, migrants are accepted, services are free and having a valid document is not a requirement (COJ, 2013). More so, if there is a need for hospital attention, the nurses will refer them to the hospital (COJ, 2013).

2.5 History of migration and access to health services in the South African context

Human migration has health implications on the experience of individual migrants, as well as that of the population or non-migrant communities, which calls for continuous and critical studies on the linkages between health and migration, as well as on the way in which these linkages contribute to the health identities of migrants in the host communities. This gives credence to further study of the situation in Johannesburg, with particular regard to the HIV treatment experiences of migrants. Spiegel and Alia (2003) note that throughout history, migrant populations have been blamed for the spread of disease, and that following these exclusions, they often live and work in poor conditions that make them vulnerable to illness. However, evidence shows that there is a healthy migrant effect, since those who choose to travel abroad are generally those healthy enough to attempt the journey (Sargent & Larchanche, 2011). Fennely (2005) argues that the healthy migrant effect wears off over time, because of social circumstances associated with migrants in general, including poverty, poor housing and limited access to healthcare.

Migrants in general and cross-border migrants in particular have experienced challenges when it comes to accessing healthcare in South Africa. Vearey (2011) argues that current health-system planning within South Africa does not adequately address the health of migrants when they are in urban and peri-urban areas, forcing them to move back home should they become too sick to work. There are legal and policy issues that may impact on the access and continuity of treatment of cross-border migrants. The National Health Act No. 61 of 2003 (section 1 (2) (a) (ii)) states that healthcare must be provided in an equitable

manner to the population in South Africa and section 1 (3) (1) (a) states that the minister must protect, promote, improve and maintain the health of the population in South Africa. This act gives cross-border migrants the same rights that the non-migrant population receive. Cross-border migrants are also allowed access to ART without Identity Documents (Gauteng provincial government memorandum (Appendix I); Department of health financial directive (Appendix J). The Sixty-First World Health Assembly calls upon member states to promote health policies that are migrant sensitive (World Health Organisation, 2008). South Africa is a member of the World Health Assembly, and so it is bound to these parameters. The draft policy framework for population mobility and communicable diseases in the Southern African Development Community[4] Region acknowledges that mobile populations are at risk of communicable[5] diseases, and therefore the framework has been developed to form the basis for programming[6] for mobile populations, when it comes to communicable diseases in the SADC region (Director for Social and Human Development and Special Programs, 2009). Though the draft policy is not yet in place, once again, South Africa will be bound because it is a member state in the SADC region. South Africa has a strict immigration law that is restrictive when it comes to cross-border migrants (Landau & Freemantle, 2010). This is because South Africa has in place policies that make it difficult for cross-border migrants to enter the country.

Related to the above, in the last few years, the South African Immigration Act has been changing, but it still maintains tight control over immigrants to the country. The Immigration Amendment Act No 19 of 2004 proves to be differing from all the other policies concerning cross-border migrants, as it states in its preamble that the purpose of the Act is to control immigrants and to state the powers of the government officials who work with immigrants. The immigration amendment Act No 19 of 2004 Section 1 (b) states that the state retains control over the immigration of foreigners to South Africa and Section 1 (d) states that employment of foreigners is enabled when their skills are needed, and that foreign investment

[4] Herein after referred to as the SADC.

[5] A communicable disease is an illness caused by a specific infectious agent, which is caught through transmission of the agent from an infected person or animal directly or indirectly to another person (Benenson (cited in Director for Social and Human Development and Special Programs, 2009).

[6] Addressing communicable disease control, with emphasis on HIV and AIDS and malaria, having harmonized policies, programmes and activities, standard systems and coordination and sharing of information across the region (Director for Social and Human Development and Special Programs, 2009).

is encouraged through facilitating the entry of exceptionally skilled foreigners, exchange students, as well as foreigner tourists. States decide who can come in to their countries and who cannot and in most cases people with skills are allowed entry (Miller, 2005). If preference to enter states including South Africa is given to foreigners with specific skills, one might argue that this poses challenges of access and continuity of ART when it comes to cross-border migrants who do not possess skills perceived as desirable by the state. This is because some of them will enter these states using illegal routes which will put them at the risk of facing threaths of deportation. It is important to ascertain how the health and migration policy play a part in the access to and continuity of antiretroviral treatment of those cross-border migrants who are affected by these policies. Cross-border migrants usually come to Johannesburg in search of an improved livelihood, so that they can fend for those remaining at home (Vearey, 2011). Staying on treatment is crucial in ensuring health and future treatment when one is HIV positive (Patel, 2009; Vervoort et al., 2007).

This research is based on the recent developments of health and treatment outcomes among cross-border migrants. According to McCarthy et al. (2009), until recently, only those with South African identity documents were eligible for ARVs at public sector facilities.[7] Although the South African government has initiated public sector facilities to stop restricting ARVs to foreigners, there are some foreigners who are still being turned away, and who end up having to go to non-governmental organisations[8] for treatment (McCarthy et al., 2009; Vearey, 2008). A study by Moyo (2010) showed that cross-border migrants were accessing treatment at a public hospital without being turned away, as those who were accessing health care at Hillbrow were not denied treatment and they were not being asked for documents unless there was a language barrier, so as to enter their names into the system. Evidence from Bygrave et al. (2010) shows that migrants from Lesotho working in South Africa experienced challenges when it came to the continuity of ART.

2. 6. Access to health services

[7] Public sector facilities are government clinics and government hospitals, or other government health services.

[8] NGO from herein after.

Studies of access to health services are drawn primarily from the discipline of public health. These studies show the challenges that were faced by migrants generally, and cross-border migrants in particular, when accessing health services in general, and how this has improved over time. They serve to show how available and affordable healthcare services are for cross-border migrants, after the different challenges that they initially face. They also show how acceptable cross border migrants are when it comes to accessing health care services.

Some scholars have looked at studies of migration and access to health looking at how available and affordable is access to health for migrants as well as their acceptability when it comes to health services (Mcintyre et al., 2009; Soskolne & Shtarkshall, 2002; Berck et al., 2003; Webber et al., 2010; Biehl, 2004). Access to healthcare is the empowerment of individuals to be able to use healthcare services when needed, and it is done by means of interaction between health care systems and those individuals (Mcintyre et al., 2009). Access has been said to be based on three dimensions, which are availability, affordability and acceptability (Mcintyre et al., 2009). According to Mcintyre et al. (2009) availability refers to the right healthcare services put in the right place at the right time to meet the needs of the population. Affordability refers to those costs for access services, which individuals are able to pay, according to the national measurements of household budgets (Mcintyre et al., 2009). Acceptability refers to the relationship between the health provider and the patient in terms of attitudes and expectations, as these will influence the ability of individuals to receive care (Mcintyre et al., 2009).

A study by Soskolne and Shtarkshall (2002) focusing on immigrants in Israel states that the availability of services to less-integrated populations may be minimal, as they might not target their needs. Soskolne and Shtarkshall (2002) argue that messages might not reach immigrants because of language or cultural barriers, and that prevention interventions should adopt individual approaches that can address a context relevant to the immigrants in question. Soskolne and Shtarkshall (2002) state that a health policy allows all individuals that it serves to have access to knowledge and skills that can enable them to access healthcare services. Berk et al.'s (2003) study done in the United States note that the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 provides financial assistance to the state to provide health services to people with HIV and AIDS, with those who are eligible being those that have been confirmed by the centre for Disease Control and Prevention to have the disease (Berk et al., 2003).

While many scholars have examined the issue of migrant access to health services, many of these studies do not look at how access determines continuity of ART among HIV positive cross-border migrants. Webber et al. (2010) argues that Cambodia has one of the highest numbers of people with HIV in Asia, mostly amongst women who are involved in rural-to-urban migration working in the garment factory (Webber et al., 2010). In this study, the environment that these women are working in is intensive, to the extent that these women are not able to afford neither a basic livelihood nor the time to access basic healthcare (Webber et al., 2010). Closely related to this, Biehl (2004) argues that AIDS mortality in Brazil has been reduced, but that specialised healthcare is given to those who visit public services as AIDS patients at an early age, but who fight for continuous treatment in the face of limited resources. These can pose challenges of treatment access and continuity when it comes to migrants who might face challenges of visiting public hospitals due to issues like documentation. Regionally, both internal and cross-border migrants face challenges when it comes to accessing health care in which international migrants are portrayed as carriers of disease, and that they tend to place a burden on the public healthcare system Vearey (cited in Segatti & Landau, 2011). One might argue that this is partly due to the attitude and policies towards migrants held within a given society. Vearey (cited in Segatti & Landau, 2011) argue that there are notions that if migrants are given free ART; it will lead to a vast influx of migrants. However, evidence shows that the longer migrants stay in a country, the higher their chances of wanting to access treatment, showing that they would have started getting sick when they had arrived in the country (Vearey cited in Segatti & Landau, 2011).

Nationally, studies have been done on the same challenges that are seen among cross border migrants, and have observed how this has improved. Pursell (2004) shows that regardless of the law – which accords rights to all, asylum-seekers are still being denied their rights to access health services, without valid reasons, and that of the 12 doctors interviewed, only one doctor from the Congo was aware that refugees with refugee documents are entitled to access treatment. Pophiwa (2009) explored the patterns of use of healthcare among Zimbabwean migrants living in Johannesburg. The results of his mixed-method study showed that most Zimbabwean migrants do not seek healthcare, and that the few who do were not denied treatment (Pophiwa, 2009). Moyo (2010) meanwhile, shows through a qualitative study that migrants were not asked for documents when accessing health services, but rather were asked for these documents only if there was a language barrier, so that their names could be correctly written. However, healthcare providers were shouting at the patients (Moyo, 2010).

In addition to this, other scholars shows that if the health of urban populations in the context of HIV and migration is to be improved, there is a need to understand the meaning of place which is where people enter and settle because it determines access to basic services, as this form the primary determinants of the health of the population (Vearey et al., 2011; Vlahov & Gelea cited in Vearey et al., 2011).

2. 7. Access to HIV treatment among migrants

A related body of literature is about HIV treatment and it is drawn from the fields of public health, from medical anthropology and from various migration studies, and shows the challenges that have been faced by migrants when it comes to accessing ARV treatment as well as the way in which this has improved over time both globally and regionally. While this is the case however, many of the studies in this body of literature do not address what HIV positive cross border migrants do to access ART.

Sargent and Larchanche (2011) note that globally migrants are marginalised, and this places them at risk of not accessing treatment. Migrants are blamed for introducing and spreading diseases (Vearey, 2011). This shapes how migrants will be accepted in their host nations, reducing their chances of accessing treatment. The UNHCR (2010) provides findings from refugees in Kuala Lumpur, in which their viral load suppression was lower than that of nationals. This is because they experienced more opportunistic infections, and had long length of stay in hospitals, due to the fact that they presented with a lower CD4 count when they initiated ART, which was not the same with nationals who had higher CD4 count (UNHCR, 2010). The barriers that were being faced by refugees in this setting included language barriers, poor nutrition, as well as fear of arrest and harassment when going to access services and discrimination (UNHCR, 2010).

Lippman, Kerrigan, Chinaglia and Diaz (2007) argue that in Brazil, there is quality HIV/AIDS prevention and care, but that at the borders, foreigners are vulnerable to HIV/AIDS since such care is not reaching them. Those seeking jobs in Brazil are mostly the less-educated without enough resources to access services, some of whom are illegal immigrants, who suffer exclusion from social services (Lippman et al., 2007). Racism and xenophobia are also common at the Brazilian borders, and hence a lack of identity may lead

people to feel reluctant to form networks (Lippman et al., 2007). Biehl (2008) shows that though some people are still facing challenges in accessing ART in Brazil and in the United States, there is a great improvement in access to ART. According to Biehl (2008, p. 99), "the battle for access has been hard fought". After making access to treatment easier in Brazil, there is still a problem of drug resistance where people are in need of more expensive line two drugs, while this is so in Brazil there is first line drugs (Biehl, 2008). This might pose challenges to undocumented migrants who are in fear of deportation to seek treatment. Closely-related to the above, Bischofberger (2008) gives another dimension of easy access to ART among cross border migrants, as it shows the challenges posed by Sub-Saharan African migrants in Switzerland, and how they seek out HIV treatment later when they are already ill posing obvious challenges for healthcare providers. This study shows that there are cross-cultural challenges that are new to the health providers in Switzerland, as patients had different realities about the HIV illness (Bischofberger, 2008). Results from this study show that ART led to families being separated from each other in their attempts to access medication in richer countries far afield, and that HIV-infected participants entered the health care system late, due to a lack of knowledge of the signs of HIV (Bischofberger, 2008).

Nationally in South Africa, scholars have also examined the issue of ART and cross-border migration. There were challenges faced by cross-border migrants, and this has also improved over time. An article by Vearey (2008) for example, looks at the challenges faced by migrants, refugees and asylum-seekers in accessing jobs following the delays in the issuing of documents to refugees and asylum-seekers by the Department of Home Affairs. This poses challenges to migrants in accessing ARV treatment as well as in accessing treatment in general when they are in Johannesburg, especially in public health facilities (Vearey, 2008). WHO (cited in Jones, 2012) shows that globally, access to ART has increased, and that in Sub-Saharan Africa there is inadequate access to ART for around 50 percent of those who need it. Jones' qualitative study aimed to find out what constitutes the barriers to access of ART in Hammanskraal-Temba, as well as looking at the factors that prevent human rights protection in different places (Jones, 2012). There are many cross-border migrants at this clinic, but they were not well represented due to the fact that they were excluded from access to treatment as foreigners (Jones, 2012). A study by Johnson (2012) in the field of public health has looked at improvements in access to ART in South Africa, up to the end of June 2011. It does not look at migrants specifically, but at people receiving ART in South Africa broadly, and includes data from NGOs (Johnson, 2012). There is a need to look at the

increase of access to ART from NGOs as well as from state-run clinics. There has been a huge increase in access to ART in South Africa and the lack of ART have been reduced by 32% among adults of the overall population in need of ART, which has resulted in close to 80% of adults having received ART by mid-2011 (Johnson, 2012). This is because 1.5 million of the people who were living with the unmet need of ART have been successfully targeted (Johnson, 2012).

2.8 Continuity of HIV treatment

Scholars have examined the challenges that are faced when it comes to continuing with HIV treatment, which factors cause people not to continue with treatment, and those that influence continuity. The UNHCR field brief (2010), gives a guideline for putting programmes into health services that promote treatment continuity, specifically to increase treatment continuity among refugees. Lima et al. (2009) argues that migration among people with HIV/AIDS is common, and that compared to people who did not migrate, highly mobile populations where more likely not to continue with ART. They also argue that when treatment became available in the 1990s, a lot of people started migrating to the cities in Canada, and it was believed that people were migrating due to the availability of ART (Lima et al., 2009). Though Canada is known for its free universal accesses to ART, there are some people who are dying because they cannot access this ART (Joy et al. and Wood et al. cited in Lima et al., 2009). Closely related to the above, a study by Vissman et al. (2011) looked at what influences the intention to continue with HAART among Latino immigrants living in the USA, since people living with HIV/AIDS continue to face challenges when it comes to continuing with treatment. Participants of this study reported not having tested for HIV before and most participants took medication soon after their diagnosis, and hence, Latino immigrants have also been reported as seeing higher numbers discontinuing with treatment than non-migrants (Vissman et al., 2011). The Latino immigrants reported having had negative experiences with the US healthcare system, which included perceived racism, lack of provider knowledge of traditional medicine, transport costs, fear of deportation as well as the interpreters not coming on time for the appointments and language barriers, which ended up causing them not to continue with medication (Vissman et al., 2011).

Regionally, there are studies that looked at treatment continuity among cross-border migrants. Patel's study (2009) undertaken in South Africa, looks at the importance of treatment continuity and the way in which treatment continuity should be done so as to prevent compromising patients' health (Patel, 2009). It then goes beyond treatment continuity to examine factors that influence treatment continuity, both positively and negatively, with respect to the patient and the healthcare provider (Patel, 2009). These negative factors include strict rules for taking treatment; side effects (which often times result in the advice from relatives to take herbal remedies instead); and psychological factors like stress, depression and anxiety, which also lead to discontinued treatment (Patel, 2009). The challenge of treatment continuity is also seen in other studies. Bygrave et al. (2010) show the challenges of continuing with treatment that is faced by cross-border migrants from Lesotho working in South Africa. They found that discontinuation was less common among cross-border migrants than the general population within the first year of treatment, and that significant difference in discontinuation among cross-border migrants would be seen after a year (Bygrave et al., 2010). An article by Whyte, Whyte and Kyaddondo (2006) shows the impact of confidentiality between the patients and the health providers on continuing with treatment, since there were some people who did not continue with treatment due to stigma. Though this does not link directly to cross-border migration, it is important for showing the way in which a lack of confidentiality might lead to people not to continue with HIV treatment, as some might prefer their status to be confidential.

In their article, Vervoot et al. (2007) note different factors that positively or negatively influence treatment continuity, including socio-economic factors, support from nurses and pharmacists, as well as the HIV-related symptoms. Hammami et al. (2004) found that there are three factors that influence treatment continuity, namely: internalising the medical information; a stronger motivation to stick to the medicine; and developing greater problem-solving capacities. Wilhelm-Solomon (2010), in his article about a study in northern Uganda, shows that many internally displaced populations have been returning home from displacement camps, and that this has posed challenges to HIV treatment continuity but treatment continuity was improved through the help of support groups.

The study by Gilbert and Walker (2009) is a qualitative study, which was done in an urban HIV/AIDS clinic in Johannesburg, showing that despite the fact that resources are insufficient and that there is a lack of social support, patients saw ART as a lifesaving intervention, and expressed their commitment to their treatment. According to Thom and

Langa (cited in Gilbert & Walker, 2009) ART in South Africa does not reach all the people who need it, due to the economic inequality and deprivation. Patients showed a dependency on ART, since they were scared about the thought of living without it, and they made use of reminders to take their treatment, as well as getting support from partners and families (Gilbert & Walker, 2009). In relation to this, McCarthy et al. (2009), in a study done in Johannesburg city, show that foreigners were doing better than nationals when it came to ART. The outcomes of ART among foreigners and nationals were compared at Nazareth house clinic in Yeoville, Johannesburg, through reviewing records of 1297 adults accessing healthcare at Nazareth clinic between April 2004 and March 2007 (McCarthy et al., 2009). 568 were foreigners, 431 were South African citizens and 298 did not have a known origin (McCarthy et al., 2009). Foreigners experienced fewer hospital admissions; fewer missed opportunities for ART initiation; faster initiation on ART; better retention in care; better response to ART after six months; and lower mortality (McCarthy et al., 2009). Despite the problems in access to treatment, foreigners see better outcomes.

2. 9 HIV and deportation

Cross-border migrants have been faced with deportation, along with perceived and real threats of deportation. This is more challenging for cross-border migrants who are on ART when they are deported, as it puts them at a risk of not continuing with their treatment. However, while these studies look at deportation, they do not look at what cross-border migrants do to access and to stay on ART in the event that they are deported.

The study by Muanamoha et al. (2010) is a qualitative study that was done in both Mozambique and South Africa, looking at undocumented Mozambicans in South Africa. In this study, non-documented Mozambican migrants were seen as taking jobs from non-migrants, and this was seen to have precipitated xenophobia and deportation (Muanamoha et al., 2010). Many of these migrants worked on farms and were not being paid on time, and when they claimed their salaries from their employers, the employers would call the police to arrest them after which they were deported (Muanamoha et al., 2010). When the Mozambican migrants were deported, they were left soon after crossing the border, because the officials could not transport them to their place of origin, which caused them to make a living selling the goods they needed in order to raise money for illegal transport returning to South Africa,

which is all they can afford (Muanamoha et al., 2010). The brief by Vearey and Wilhelm-Solomon (2011) looks at challenges of access to healthcare, as well as the challenges of staying on treatment, circumstances that are faced by Zimbabwean migrants who did not have documents after the Zimbabwean documentation process of 2010. These migrants are faced with deportation and the risk of transmission of diseases at Lindela, include overcrowding and challenges of subsequent access to healthcare (Vearey & Wilhelm-Solomon, 2011).

2.10. Social Networks and belonging

Studies of social networks can be seen in a study by Whyte (2009) from the analytical perspective of medical anthropology, examining the formation of health identities, by drawing on two main theories. These are the politics of identity, which focuses on social movements and organizations concerned with discrimination, and the biopower approach, which is about examining discourse and technology in the way that it influences new forms of sociality (Whyte, 2009). Rabinow (cited in Whyte, 2009) formulated the concept of biosociality, which concerns the identities formed through shared diagnostic practice and shared biological conditions, in which people form new networks, and examines the health practices in which they engage. Whyte's (2009) study looked at different chronic illnesses globally, including responses to and treatment of HIV and AIDS, which have led to health identities and social exclusion. However, the study does not look at how cross-border migrants on ART form social networks and this is the subject that this study aims to address. Closely related to the above, a recent study by Muanamoha et al. (2010) shows that social networks play an important role in Mozambican migrants' lives when it comes to places to stay, jobs, and in times of need, such as illness and unemployment, which has helped them to adapt to society. The social networks that Cambodians form when they leave their families influence the way that they become involved in sex work in order to supplement their salaries (Webber, 2010).

Furthermore, a study by Madhavan and Landau (2011) is a mixed method study done in the three African cities of Maputo, Nairobi and Johannesburg. Less than half of foreigners reported having trust in their fellow nationals, although in Johannesburg more migrants reported having trust among migrants compared to locals (Madhavan & Landau, 2011).

Vearey (2008) notes that HIV-related illness before ART made cross-border migrants to rely on others, until they recover.

Some studies have shown that social networks have helped with access to ART through international donors (Robins & von Lieres, 2004; Cassidy & Leach, 2009; Nguyen, 2005; Mogensen, 2010). Though International donors have led to improved access to ART they have led to the health identities in which there has been a certain way of how HIV positive people should live putting an emphasis on being part of support groups (Robins & von Lieres, 2004; Cassidy & Leach, 2009; Nguyen, 2005). AIDS treatment has promoted new forms of activism in order to receive treatment but also new types of transnational relationships (Robins & von Lieres, 2004; Nguyen, 2005). Some people are impelled into thinking that only HIV positive people can understand them, even when compared to their families (Nguyen, 2005). This is mostly because HIV positive people do not have an influence on how they should live and how the global funds they receive should be used (Cassidy & Leach, 2009). In Gambia, people have reportedly attended support groups to obtain economic and social support (Cassidy & Leach, 2009). While people get help in support groups, there is nonetheless acknowledgement amongst them of the importance of kinship networks (Robins & von Lieres, 2004; Nguyen, 2005).

Studies on belonging are closely linked to the studies on social networks, and they show the challenge faced by cross-border migrants when it comes to issues of belonging. Landau and Freemantle (2010) in their study found out that foreigners were using cosmopolitan tactics that enabled them to experience some inclusion in the face of restrictive immigration laws. Nelson and Hiemstra (2008) note that Latino immigrants do not assimilate into the American culture, because they are not interested in becoming citizens but that they just want to attach themselves to the American host and benefit from it while maintaining their cultures. Nelson and Hiemstra (2008) have argued that structures of race, class and illegality tend to shape whether migrants are seen or see themselves as belonging. Landau and Freemantle (2010, p. 376) note that, “there is xenophobia in both the government and the host population, as seen by the way they are restricting foreigners in the country.”

2.11 Theoretical Framework

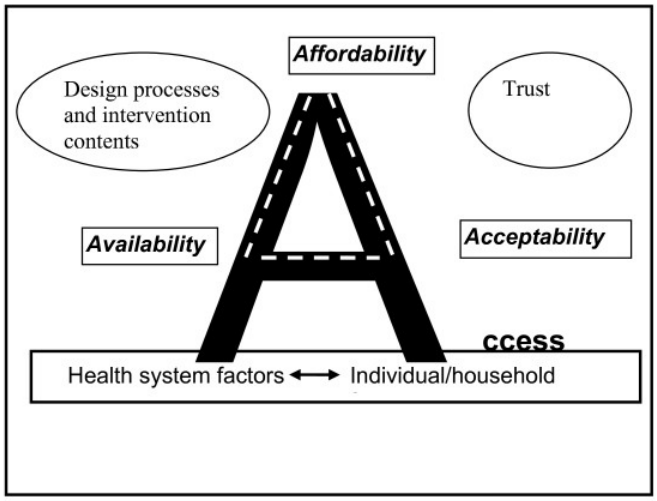
Introduction

This section presents the conceptual framework that was used to guide this research. Most importantly, it aims to locate and contextualise the study by drawing from various theoretical resources, which will be discussed in this section, taking on the issues of access and continuity in the context of social networks and belonging in the treatment experiences of HIV positive cross-border migrants on ART.

2.11.1 Access Evaluation Framework

Below is the access evaluation framework. The framework was important to use in this study as it focused on both patient and health provider perspectives in order to look at what HIV positive cross-border migrants in the city of Johannesburg do to access and continue with ART, while examining their social networks. Closely related to this, the study looked at how available and affordable ART is for cross-border migrants, as well as looking at how acceptable cross-border migrants are when it comes to ART access and continuity at Albert street clinic and Joubert Park Clinic.

Figure 1: Access Evaluation Framework



Source: Extracted from Mcintyre, Thiede and Birch (2009).

2.11.2 Social Networks

According to UNAIDS (1999), the social network theory looks at social behaviour through relationships and articulates that unlike many other health behaviours, HIV directly involves two people. In addition to this, the study of social networks emphasised by the theory leads to fresh insight on the impact of selective mixing in terms of how different people choose who they mix with (UNAIDS, 1999). This research builds on Whyte's (2009) study in this area, by looking at how cross-border migrants who have different experiences of staying on HIV treatment form new social networks based on their diagnosis and on their 'health identities'. It also looked at the different health identities that cross-border migrants form about themselves as people on ART; how it shapes the social networks they form, as well as how these social networks help them to stay on treatment.

Coleman (1988) and Bourdieu (1986) developed the concept of social capital, which they defined as the ability of a person to have access to benefits and support through being part of a group (Portes, cited in Madhavan & Landau, 2011). According to Lyon; Lyon and Snoxell (cited in Madhavan & Landau, 2011), trust is not a good indicator of social connection, but it helps produce connections that help to reduce costs and promote investments and other opportunities. Trust is taken as the condition for the building of social capital, which is taken from social networks, and means that they are dependent on each other (Madhavan & Landau, 2011). Madhavan & Landau (2011) argue that trust is assumed to be strong among people who share a common place of origin, as well as on cultural characteristics that in turn form bonding capital. Homogeneity is one type of social capital in which people share characteristics such as ethnicity, and in which they have mutual bonding capital (WoolCock, cited in Madhavan & Landau, 2011). In bonding capital, there is also thick trust and more interaction (Putnam, cited in Madhavan & Landau, 2011). Putnam (ibid.) argues that thick trust prevents migrants from forming new networks with other communities. Bridging capital is another type of social capital in which group boundaries are clear, and people are able to approach different networks, which means that they go beyond ethnicity (Cheong et al. and WoolCock, cited in Madhavan & Landau, 2011).

The social network theory has certain limitations, which include a lack of the tools by means of which to explain what motivates people to form the relationships they have, as well as to explain the meaning of those relationships; and it therefore cannot produce reliable results of

the effects of networks in their lives (Tzatha & Schepers, 2009) and may miss some important data (NOAACSC, 2009). While these are real limitations, this theory was used here because it was helpful in identifying the social networks that exist in the lives of the HIV positive cross-border migrants.

2. 11.2.1 Belonging

Miller (2009) argues that there is no agreed upon definition of belonging, but that belonging can be taken in three parts, namely in terms of social connections with other people; historical connections, which are about sharing history; and sharing geographical connections or place. Taking the theory of social networks into account, the study looked at how HIV positive cross-border migrants on ART define their belonging, as there is no agreed upon definition of belonging possible. The study looks at whether the social networks that they have in their lives help them to have a sense of belonging. Long-term treatment reshapes hopes and their expectations of the future, including expectations of return for reasons such as continuation of treatment, and new support networks that may be created through shared diagnosis. Trudeau (cited in Nelson and Hiemstra, 2008) argues that the concept of belonging is tied to place, and hence Probyn (ibid.) argues that belonging captures the desire to attach to people, places and ways in which groups that ‘want to belong’ ‘want to become’. Warner (1994) opines that there should be a focus on both time and memory, in terms of how refugees consider their country of origin and their return to it, as well as what they hope for if they return, in comparison to their actual experiences as refugees.

2.12 Conclusion

Based on the literature reviewed, there is a gap in terms of looking at what HIV positive cross-border migrants do to access and continue with ART. The issues of social networks when it comes to HIV positive cross-border migrants on ART, have not been deeply explored, and include whether their social networks help them to have a sense of belonging and to continue accessing and undergoing ART. The access evaluation framework was important in this study as it looks at access from both the patients and the healthcare

providers. Regardless of the limitations associated with social network theory, it was important to use this study given the category of participants it considers, namely cross-border migrants that are HIV positive and on ART. The social network theory emphasises the relationships formed due to diagnosis. Hence, it leads to a better understanding of issues related to a sense of belonging.

CHAPTER THREE:

METHODOLOGY

3. Introduction

This chapter discusses the methodology that was used in exploring what HIV positive temporary cross-border migrants in Johannesburg do to access and to continue with treatment, looking at their social networks. The study involved 10 patients, who are HIV positive cross-border migrants on ART, along with 5 health providers.

3. 1 Research Design

The study adopted the qualitative research method, which made use of semi-structured interviews, with audio recordings of participant observations. Creswell (1994) argues that qualitative research is interested in how people make meaning in their lived experiences and how they make sense of the world around them. Qualitative methods allow the researcher to study the participants' issues in detail, getting in-depth information and at the same time increasing an understanding of the subject of scrutiny (Denzin and Lincoln, 2011; Patton, 1990; Marriam & Associates, 2002). The understanding is an end in itself, and is not meant to predict what might happen in the future (Merriam and Associates, 2002). Hence Merriam and Associates (2002) argues that in qualitative research, there are many constructions and interpretations of reality which also change over time.

Related to the above, this study did this by following an interpretive paradigm. Terre-Blanche, Durrhein and Painter (2011) argue that the interpretive paradigm involves taking people's subjective experience seriously as the essence of what is real for them. Denzin and Lincoln (2011, p. 5) argue that, "the interpretive binocular understand that research is an

interactive process shaped by one's personal history, biography, gender, social class, race, and ethnicity and those of the people in the settings". Qualitative methods were considered appropriate to this study, due to experiences and responses of the participants, and the way in which these shape their health identities and their notions of home and belonging were explored so as to ascertain the internal and subjective experiences that can best be recorded through direct contact. Vervoot et al. (2007) by using a qualitative study, managed to show results that are in-depth, and went on to get a better understanding of factors associated with non-adherence, the different factors that positively influence adherence, as well as negative factors that influence adherence. The research was an exploratory descriptive study on the experiences and responses of cross-border migrants, in terms of what they do to access and to continue with HIV treatment in the city of Johannesburg. The methods used included the population size, sample size, sampling method, the place where research took place, as well as the analysis method.

3. 2 Population and sample size

The population of the study were both the staff and the clients at the primary healthcare clinics. These were healthcare providers and HIV positive cross-border migrants on ART, both male and female, who were 18 years and older. The sample were healthcare providers working with HIV positive cross-border migrants on ART, who have been working for a period of three months, and the HIV positive cross-border migrants who are accessing treatment at Albert street[9] clinic and Joubert Park[10] clinic in Johannesburg city. The aim was also to interview those attending support groups, which were going to be identified through the clinics. Unfortunately, none of the clinics had a support group running at the time of research or a support group linked to them, and the focus shifted to interviewing only patients at the clinic instead. This provided an opportunity to investigate the reason why such groups were not available to patients. Ten participants, who are HIV positive cross-border migrants on ART, were selected for this study. In addition to this, five nurses from both clinics were also selected for the study. The reason for this was that these people were key informants,

[9] AS from herein after.

[10] JP from herein after,

knowledgeable about cross-border migrants and the way in which they access and stay on treatment, since they work with them on a daily basis. The participants who were selected for this research were those who had been accessing ART in Johannesburg for a period of six months and more, exposed to some experience of what they do to remain on treatment. Those who started treatment at home and continued in Johannesburg were also included, but they also had to have been accessing treatment for a period of six months in order to be included in the study. Having both men and women helped further in giving the opportunity of looking at issues of how social constructions of masculinity and femininity impacted on ability to access and stay on ART.

3. 3 Sampling Research Participants

In this study I used both purposive and snowball sampling to select participants.

3. 3. 1. Purposive Sampling

I made appointments with clinic managers from both clinics. I went there on different dates, and when I got there I contextualised myself by introducing my programme and the subject of the research study. I also handed to the clinic managers a copy of the ethics clearance from the ethics committee of the University of the Witwatersrand, along with an approval letter from the City of Johannesburg and another approval letter from the Gauteng department of health. I asked permission from the clinic managers to do the research at the clinics at which permission was granted. From both clinics, the clinic managers introduced me to the health providers, as well as other clinic staff, communicating my purpose at the clinics. This helped me to start the research well, since I was now known at the clinics by all the people who worked there.

The sample recruitment was made through purposive sampling of HIV positive cross-border migrants who were receiving ART in Johannesburg at AS and JP clinics and consent was sought to only from those who had accessed treatment for a minimum of six months. Creswell (1994) notes that the idea of qualitative research is to purposefully select informants

that will best answer the research question. According to Merriam and Associates, (2002) purposive sampling begins with determining those criteria essential in choosing the participants, who can be interviewed, or what sites are to be observed. The researcher purposefully selected AS Clinic and JP Clinic as the two clinics as the sites of study due to the fact that in previous studies done in South Africa, cross-border migrants were having problems accessing health care at the public hospitals, government clinics and local clinics in the city of Johannesburg, where some were being asked for identity documents that they did not have, and ended up going to NGOs (Vearey, 2008; McCarthy et al., 2009.). These clinics were selected because they had the potential of giving the HIV positive cross-border migrants needed for this study, since these clinics also work a lot on providing ART to HIV positive cross border migrants amongst other primary healthcare services. According to Barbour (2009), purposive sampling allows the researcher to be in control and thus be unconcerned about bias, while Merriam and Associates (2002) argues that it is important to select a sample from where adequate information can be found. These principles were followed in this study.

3. 3. 1.1. Health care providers

After being introduced by the clinic managers to the health care providers I approached them and asked if they were willing to participate. These participants were also purposefully selected, because I was looking for those who were willing to take part in the study and who would be able to provide the information adequate for this research. I managed to get four nurses from both clinics who were interested in taking part in the study and I sought formal written consent. Though the plan was to do interviews with counsellors as well, none were interested in taking part in the research. Given this the research was done with nurses only and at the end I had interviews with five nurses from both clinics.

3. 3. 1. 2. HIV positive cross-border migrants

At both clinics I spoke to the nurses who worked at the ART department and asked them if they could refer to me should they come across a cross border migrant accessing ART. They agreed, and since I spent time at the clinic in wait of potential participants, I was able to meet

them as they were there to receive treatment. When they were referred to me, I would ask to speak to the person in private. I would introduce myself to the participant, noting the purpose of the research, discuss confidentiality, and then ask the participant if he or she might be interested to take part in the research. If they agreed to take part, I would ask them for how long they have been on treatment before they sign or before asking for health providers to become witnesses on the logged verbal consent. If they were on treatment for six months or more, I explained to them the two options for consent that were available, which was the written consent and the logged verbal consent, for which two witnesses were needed, and I asked them which one they preferred. I further explained all the other issues on the information sheet and consent was sought only from those who were on treatment for six months or more. While sitting on the chairs were ART patients were sitting waiting to access treatment, I also conversed with the patients informally, by means of which I was able to locate some of the participants.

3. 3. 2. Snowballing Sampling

Snowballing was used, as it works well with purposive sampling. This sampling method allowed for the inclusion of some respondents identified by other HIV positive cross-border migrants. According to Terre-Blanche et al. (2011), when we find an appropriate participant, in most cases that person is able to lead to others who can participate in the research. Some HIV positive cross-border migrants were in the position of knowing other HIV positive cross border migrants, who were accessing ART and who had been accessing it for a minimum of six months. I asked every third participant if he or she could identify another person in the same situation and who is accessing ART at either JP Clinic or AS Clinic. Mack et al. (2005) note that snowball sampling is accepted as a part of purposive sampling. This sampling strategy enabled me to meet one participant through chain referral. I phoned the person that I was referred to and asked to meet her.

Table 1: Demographic Characteristics of the participants

Patients

Participant Name	Gender	Profession	Age	Marital status	Country of origin	Period of time on treatment	Reasons for living country of origin	Length of stay in Johannesburg	Place of access of treatment
Zoro	Female	Hairdresser	33	Widowed	Zimbabwe	8 months	Poverty	4 years	Albert Street Clinic
Fungai	Female	Unemployed	28	Single	Zimbabwe	1 year 9 months	Poverty	5 years	Joubert Park clinic
Ratidzo	Female	Cook at a preschool	43	Single	Zimbabwe	5 years	Poverty	1 year	Joubert park clinic
Sarue	Female	Domestic worker	40	Living together with a partner	Zimbabwe	6 months	Poverty	1 year 6 months	Joubert park clinic
Garikayi	Male	Dress maker	36	Single	Malawi	4 years	Poverty	1 year 6 months	Albert street clinic
Edwin	Male	Sales person	43	Single	Tanzania	1 year	Poverty	2 years	Joubert park clinic
Charles	Male	Security guard and dress maker	61	Married	Lesotho	2 years	Unemployment	30 years	Albert street clinic
Evans	Male	Domestic worker	38	Married	Malawi	2 years	Poverty	4 years	Albert street clinic
Jeremy	Male	Tiling job	26	Single	Mozambique	5 years	poverty	5 years	Albert street clinic
Dorothy	Female	Waitress	28	Married	Zimbabwe	6 months	Poverty	9 years	Joubert park clinic

Health professionals

Participant name	Gender	Profession	Age	Knowledge about the migration policy	Marital status	Country of origin
Gladys	Female	Nurse	65	No	Widowed	South Africa
Talent	Female	Nurse	51	No	Divorced	South Africa
Eddie	Male	Nurse	39	Yes	Married	Zimbabwe
Kelvin	Male	Nurse	39	No	Married	South Africa
Bev	Female	Nurse	39	No	Married	South Africa

3. 4. Data Collection Method

The first step to data collection was a pre-testing, aimed at testing and adjusting the interview guide. After pre-testing, administration of face-to-face indepth semi-structured interviews with open-ended questions with the participants of the study followed. These generated detailed, in-depth data on the subject of accessing and staying on treatment, on support networks and on sense of belonging. Interviews were done in English, Shona, Ndebele and Zulu, because these are the languages that I speak, and I did not use a translator. Participants who could not speak one of these languages were not interviewed. During the interview, I met one participant who could not speak any of these languages who was excluded, along with several others who were excluded because they did not meet the criteria of the length of time on ART.

3. 4. 1. Primary Data

Primary data was collected from the respondents through qualitative instruments for data collection. The data was recorded in the form of narratives from the respondents.

3. 4. 2. Instruments for data collection

3.4. 2. 1. Semi-structured Interviews

Semi-structured interviews with a number of questions that allowed flexibility were used and the data was audio recorded and manually transcribed. The questions were designed on the basis of the objectives of the study. Mack et al. (2005) states that indepth interviews are appropriate in collecting data, especially when the topics are sensitive. Some authorities' note that qualitative methods comprise three types of data collection: indepth interviews, direct observation, and written documents (Patton, 1990; Merriam & Associates, 2002). Merrian and Associates (2002) argue that the semi-structured interview contain a mix of more and less structured questions and that in most cases there is specific information expected from all the participants which forms the structured part of the semi-structured interviews. They went on to say that the bigger part of the interview is that it is guided by issues to be discovered (Merriane & Associates, 2002). Through using semi-structured interviews, I was able to explore some issues such as what a cross-border migrant within Johannesburg who is on ARVs does to access and stay on treatment, a question which generated in-depth data from the participants.

3.4. 2. 2. Observations

Observations were made on the behaviour of migrants while they were accessing treatment so as to get an accurate sense of their experiences and responses. Moreover, from their conversations and attitudes, observations were made so as to understand the things that were not spoken. Mack et al. (2005, p. 2) notes that "participant observation is for collecting data on naturally occurring behaviours in their usual contexts". According to Marriane et al. (2002) a complete observer is unknown to those being observed either behind unseen places or on an open place, and when observation is used, together with interviewing, the term fieldwork is used. During the fieldwork I conducted non-participant observations where participants were not aware that they were being observed (Marriane et al., 2002) so as to get a fresh perspective on what cross-border migrants do to access and stay on ART. Marriane

and Associates (2002, p. 13) notes that, “observation is the best technique when an activity, event, or situation can be observed first-hand, when a fresh perspective is desired, or when participants are not able or willing to discuss the phenomenon under study”.

3.4. 2.3. Field Notes

Brief field notes were undertaken during the fieldwork and they would be expanded later. This was done so that I would not forget what had happened during the day. Some authorities note that its practical to make brief notes during fieldwork and expanding them should be done within 24 hours of writing field notes, so as to avoid forgetting important things that happened (Mack et al., 2005). I followed this suggestion. Though my analysis was not entirely based on field notes, they were important in my research for giving me a background on what was happening when it comes to how they access treatment. The field notes were written mostly on the observations that I made and the conversations that I engaged with while in the field.

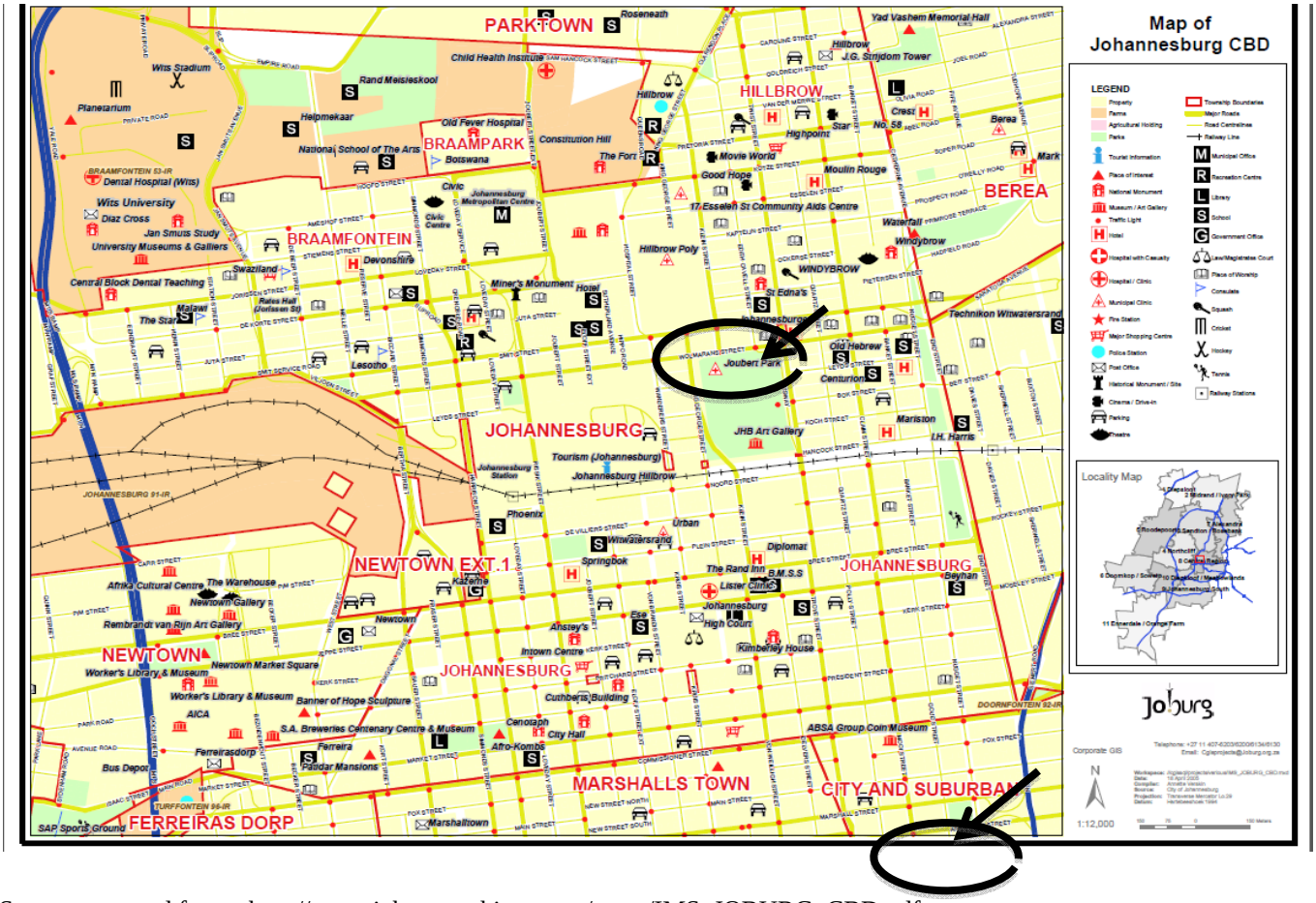
3. 4. 3. Secondary Data

The literature on HIV and information from the internet was used to clarify the current situation for cross-border migrants when it comes to accessing and continuing with HIV treatment in Johannesburg. Posters and other information from the clinics were also a good source of information in terms of what they say about ART and staying on treatment, which might have had a big influence on how cross-border migrants stay on treatment in Johannesburg. This is specifically seen in both clinics where it was possible to see articles on the importance of staying on treatment as well as pictures showing how people who were very sick managed to live healthily on ART. On all the posters that I saw at the clinics, nothing specifically referred to either cross border migrants or South Africans as respective groups. All the information that I came across at the clinics referred to patients as one group. Since most of the participants in this research showed their compliant to ART the posters could have influenced them to stay on ART so as to remain healthy.

3. 5. Research Areas

JP clinic and AS clinic are in the inner-city of Johannesburg. There are some MSF[11] nurses that work in these clinics to facilitate access to health care for migrants. MSF has been working in South Africa to respond to HIV and TB illnesses, as well as to increasing the access to healthcare for vulnerable migrants (MSF-SA Association, 2012). Johannesburg is a city where law enforcement is active. Therefore, there was likelihood that there are undocumented HIV positive cross border migrants in Johannesburg who are faced with the threats of deportation and mobility; circular HIV positive cross-border migrants in search of improved livelihoods; and some facing other challenges. With limited time and finances in which to do the study the costs were cheaper for the research to take place in Johannesburg.

Map 1: Map of the Johannesburg inner-city



Source extracted from: http://www.joburg-archive.co.za/maps/IMS_JOBURG_CBD.pdf

[11] Medecins Sans Frontiers (Doctors without borders).

3. 6. Data Analysis

Firstly, recorded data was manually transcribed into readable data. From there on, data was analysed through thematic analysis. The thematic analysis made use of the six stages provided by (Braun & Clarke, 2006). Braun and Clarke (2006) argue that thematic analysis identifies, organizes, analyses, richly describes in detail and reports themes within the data and that it often goes beyond this by interpreting different aspects of the topic under study. Although Boyatzis, Ryan and Bernard (cited in Braun & Clarke, 2006) classify thematic analysis as just a tool used for analysis alongside other methods, Braun & Clarke (2006) argue that it is an analysis method. Thematic analysis was used in this study because of its flexibility in the use of data generated to produce rich and in-depth knowledge, by enriching the participants' views. Creswell (1994) argues that data analysis requires that the researcher be comfortable with developing categories as well as making comparisons and contrasts, hence thematic analysis allowed the researcher to see both comparisons and contrasts. After collecting data I firstly read through it, after which coding was done manually continuously from the time of data collection until the research was finished. This was done simultaneously with collection, data interpretation and report writing. In the qualitative analysis, several simultaneous activities took place, ranging from data collection, categorisation and writing of the qualitative text (Marriane and Associates, 2002; Creswell, 1994). In this way, meaning of the findings and an understanding of what cross-border migrants' do to access and stay on HIV treatment was made. The data was analysed by the following steps, as noted by Braun and Clarke (2006).

3. 6. 1. Phase 1: Familiarizing with the data

The first thing I did was to manually transcribe the data into readable form so that it could be used to do thematic analysis. I did this by doing a verbatim account of what had happened during the interviews, so that I could be able to maintain what was said during the interview and maintain originality of the data. Furthermore, I checked the data with the verbal account of the interview, so as to check if I had captured everything that was said during the interview. Braun and Clarke (2006) argue that when the data is in verbal form, it must be transcribed so as to allow analysis to take place. They also went on to say that transcription

should be done as a verbal account, as well as checking the data with the audio (Braun & Clarke, 2006).

Closely related to the above, I read through the data over and over again so as to understand my data in more detail, as well as to familiarize myself with the issues revealed by the data. Braun and Clarke (2006) argue that in this stage it is important that the researcher familiarise with the data to the extent that the data is understood indepth, finding meanings and patterns. They also argue that this stage involves starting to mark ideas for coding that can then be used in the later stages of data analysis (Braun & Clarke, 2006).

3. 6. 2. Phase 2: Generating initial codes

Braun and Clarke (2006) state that this stage is about producing initial codes and looking for interesting aspects of the data that can be taken as themes. Coding was done manually in order to produce the themes through using highlighters.

3. 6. 3. Phase 3: Searching for themes

Braun and Clarke (2006) note that at this stage you will have a long list of coded data and then you put the different codes into themes and one might use tables or mind maps and that nothing should be abandoned at this stage. During this stage I put all the codes I had in different themes. I also put all of them at this stage as I did not want to miss any important data later on. I also used tables, so as to put all the codes in to their bigger themes.

3. 6. 4. Phase 4: Reviewing themes

This stage involves the refinement of themes (Braun & Clarke, 2006). During this stage, I removed some of the themes that were not necessary and managed to regroup the themes into the other relevant overarching bigger themes.

3. 6. 5. Phase 5: Defining and naming themes

This stage involves defining and assigning names[12] to the potential themes in preparation for a detailed analysis of each theme as well as checking if each theme does not contain any hidden sub-themes (Braun & Clarke, 2006). During this stage, I looked at the themes I had and started to refine them so as to prepare for the final write up of the analysis. These are the final themes that were then reflected in this research report in the findings chapter.

3. 6. 6. Phase 6: Producing the report

Braun and Clarke (2006) note that this is where final analysis takes place as well as the write up of the final report, whereby the interesting account of the story is given. Here I looked back at the analysis that I had done, so as to see if there were other interesting themes that I had perhaps overlooked. I then started to write up the analysis presenting the results and the discussion of the results that were found in this study.

3. 7 Ethical Considerations

Permission to do this research was requested through applying to the City Metro Health and Gauteng Department of Health. Clearance by the Medical ethics committee of the University of the Witwatersrand was sought, protocol number M121032. On completion of the research the participants were issued with the results of the study by giving the clinics where the research was conducted a written report on how HIV positive cross-border migrants on ART access and stay on treatment and also the City of Johannesburg. The following ethical considerations were involved in this study.

[12] The assigned names will be precise and concise so that any reader can have an insight of what lies in the theme.

3. 7. 1. Informed Consent

Even though this study did not look directly at how people understand HIV, it was working with HIV positive cross-border migrants who were accessing HIV treatment. This in itself poses challenges because of the stigma that is still associated with being HIV positive, even after years of talking about HIV as well as these participants being migrants and others being undocumented. The participants were informed of their rights to withdraw from the study at any time without any loses. The participants were issued with an informed consent form which they signed to show their willingness to participate in the study. In case that any participant did not want to sign a written consent a logged verbal consent was used since patients were treated anonymously because legally patients are not asked to produce an Identity Documents to be treated. In this verbal logged consent the researcher asked health providers to act as witnesses since two witnesses were required for this type of consent. However for the staff no logged verbal consent was used but only written consent. Furthermore an audio consent was issued to the participants so that they could sign it to show willingness that they agreed that the interview be audio recorded. For the participants who opted for logged verbal consent, logged verbal consent for audio recording was also used.

3. 7. 2. Benefits

The benefits of the research were shared with the participants. They were told that the research may or will not be of benefit to them but might be of benefit to others who did not participate in this research.

3. 7. 3. Confidentiality

Confidentiality was maintained and anonymity was maintained through the use of a code number specific for each participant. Participants were told that their information will be shared with the supervisor as well as with the University of the Witwatersrand. Participants

were also told that their names will not come up in the report and the information that they would have shared would not be traceable back to them.

3. 7. 4. Language Barrier

In this research interviews were done with people who can speak the languages that I spoke therefore I did not expect to encounter any language problems. People who did not speak any one of these languages were not interviewed.

3.7.5. Vulnerability versus double vulnerability

The major challenge was that nonverbal consent was not approved for the research and participants had to choose between written consent and logged verbal consent which required other two people as witnesses. This posed challenges during the field work because other participants were not comfortable with written consent but they opted for it than having other two people witness their consent, hence this posed double vulnerability for the participants in that first the group of HIV positive cross border migrants are vulnerable in that they are cross border migrants faced with different challenges in Johannesburg. They were also vulnerable in that they were on HIV treatment. Because they wanted to participate in the study they felt signing was a better option for them even though they were not comfortable with it. However the participants were also given an option of not to participate if the two options given to them for consent did not suit them. More so talking to them could have exposed them to double vulnerability as it could have evoked feelings of what they go through when accessing and negotiating treatment continuity. I offered each HIV positive cross border participant with an information sheet to take with because it had the phone numbers for Gaudence and Marivic from the Centre for the Study of Violence and Reconciliation (CSVR) whom I had made arrangements with to refer participants should they require counselling services.

3.8 Limitations

The study of HIV is a complex issue, as people are still not comfortable talking about HIV because of the perceived stigma. Challenges exist in negotiating entrance to the clinics and identifying participants who can take part in this study. Another challenge that I faced was that people who had agreed to take part in the study and agreed with me to do a follow up interview refused to turn up for the second meeting with me, though it could have been ideal to do follow up interviews to clarify some of the themes in the research. As the data collection was done late due to the delays with the ethics committee follow up interviews could not be done on their next due date to collect treatment because some of them were receiving their treatment for several months and hence could not be interviewed again within the time constraints of this research. Another limitation is that trauma could have been evoked, hence counselling for the participants was necessary. I made arrangements with Gaudence and Marivic from CSVR to refer participants on should there be need for any of them to have counselling. During the time of the interviews, none of the participants posed with this challenge.

There was a delay with the ethics committee, because the researcher's approval to conduct the research took longer than was expected. The field work only started in December, since interviews could not be done without clearance from the ethics committee. More so, permission from the City of Johannesburg took a long time, and it was given in December, which also caused delays since research could not be done in the clinics without their permission.

The limitations of this study are that the study focused on temporary cross-border migrants alone, hence there are other groups of migrants who might face similar experiences, but were not included in this study. For example, HIV positive internal migrants and refugees were not included in this study and there is a need to understand the treatment experiences of internal migrants and refugees in the city of Johannesburg when it comes to issues of access, continuity and social networks. Moreover, there are quite a number of internal migrants moving to Johannesburg on a regular basis and understanding their experiences will add valuable knowledge in the field of migration and ART.

3.8.1. The voice of the researcher

Another limitation is that the role of the researcher might have influenced the way in which the healthcare providers responded during the interviews. Knowing that as a researcher I had permission from the city of Johannesburg and from the Gauteng department of health and that the results of the research would be shared with them, they might not have responded truthfully, due to the fact that they know exactly what to say. Hence, the responses from some of the nurses who participated in this study might not be as truthful. However, this cannot undermine the findings of this research, as it shows valuable insight on the Treatment experiences of the HIV positive cross-border migrants in Johannesburg: Access, treatment continuity and social networks., I met other Zimbabwean cross-border migrants as a Zimbabwean cross-border migrant myself, and this could have made an impact on their participant responses. As a student I met other people of higher profile, for example some of the nurses of this study, and this could likewise have had an impact on their responses.

3. 9 Conclusion

In conclusion, the qualitative design was the best method for this study because of its flexibility in exploring the narratives of the treatment experiences of the HIV positive cross-border migrants in the city of Johannesburg. Thematic analysis was the best method of analysis for this study, so as to understand the themes that were associated with the treatment experiences of the participants. Hence, the role of the researcher on data collection might have influenced the nurses and clients at the clinics not to give accurate data, since they know that I had received permission from the Gauteng department of health and from the city of Johannesburg with whom they liase.

CHAPTER FOUR:

FINDINGS AND DISCUSSIONS

4. Introduction

This chapter serves to present the findings and discussions of this study. It will start by giving a brief summary of each participant, followed by the results and the discussion of the results. It provides perspectives of both the nurses from JP Clinic and AS Clinic, as well as the HIV positive cross-border migrants. While this is the case, the purpose of this chapter is to provide new insights on how HIV positive temporary cross-border migrants in the city of Johannesburg negotiate treatment access and treatment continuity when looking at the issues of social networks.

4.1 HIV positive cross-border migrants

The HIV positive cross-border migrants who participated in this study came from various countries in Africa which included Zimbabwe, Malawi, Lesotho, Tanzania and Mozambique. Their ages ranged from 26 years to 61 years of age and they have been in the city of Johannesburg for a period of 1 to 30 years. They have been on treatment for a period of 6 months to 5 years. The majority ended their education at primary school level, while some of them did not finish secondary school, with only one participant who finished secondary school level and has a professional certificate. Five of the participants were non-documented and the other 5 were documented. While all of them came to Johannesburg due to poverty, all of them rent the houses in which they stay. One of them is a widow, 5 of them are single, another is staying with a partner, and 3 of them are married.

Table 2: Themes

Categories	Sub-categories	Sample quotations from the patients	Sample quotation from healthcare providers
Treatment access for cross-border migrants	Availability of ART Affordability of ART Acceptability of HIV positive cross-border migrants on ART	*"I go every month to collect treatment."* *"I make sure that I don't stay far away from the clinic to avoid facing transport challenges."*	*"If they find someone who can interpret for them we help them we don't have a problem."* *"Everybody is accepted."*
Treatment continuity for cross-border migrants	Keeping old residential addresses Getting a transfer letter from both countries of origins and the city of Johannesburg Taking medication on time Getting treatment from different clinics Negotiating continued access and continuity in country of origin	*"If it happens for me to travel home, they give me for 2 months."* *"I did not tell them I moved to Carlfontein."* *"I have to hide go to the toilet I drink my medication."*	*"They do take time off and they negotiate to know if you open on certain days."* *"Most of them use alarms and some use TV programs."*
Other challenges common to all migrants	Stigma about HIV lack of documentation Lack of employment Harassment by the health care workers Lack of interpreters in	*"…the stigma is still there…"* *"It's expensive to go and stamp my passport every month."* *"Getting a well-paying*	*"I think the problem was with them because they did not want other people to know about them being on ART."*

	clinics	*job is a challenge…"* *"…the nurses did not answer me well at all."*	
Availability of social support networks in Johannesburg and their countries of origin	support from available networks Openness, trust Secrecy, belonging Lack of support from available networks	*"I am not part of a support group but my family back home is very supportive and it helps me to stay on treatment."*	*"What I do is that I usually refer them to the social worker."* *"Everyone is treated the same here."*
Perceptions of cross-border migrants on ART by both healthcare providers and the patients	Strength in ART Positive and negative perceptions of self Life with hope in ART Compliant, Poor Nomadic nature of cross-border migrants	*"Before I was HIV positive I was free spirited."* *"I feel good and I see hope in ARVs."*	*"The ones that are on ART are compliant."* *"…I see them as people who are in need."*
Policy issues in relation to cross-border migrants on ART	Knowledge of healthcare providers of the migration policy Implementation and practice		*"I understand the migration policy."* *"I don't want to talk about it because I understand it."*

4.2 Presentation of cases

This section serves to describe the demographic information of the participants of this study so as to give a background of who the participants where, the countries they came from, where they access their treatment from, as well as when they started accessing treatment. Pseudonyms are used to present the cases. It will also give a presentation of healthcare providers who took part in this study. However, for confidential purposes, the clinic at which the nurses work shall not be revealed. The healthcare providers who took part in this study were all nurses. Three were female nurses, who were all South African citizens, while two of them were male nurses, one of whom was a South African citizen and the other one was a Zimbabwean citizen. Their ages ranged from 39 to 65 years. Three of these nurses were nurses that were placed in these clinics by MSF, which is working in the inner-city to facilitate access to healthcare for migrants. MSF nurses work on providing quality care regardless of race or ethnicity and they are trained to provide humanitarian care ((MSF-SA Association, 2012). More so this shows that they are better equipped than non MSF staff when it comes to facilitating access to healthcare for migrants as well as having a better attitude on them and therefore they benefit the primary health care clinics.

4.2.1 Presentation of case: Zoro

Zoro is a 33 year old female participant from Zimbabwe. She survives by being a hairdresser and she is a widow. Zoro came to Johannesburg due to poverty. She came informally[13] through the *malaichas* (taxi drivers). She ended her education in Grade Seven. She has been in Johannesburg for 4 years. She tested HIV positive in 2008, and she went to test because in 2007 she had suffered from tuberculosis. She started accessing treatment at AS Clinic and she has been accessing it for 8 months. Zoro is not in Johannesburg with her family members and where she is staying she rents the flat located in the slums in the inner-city Johannesburg.

[13] Entering the country using routes alternative to the border post.

4.2.2 Presentation of case: Fungai

Fungai is a 28 year old female participant from Zimbabwe and she is single. She came to the city of Johannesburg informally and she came because of poverty. Fungai is currently unemployed and she ended her education in Form One. She has been in Johannesburg for 5 years. She started accessing her treatment at JP Clinic and she had been on treatment for 1 year and 9 months when she stopped treatment in November 2011 as she had become pregnant. Fungai is now staying with her child and she rents the flat in the slums in the inner-city Johannesburg. When Fungai got pregnant, she stopped ART, as she said that she was told to take AZT for pregnant women. After giving birth, she had a stroke and was admitted into hospital. After she came out of hospital she went back to JP Clinic so that she could go back on ART, but she faced challenges from the nurses and she stopped treatment. At the time of research Fungai was not ART.

4.2.3 Presentation of case: Ratidzo

Ratidzo is a 28 year old female participant from Zimbabwe and she is married. Ratidzo did Ordinary level in Zimbabwe and came to Johannesburg because of poverty. Ratidzo came to South Africa informally. She is a waitress. She has been in Johannesburg for 9 years and she has been on treatment for 6 months. Ratidzo accesses her treatment at JP Clinic and she started accessing treatment while she was in Johannesburg. Ratidzo stays with her child and husband, with whom she rents a house.

4.2.4 Presentation of case: Sarue

Sarue is a 43 year old female participant from Zimbabwe and she is single. Sarue came to Johannesburg due to poverty, and she cooks at a pre-school. Sarue came to South Africa

formally[14] and she started accessing treatment back home. She has been in Johannesburg for 1 year and she has been on treatment for 5 years. Sarue has been accessing treatment back home through relatives who have been bringing it for her, but after some time the healthcare providers at the clinic she was accessing treatment from refused to give treatment for her, as they said she had to come and get treatment for herself. She then decided to approach Joubert Park Clinic for help on treatment continuity through a friend that she met at church. As she does not have a transfer letter from home, Sarue is accessing treatment every month at JP Clinic as a visitor. Sarue left school in Grade 7. Sarue stays with her two sons and she rents a flat in the inner-city of Johannesburg.

4.2.5 Presentation of case: Dorothy

Dorothy is a 40 year old female participant from Zimbabwe and she is staying with a partner. She is a domestic worker and she has been in Johannesburg for 1 year and 6 months. She is accessing treatment at the JP Clinic and she has been accessing it there for 6 months. Dorothy started accessing treatment in the Johannesburg. Dorothy came to South Africa formally using a passport and she came due to poverty. Dorothy left school in Standard 7. She rents a flat in inner-city of Johannesburg.

4.2.6 Presentation of case: Garikayi

Garikayi is a 36 years old male participant from Malawi. He came to South Africa because of poverty and he came formally using a passport. Garikayi first came to Mpumalanga, where his brother was located before moving to the city of Johannesburg. Garikayi left school in Standard 3. He first started accessing treatment in Mpumalanga and now he is accessing it at AS Clinic. Garikayi is renting a flat in the inner-city of Johannesburg and stays with his only son. He has been in Johannesburg city for 1 year 6 months and he has been on treatment for 4 years. He is a dress maker.

[14] Coming to Johannesburg using a passport or any other formal route through the border.

4.2.7 Presentation of case: Edwin

Edwin is a 43 year old male participant from Tanzania and he is single. Edwin came to South Africa informally and he came due to poverty. He left school in Grade 7 and he sells clothes at a flea market in the inner-city Johannesburg. Edwin has been in Johannesburg for 2 years and he has been on treatment for 1 year. He rents a house outside the inner-city of Johannesburg. He is accessing his treatment at JP Clinic and he started accessing it there.

4.2.8 Presentation of case: Charles

Charles is a 61 years old male participant from Lesotho and he is married. Charles came to South Africa formally using his passport. He came because they had transferred him at work. He first stayed in KwaZulu-Natal before coming to city of Johannesburg. He is accessing treatment at AS Clinic and he started accessing it there. He has been in Johannesburg for 30 years and he has been on treatment for 2 years. He left school in Standard 4 and he stays with his family. He rents the house he is staying. Currently he works as a security guard and a dress maker. Charles receives no support from his wife.

4.2.9 Presentation of case: Evans

Evans is a 38 years old male participant from Malawi and he is married. He came to South Africa formally and he came to Johannesburg due to poverty. Evans has been in Johannesburg for 4 years and he started accessing treatment at home. He has been on treatment for 2 years and he is accessing treatment at AS Clinic and he has been accessing it for 2 months in Johannesburg. He faced financial problems and he was not able to go home and get his treatment as he did not have money for transport. Evans left school in Standard 7

and he is currently working as a domestic worker. He is not here with his family and he rents a flat in the inner-city of Johannesburg.

4.2.10 Presentation of case: Jeremy

Jeremy is a 26 years old male participant from Malawi and he is single. He came to Johannesburg formally using his passport and he came due to poverty. He is accessing treatment at AS clinic and he started accessing it there. He has been in Johannesburg for 5 years and he has been on treatment for 5 years. He left school in Standard 8. He stays alone and where he is staying, he rents a flat in the inner-city Johannesburg. Currently he is working as a tiler.

4.2.11 Healthcare providers

4.2.12 Presentation of case: Gladys

Gladys is a 65 year old female nurse who is a widow. She is a South African citizen who was born in Johannesburg. She has a nursing diploma and a teaching diploma. She has been working at the clinic for 3 years. She is one of the MSF nurses.

4.2.13 Presentation of case: Talent

Talent is a 51 years old female nurse who is a divorcee. She is a South African citizen, who was born in Johannesburg. She has a diploma in general nursing, a diploma in midwifery and a diploma in primary health care. She has been working at the clinic for 3 years. She is one of the MSF nurses.

4.2.14 Presentation of case: Eddie

Eddie is a 39 year old male nurse from Zimbabwe. He came to Johannesburg for economic reasons. He was a nurse in his country of origin. He is married and he has a degree in nursing. He is not in Johannesburg with his family. He has been working at the clinic for 2 years. He is one of the MSF nurses.

4.2.15 Presentation of case: Bev

Bev is a 39 year old female nurse. She was born in Johannesburg and she has a higher diploma in nursing. She has been working at the clinic for 2 years, and she has been a nurse for 5 years. She is married.

4.2.16 Presentation of case: Kelvin

Kelvin is a 39 year old male participant. He was born in Johannesburg. He has a higher diploma in occupational therapy and has been working as a nurse for 13 years. He has been working at the clinic for 3 years. He is married.

4.3 FINDINGS

Introduction

This section serves to present the results about what both the HIV positive cross border migrants on ART and the nurses said about what HIV positive cross-border migrants on ART do to access and to stay on treatment. Regardless of the challenges that the HIV positive cross-border migrants on ART face, most of them are managing to access and to continue with their treatment. Nine of the participants were successful in accessing and staying on treatment whilst another participant faced challenges and stopped taking treatment. The

themes that emerged from both the HIV positive cross-border migrants on ART and the nurses include: treatment access for cross-border migrants; treatment continuity for cross-border migrants; others challenges common to migrants; availability of social support networks in Johannesburg and their countries of origin; perceptions of both cross-border migrants on ART and the health care providers about the HIV positive cross-border migrants on ART; as well as the policy issues in relation to cross-border migrants.

4.3.1 TREATMENT ACCESS FOR CROSS-BORDER MIGRANTS

Availability of ART

Going to the clinic every month to collect treatment

ART is available for HIV positive cross-border migrants at JP Clinic and AS Clinic. All the participants agreed that to negotiate continued access and continuity they go to the clinic to collect their treatment on their due date, given to them by the nurses on a monthly basis. At these clinics, ART is free and HIV positive cross-border migrants on ART get it for free, as do citizens. Below is a recount of what Ratidzo, a 28 year old female participant from Zimbabwe said during the interview (JP interview conducted on 05/12/2012).

> *"I don't have any challenges there. I always come every month to get my treatment. If it happens for me to travel home, they give me for 2 months"* [sic].

This was reiterated by other participants on ART from both JP Clinic and AS Clinic. Closely related to what Ratidzo said, Jeremy, a male participant from Mozambique (As interview conducted on 15/01/2013) said that he always come to the clinic on the due date for treatment. Furthermore Dorothy a female participant from Zimbabwe said the following during the interview (AS interview conducted on 13/12/2012).

> *"Every month I go to Joubert park clinic to get my medication"* [sic].

Furthermore, Jeremy and Garikayi stated in their interviews that sometimes they give them treatment for three months so they don't always need to go to the clinic every month.

Some of the participants have been getting their treatment at home. When they could not get it because of financial challenges, as well as not being able to get people who can bring treatment to them, they went to the clinics and spoke to the nurses, who agreed to give them treatment. Sarue, a 43 years old female participant from Zimbabwe, said the following during the interview (JP interview done on 05/12/2012):

> *"...so I was sending people who would go there and bring the tablets for me, so it was after some time when I sent them that they told me that those people are now refusing to give them the tablets they are saying they want me to come and get the tablets for myself because the money I get is small, it was not possible for me to travel to go and get medication from home. After they had brought the cards for me that's how I came here and asked for help to get medication then they said no we can't help you because we need a transfer then I told them that as for the transfer I will try to ask them to bring me so they gave me a month's treatment and I went and drank it. …so from then they have been giving me treatment as a visitor"* [sic].

Describing something similar, Evans, a 38 years old male participant from Malawi (AS interview conducted on 14/01/2013) said when he went home he took tablets for 6 months in Malawi, so for his next due date he did not have money to go home, and that is why he came to the clinic to talk to them and to ask them to help him with tablets so that he continues with treatment and they have agreed to give him treatment monthly until he goes back to Malawi.

The HIV positive cross-border migrants and the healthcare providers shared the same views when it comes to availability of ART, which they also believe its highly available for cross-border migrants as it is for citizens. The majority of the nurses from both clinics agreed that HIV positive cross-border migrants on ART go to the clinics every month to get their treatment. They said they will go on the date that they would have been given by the nurses in order to collect their medication and usually that is the day that their treatment for the month would be finished, or they will be left with a few days. Below is an account of what Bev, a female nurse, said (interview conducted on 11/12/2012):

> **"***As for their treatment they come every month on a date that you would have given them to collect their treatment"* [sic].

Corroborating this, below is a recount of an interview with a male nurse, Eddie (Interview conducted on 29/11/2012):

> *"…the cross-border migrants just come to the clinic every month to collect their monthly treatment when* [what they have is] *finished. As MSF nurses, we are there to make sure that cross-border migrants have access without any challenges as well as promoting cross cultural counselling and intervention*[15] *to assist both the migrants and the nurses, so as to see if the issue will be with the health providers or with the patient and to try to be in the middle and see which way to make it well with them"* [sic].

Adding to this, Kelvin a male participant had the following to say (Interview conducted on 13/12/2012):

> *"…so they just come every month to collect their treatment"* [sic].

While the majority of the nurses agreed that the HIV positive cross border migrants on ART come every month to collect their treatment, there is one female nurse who had something different to say. Gladys, during her interview (done on 28/11/2012), said they sometimes give all patients including cross-border migrants a supply for three months, so that when they are not able to come on the following month, they have some medication for three months. This supports what Mcintyre et al. (2009) say about availability being about when the right healthcare services are put in the right place at the right time to meet the needs of the population.

Affordability of ART

Treatment is affordable for the HIV positive cross-border migrants, as they do not pay for treatment, but get it for free because these clinics are primary healthcare clinics run by the city of Johannesburg. However, the cost that can be associated with it is when it comes to the lack of interpreters at AS since the HIV positive cross-border migrants will have to find

[15] This includes language and behaviour acceptable in other cultures.

interpreters for themselves so that they can access ART. None of the participants complained about transport challenges when accessing treatment in the inner-city clinics, as the majority of them stay in the inner-city of Johannesburg where they can easily access treatment without paying for transport but walk to the clinics. Charles, a male participant from Lesotho, said the following during the interview (AS interview conducted on 14/01/2013):

> *"I make sure that I don't stay far away from the clinic to avoid facing many challenges like transport…"* [sic].

This also allows patients time to get to the clinic to obtain treatment, because if they were staying far away, such time would be a cost. Closely related to what Charles said, there are some nurses who also agreed that most of the HIV positive cross-border migrants stay around the inner-city of Johannesburg, making it easier for them to come and access treatment. It is important to note that they are getting treatment from these clinics because they stay in the inner-city however, it is also important to note that this also saves them money. Below is a recount of what Bev said during the interview (Interview conducted on 11/12/2012):

> *"I treat people who stay around the clinics I haven't met someone who comes from his or her country of origin and coming every month to get treatment"* [sic].

Closely related to the above, Kelvin, one of the male participants said that some of them stay nearby so they just come every month to collect their treatment.

While the majority of the participants stayed in the inner-city close to the clinics, a few of the participants moved out of the inner-city and were travelling to get treatment, since they did not change their addresses, and continued to get treatment from the clinics that were far from them. Below a recount of what Edwin a male participant from Tanzania said during the interview (JP interview conducted on 11/01/2013). Another participant Ratidzo was also staying in Bezuidenhout Valley, but accessing treatment in the inner-city of Johannesburg:

> *"I did not tell them I moved to Carlfontein because they were going to tell me to get a transfer letter because maybe I was going to face problems"* [sic].

Closely related to the above, one of the male nurses Eddie during the interview (Interview conducted on 29/11/2012) said that some of them are still keeping their old addresses and

coming to the clinics that might be far from them, because it might take time before they get a transfer letter. This shows the importance of having a transfer letter when moving to a new place. While clinics might be far for some of the participants, they indeed prefer to travel than to become susceptible to potential transfer delays.

Interpreters

While none of the participants of this study complained about the issue of interpreters, most of the nurses from AS related that some HIV positive cross-border migrants look for interpreters to help them when there is a language barrier. They said when they bring the interpreters along with them then they get treatment. Below is an account of what Bev, a female participant said (interview conducted on 11/12/2012):

> *"…because we do not have interpreters at the clinic so in most cases when there is a language barrier I ask them to go and find an interpreter"* [sic].

In supporting what Bev said below is an account of what Kelvin said (Interview conducted on 13/12/2012):

> *"… when there is a language barrier I ask them to go and bring someone who can speak local languages or English"* [sic].

While other nurses agreed that HIV positive cross-border migrants on ART find interpreters for themselves, there is a nurse from the same clinic who said they have interpreters. Talent said in their clinic they are lucky, because they work with some people from other countries who work as interpreters (Interview conducted on 28/11/2012). There is a need at AS of introducing the staff to language skills so as to make access to ART affordable for the cross-border migrants who cannot speak local languages. This finding confirms a study done by Soskolne and Shtarkshall (2002) in Israel, which showed that messages might not reach immigrants due to language or other cultural barriers.

Acceptability of the HIV positive cross-border migrants

Negotiating with the nurses

Negotiating with the nurses refers to the way that the HIV positive cross-border migrants on ART talk to the nurses so that they can come on a day that they will not be going to work. It also refers to the way they talk to the nurses to get more treatment to take them for the period that they will not be in the city of Johannesburg in the event that they are visiting home temporarily. The participants in this study are accepted at JP and AS clinics where they are accessing ART. The majority of the participants agreed that when they are to travel home temporarily the nurses don't have a problem they understand and they give them treatment which is enough for the time that they will be at home. This shows that HIV positive cross-border migrants on ART are being accepted at the clinics that they access ART because their situations are being understood by the nurses. Below is a recount of what Garikayi a 36 years old male participant from Malawi said during the interview (AS interview conducted on 13/12/2012)

> *"Before I go home I come here and I explain to them that I am going home for a certain period of time so they will give me medication equivalent to the time that I will be away"* [sic].

There are some participants who had different views on what they do if they travel home temporarily so that they can access and stay on treatment. There are also other participants who said that they can leave their treatment cards with other people to get them treatment and send it home since the nurses do not have a problem with that. Below is what Zoro a female participant from Zimbabwe said (Interview conducted on 03/12/2012):

> *"… sometimes I leave the card with someone that I trust, who will go and take the medication for me and send it through the bus drivers to Zimbabwe*" [sic].

Some nurses corroborated the fact that the cross-border migrants on ART talk to them so that they can come on a different day and when they are going home temporarily they will ask for more treatment for the time that they will not be available. Bev, a female nurse (interview conducted on 11/12/2012) states in this regard:

> *"If they are going home I ask them when they are coming back and I give them treatment enough for the months that they will be at home"* [sic].

In support of what Bev have said Gladys, one of the female nurses (Interview conducted on 28/11/2012) stated that HIV positive cross-border migrants on ART take time off and they negotiate with the nurses to know whether they open on certain days because maybe they work on those days when they would be asked to visit the clinic for their treatment. This confirms what Mcintyre et al. (2009) have stated about acceptability, as they argue that it has to do with the relationship between the health provider and the patient, which has an influence on the ability of individuals to receive care. The relationship between the participants of this study and the health care providers is influencing them to stay on ART.

Equal treatment

Most of the participants reported being treated the same as citizens when it comes to treatment access and continuity. Zoro, a female participant from Zimbabwe, during the interview (conducted on 03/12/2012) said here she is treated equally and when treatment is not enough for her it is also not enough for South Africans. Garikayi, Edwin and Charles, during their interviews, likewise said they access their treatment freely. Garikayi said the following (Interview conducted on 13/12/2012):

> *"The way I stay when I am at home and the way I stay and live when I am here is the same"* [sic].

However, one participant reported that she was shouted at by the nurses. When she went back to JP where she was accessing treatment to recommence they refused to take her for ART and they shouted at her. Fungai said the following (Interview conducted on 03/12/2012):

> *"I was not answered well and that made me to stop ART"* [sic].

The nurses also reported treating HIV positive cross-border migrants the same as other patients. One might argue that the HIV positive cross-border migrants of this study are doing well in treatment because they are being treated equally in the clinics in Johannesburg. During the interview, Kelvin, a male nurse, said the following (interview conducted on 13/12/2012):

> *"Everyone is accepted here and we treat them equally and I am a friend to everyone"* [sic].

The same views were also shared by Bev, Gladys, Eddie and Talent. Equal treatment was also extended by the healthcare workers to the way they deal with drug resistance. From the five nurses, Bev and Gladys had never had any experience, but all the nurses agreed that they ought to deal with drug resistance the same way they deal with it when it comes to South African citizens. This confirms a study done by Moyo in 2010, which shows that cross-border migrants were treated the same as nationals in the public healthcare facilities.

4.3.2. TREATMENT CONTINUITY FOR CROSS-BORDER MIGRANTS

While the majority of the participants said that they asked for treatment to keep them going in the event that they are travelling home temporarily, some participants said that they go home and come back before their next due date, which was before their medication was finished. Zoro a female participant from Zimbabwe said (Interview conducted on 03/12/2012):

> *"Sometimes I go home and come early before my treatment is finished"* [sic].

To support what Zoro said, Dorothy, a 40 years old, female participant from Zimbabwe at JP (Interview done on 13/12/2012) said that ever since she started taking ARVs, she has gone home two times, and in all the circumstances she went home for a short period of time and came back before her medication was finished.

Eating healthy food

Some of the HIV positive cross-border migrants pointed out that eating healthy food helps them to continue with treatment. Below is an account of Zoro, a female participant from Zimbabwe (Interview conducted on 03/12/2012):

> *"I plait people's hair so that I can get money to buy body building foods, but if I don't get a client the woman from my country that I stay with gives me food so that I can stay on ART"* [sic].

Closely related to the above, Garikayi and Dorothy shared the same view, Jeremy a male participant from Mozambique attending AS (Interview done on 15/01/2013) said that going

to the border to stamp his passport every month finishes his money, because he needs the money to buy healthy food, which he needs in order to eat, so that he can stay on ART.

Some nurses shared the same views with the participants, as they said for HIV positive cross-border migrants to continue with ART, they make sure that they eat healthy food. One of the nurses, Gladys (interview conducted on 28/11/2012), said the following during her interview.

> *"Once they are here in South Africa they try to get a job somehow to keep them going so that they have a place to stay and food so that they get a well-balanced diet"* [sic].

This was also shared by the other two nurses Bev and Talent.

Getting a transfer letter

Getting a transfer letter is part of the process of continuity on ART when moving to a new clinic. Some of the participants made use of transfer letters so that they can continue with ART at the clinics in this study. One of the participants said that he started accessing treatment in Mpumalanga, and when he was coming to Johannesburg he brought a transfer letter. Garikayi said the following (AS interview conducted on 13/12/2012):

> *"I went to the clinic where I was accessing treatment and I told them that I was now moving to Johannesburg and they gave me a transfer letter so that I could continue accessing and staying on treatment"*.

Sarue, a 43 years old female participant, did not get a transfer letter when she was coming to Johannesburg. She said when she explained to the healthcare providers at Mpilo Hospital where she was accessing treatment that she will be going to Johannesburg they said that she can be sending people who will be getting treatment for her but after she got treatment for a few months they refused to give her treatment as they want her to come back and get treatment for herself. Though she is getting treatment as a visiting immigrant due to the fact that she does not have a transfer letter from home, she fears non-continuity of treatment. A female nurse Gladys stated that (Interview conducted on 28/11/2012):

> *"When they come to the clinic I ask them if they have a transfer letter, because the rule in South Africa is that they should have a transfer letter"* [sic].

Taking medication on time

The majority of the participants said they do not use any reminder but they just know when it's their time to take their medication. These were two females and four males. Zoro said the following during her interview (AS interview conducted on 03/12/2012):

> *"I don't have any reminder that I use. I know my time"* [sic].

Zoro also pointed out that sometimes when she is at home in her country of origin, her family reminds her to take her medication when it's time for her medication. Ratidzo, Garikayi, Edwin, Evans and Jeremy also said they did not use any alarms, Fungai also said that by the time that she was on ART, she did not use any alarm but she just knew when it was time for her to take her medication. Among the other three participants who use an alarm as a reminder, two were females, and the other one was a male participant. Charles a 61 year old male participant from Lesotho had the following to say about the use of reminders (AS Interview done on 14/01/2013):

> *"I just set an alarm on my phone and that's the one I always use to remind me to take my medication"* [sic].

Some of the healthcare providers pointed out that cross-border migrants make use of reminders, which help them to know that it's time for them to take their medication which include alarms and television programs or even people that remind them. Kelvin (interview 13/12/2012) said,

> *"They use the alarms, some of them use the programs that play on TV like generations… while some have people that remind them"* [sic].

In support of what Kelvin said, Eddie and Gladys from a different clinic said that (Interview done on 07/01/2013) what helps them is that they use alarms so that they remember the time to take their medication. While the majority of the participants did not make use of reminders, the use of reminders confirms the study done in which patients made use of reminders to take their treatment, as well as some getting support from partners and families (Gilbert & Walker, 2009).

Negotiating continued access in country of origin

All participants shared similar views on what they would do to stay on treatment if they experience unplanned movement, and if they decide to go home forever. The participants pointed out that if they experience unplanned movement, they would go to their nearest clinic or hospital in country of origin where they would explain what has happened to them, so that they could continue with their medication. Below is a recount of what Jeremy, a 26 year old male participant from Mozambique, said during the interview (AS interview conducted on 15/01/2013):

> *"I will just go home straight to the hospital and explain to them what has happened and then I will continue with treatment"* [sic].

Likewise, Dorothy a female participant from Zimbabwe explained (JP Interview conducted on 13/12/2012):

> *"I will go to the clinic and explain what have happened…"* [sic].

In terms of going home forever, in the event of planned movement, all the participants shared the same view that they would go to the clinics where they are getting medication and tell them that they will be going home permanently. They also indicated that they will ask for a transfer letter, which they will present in their countries of origin in order to access and to stay on treatment. Below is a recount of what Charles from Lesotho said during the interview (AS interview conducted on 14/01/2013):

> *"I will come to the clinic then I tell them that I am moving back home and I will ask for a transfer letter which I will take to the closest clinic or hospital at home"* [sic].

Dorothy, a female participant from Zimbabwe, said (JP Interview conducted on 13/12/2012) when she decide that she wanted to go home forever, that she would go to Joubert Park Clinic and ask for a transfer letter so that she could present it at home in order to continue with ART.

HIV positive cross border migrants in the city of Johannesburg on ART were confident that if they experience planned or unplanned movement, they would continue accessing and staying on ART. This shows some of the characteristics that HIV positive cross-border migrants possess when it comes to attitude towards their treatment, because they show an interest in wanting to continue with their treatment.

4.3.3. OTHER CHALLENGES COMMON TO ALL MIGRANTS

The majority of the participants face challenges common to other migrants, but these do not prevent them from negotiating continued access and continuity of treatment.

Stigma

The majority of the HIV positive cross-border migrants on ART had a fear of being stigmatised by the communities they live in either here in the city of Johannesburg or back home. They agreed that this fear of being stigmatized causes them to be secretive about their status and treatment with others. They also agreed that there is still stigma out there, and that therefore, they cannot tell people that they are on ART. The stigma associated with being HIV positive was also taken on ART.

Below is a recount of what Ratidzo, a female participant from Zimbabwe, said during the interview (JP interview conducted on 05/12/2012):

> *"If I visit I feel embarrassed to take my medication… I don't know how they will react the stigma is still there"* [sic].

To support what Ratidzo has said, Sarue, a female participant from Zimbabwe said (JP Interview done on 05/12/2012) that she looks after other people's children it concerns her that they might become uncomfortable if they knew about her status.

What Ratidzo and Sarue said about stigma was common among all the other participants. Among all the nurses however, only one nurse pointed out that stigma is a challenge for the HIV positive cross-border migrants. Gladys, a female participant, said (interview conducted on 28/11/2012) the support group stopped also because they did not want other people to know about their status for fear of stigma. This confirms what Gilbert and Walker (2009)

found in their study, that the stigma associated with being HIV was also associated with ART. This also confirms what was found in Jones' study done in 2012 at Hammanskraal-Temba. Though his study looked at every person accessing ART (both nationals and foreigners), his study found that there was stigma associated with being HIV positive, which was further transferred to ARVs, where some were not happy about disclosure (Jones, 2012). However, what is different is that participants in Jones' study ended up not seeking treatment, whereas in this study, they sought treatment but did not want to disclose it, fearing stigma.

Documentation and Fear

Some of the participants were facing challenges when it came to getting stamps on their passports at the border which allow them to stay in Johannesburg. This is because it was expensive for them to go there every month, and some of them ended up lacking documents, because they had not stamped their documents. Jeremy, a male participant from Mozambique, had the following to say during the interview (AS interview conducted on 15/01/2013):

> *"The problem I have is about my passport because I am a Mozambican citizen and I use my passport and at the border they give me one month so which means I have to go there all the time to get a stamp and it's expensive for me"* [sic].

To support Jeremy, Evans, a male participant from Malawi said (AS Interview done on 14/01/2012) the challenge that he has is that he does not have documents, since he failed to stamp his passport, and this causes him to undergo harassment from police when travelling around the inner-city.

This challenge also led to the participants' fear of deportation, because some of the participants live in the inner-city slums, where the police go to raid the houses. Zoro, a female participant from Zimbabwe during the interview said (AS interview conducted on 03/12/2012):

> *"Sometimes we are scared to be deported but God is the one who protects me. Even as you walk in the road you can see that there is*

> *someone who has been caught by the police or the police can come and raid at the flat…"* [sic].

Some participants reported wanting documents to secure their stay. Jeremy a male participant from Mozambique (AS interview conducted on 15/01/2013) said if home affairs could help him to get a permit, his life would be better. More so, he said that as a person on ARVs though he goes to the border every month to secure his stay in Johannesburg getting documents from the government would help in reducing the costs of going to the border, as it is expensive for him.

Unemployment- Survivalist Livelihoods

The majority of the participants work in the informal sector. This confirms a study done by Vearey (2008), who found that the majority of cross-border migrants were working in the informal sector. While one of the female participants, Fungai from Zimbabwe, said she does not work, the majority of the participants agreed that they did not have well-paying jobs. Sarue, a female participant from Zimbabwe, said the following during the interview (05/12/2012):

> *"...the job that I am on is okay for giving me a place to sleep, pay my child's school fees and food but sometimes I don't get enough body building foods because the money is not enough"* [sic].

Related to the above, Jeremy a male participant from Mozambique, said (AS interview conducted on 15/01/2013):

> *"When it comes to getting jobs, most people are biased towards foreigners if they don't have documents, so the job I have is not well paying"* [sic].

Participants felt that lack of documentation was hindindering them from getting secure jobs. This confirms a study done by Vearey (2008) who notes that lack of documentation caused by the delay with the department of home affairs prevented migrants from getting jobs.

Lack of Interpreters

In one of the clinics, the challenge that HIV positive cross border migrants on ART are facing is the issue of not having interpreters at the clinic. Due to this, they will be asked to go and look for someone who can interpret for them, so that they can access treatment. However, none of the participants interviewed had experienced a challenge with this. One might argue that the lack of interpreters compromises their confidentiality and their security in the communities they stay in. If asked to go and look for interpreters, confidentiality is broken, as other people will end up knowing about the statuses of the HIV positive cross-border migrants, especially if they are not ready to disclose.

Despite the different challenges that HIV positive cross-border migrants are facing when they are in the city of Johannesburg, nurses agreed that they show an interest in wanting to continue and that they stay on their treatment. Gladys, from Joubert Park Clinic, pointed out that they never want to go without treatment (Interview done on 28/11/2012).

4.3.4. AVAILABILITY OF SOCIAL SUPPORT NETWORKS IN JOHANNESBURG AND THEIR OWN COUNTRIES OF ORIGINS

One of the key findings of this thesis relates to the support networks that HIV positive cross border migrants have, how they form the social networks, and whether these networks help them to stay on treatment. From all the interviews done, the participants have reported that they are not part of any support group and that they have not heard of any support groups in Johannesburg. For most of the participants, the locus point of their support networks has remained the family back home in their countries of origin, and family members that are in the city of Johannesburg. For many of the participants, HIV treatment access and continuity is not leading to support networks in the city, because many people are not disclosing in the city, but back home. The interviews also showed that there is a great deal of secrecy when it comes to treatment access and continuity. The majority of the participants stay in the buildings that are in the inner city of Johannesburg, whereas some of them stay in the slums of the inner-city. Among the latter, only two of them managed to disclose to South African citizens in the inner-city of Johannesburg, showing that there is a significant amount of secrecy in these buildings as trust is rather developed with family members as well as friends

from further afield in their countries of origin. This confirms what Vearey et al. (2011) found in her study in Johannesburg, as they showed that there is a need to understand the meaning of place where people enter and settle, which determines the health of the population. The inner-city buildings are associated with secrecy and this has determined the secrecy that is happening among HIV positive cross-border migrants on ART. On another note when it comes to treatment access and continuity the inner-city as a place that cross-border migrants enter and settle has not determined their chances of treatment access and continuity as the relationships that are taking place between the clinic staff and the clients have also helped treatment access and continuity.

There are also relationships with the healthcare providers that are helping them to negotiate continued access and continuity of ART. Nurses note that social workers provide social support that was available to these migrants. In all the interviews, it showed that there is no support group however, running at both the clinics. There were different reasons why they are no extant groups. At Joubert Park they once had one. Some of the nurses who work there believed that the reason why it's no longer in existence is because of the HIV positive cross-border migrants themselves, who were scared of stigma so they did not want to be seen and there was a logistical problem in finding a time convenient to those who worked a variety of different hours. At Albert Street Clinic, there were reasons that involved a lack of help so as to organize the support group. However, from all the nurses there was an agreement that there were some support groups running in the city, though not attached to the clinics in which they worked. They said that these support groups were run by cross-border migrants and HIV positive cross border migrants were being easily accepted. This descrepency might be due to lack of information on support groups when it comes to HIV positive cross-border migrants. All the nurses agreed that when the support groups start at the clinics, they will not encourage discrimination; but that they will make sure that everyone is accepted in the support groups, including HIV positive cross-border migrants on ART.

Positive support (openness, trust and secrecy)

The majority of the participants maintained their family networks as part of their social networks even in the city of Johannesburg. Below is an account of what Jeremy, a male

participant from Mozambique, said during the interview (AS interview conducted on 15/01/2013):

> *"I am not part of any support and I get support from my friends who are from my country of origin who are here in Johannesburg, my cousin as well as my family back home"* [sic].

Ratidzo, a female participant from Zimbabwe concurred with the following during the interview (JP interview conducted on 05/12/2012):

> *"My family knows and they provide me with support. Here I haven't disclosed to anyone except to my husband and my family back home"* [sic].

There are participants who reported disclosing to certain family members and not others fearing the consequences. This confirms what Mogensen (2010) found in his study in Uganda that some of his participants were disclosing to certain family members and not to others. Out of the ten participants in this study, two disclosed to certain family members and not to others. Ratidzo, a female participant from Zimbabwe, had the following to say during the interview (JP interview conducted on 05/12/2012):

> *"At home, my sister, my brother and my mother are the only people who know that I am HIV positive and my father doesn't know because I know he has got temper he will just disown me"* [sic].

Among all the participants only one of the participants Garikayi a male participant from Malawi said that he did not disclose to any member of the family back home but from friends who are from the same country. Garikayi from Malawi said the following (AS Interview done on 13/12/2012):

> *"I have a person that I confide in, he is a friend, but he is an adult to me and he comes from Malawi… back home they don't know that I am HIV positive and that I take ARVs. I am not worried that they might tell people from my family because they don't know my family and we don't come from the same areas"* [sic].

While the majority did not disclose in the city, a few did. Below is an extract of how Sarue, a female participant from Zimbabwe, disclosed to her South African friend. During the interview, she had the following to say (JP interview conducted on 05/12/2012):

> *"I met (Betty) because she is a lady who usually comes to bring her children at crèche and then I got used to her a bit then we started going together at church… when I was praying there and doing confessions things like that at church that's when I spoke that I had a problem that I needed to go home to look for ARVs then that's how she got to know about it then she is the one who came and showed me the clinic"* [sic].

Similarly, Zoro, a female participant from Zimbabwe, noted (AS interview done on 03/12/2012) that the way she met her South African friends was at the clinic when they were also accessing ART, and realising that they stay at the same place, she became friends with them. While this is the case, staying at the same area and sharing the same diagnosis also shaped trust among some participants, as seen in Zoro's case. While this is a minority it can not be denied that social organizations like churches motivate people to have trust and to be able to confide in the people with whom they worship with.

All of the participants said that they all receive support from those to whom they disclose, which was helping them to negotiate continued access and continuity of ART. Below is a recount of what Zoro, the female participant from Zimbabwe, said during the interview (AS interview conducted on 03/12/2012):

> *"My aunt encourages me to stay on medication. Even if she hears that I drank beer she will be angry because she wants me to eat healthy food, she even ask me to come and stay with her in Musina if I am not coping in Johannesburg. With my friend we always talk about going to get our treatment and this in a way helps me to stay on treatment"* [sic].

HIV positive people are assumed to function better when in support groups (Muanamoha et al, 2010; Nguyen, 2005), but this study challenges that, as the participants of this study are doing well when they are not in support groups. Furthermore, none of the participants complained about not being in a support group. The phenomena of bio-sociality which was

adopted by Rabinow (cited in Whyte, 2009), was not taking place among the migrants in this study. This is because the bio-sociality concept argues that people come together due to a shared diagnosis, but only a minority of participants reported having relationships with nationals based around HIV status. The study supports the findings of Landau and Madhavan (2011), which discuss the homogeneity of social capital, which is associated with thick trust and associated with ethnic relationships. This study found that the HIV positive cross-border migrants on ART in the city of Johannesburg are homogenous and that they have bonding capital. This is mainly because their social networks are mostly built on ethnic origins.

Participants had different strategies that they use to stay on treatment when they visit relatives or friends who do not know about their status. Below is a recount of what Zoro a female participant from Zimbabwe said during the interview (AS interview conducted on 03/12/2012):

> *"I have some in containers but yesterday I carried these ones in a packet I carried them on my handbag on my side even if I go anywhere I will just wake up and drink them but I would have mixed them as three types all in one packet when I get to my friend's place I will just drink she won't know what they are for"* [sic].

Closely related to what Zoro said, Garikayi, a male participant from Malawi whose family does not know that he is on treatment, said the following during the interview (AS interview conducted on 13/12/2012):

> *"When I go home to visit I just take my tablets no one will know because people always travel with tablets..."* [sic].

Ratidzo, a female participant from Zimbabwe, during the interview had the following to say in contrary to what Zoro and Garikayi said (JP interview conducted on 05/12/2012):

> *"I have to hide or go to the toilet to drink my medication, that's it"* [sic].

Regardless of the fact that other people in their lives do not know about their status, hiding their status, HIV positive cross-border migrants on ART manage to stay on treatment because they will be looking healthy like any other people that manage to hide the fact that they are on ART. This confirms what Mogensen (2010) says, that ART has brought about new possibilities for hiding the disease.

Relationships with health care providers

The majority of the participants reported negotiating with nurses when in need of ART if they are travelling home temporarily. Closely related to this, Bev and Kelvin from the same clinic had a different perspective from all the other nurses. They believed that having a good relationship between the healthcare providers and the HIV positive cross-border migrants on ART, helps them to stay on treatment**.** They believed that it motivates them to come every month to get their treatment. During the interview (interview conducted on 11/12/2012) Bev said:

> *"I believe that in treatment access and continuity the health worker plays an important role, because if people are treated badly, they will not have treatment and they will stop to come to the clinic; but if they are cared for through telling them the importance of treatment, they will come, and they will continue with their treatment"* [sic].

To support Bev's claims, Kelvin also said that everyone is treated the same at their clinic and it helps patients to come to the clinic to receive treatment (interview conducted on 13/12/2012). Below is an observation made at the same clinic where Bev and Kelvin work:

> *It was at around 9:30 am, when I got to the clinic. Patients were sitting on the chairs in the waiting area listening to people who were presenting from the clinic on Human Papilloma Virus (HPV) in men. As people began the discussion and started asking questions there was a woman from Zimbabwe who stood up to ask a question. When she was asking, the woman who was answering questions could not get her properly, since she started asking in English and all the other people before her were asking in local languages. The Zimbabwean woman said "okay I will try to speak in Xhosa". The woman who was answering question said "don't worry about that just speak in the language you are comfortable with".* (Field notes observation, 15/01/2013).

The field notes supports Bev and Kelvin's statements in that at the clinic in which they work, there is a good relationship that is facilitated by the nurses amongst all patients, regardless of their nationality.

While this was the case in one clinic it was different in another. One of the female participants from Zimbabwe, Fungai, aged 28 years old, said she is no longer on treatment. She said she started treatment in 2010 in February and everything was going well as she used to go and get her medication every month. When she was pregnant, she was transferred to maternity at Joubert Park to access her treatment from there and she was told to go on AZT, which is for pregnant women, which she accessed for nine months. When she went back to continue with ARVs, she was told she was not supposed to stop ARVs from the beginning and that she must get a letter confirming that she was told to stop. When she went back to maternity, she was shouted at by the healthcare professionals and she stopped the whole process and is no longer on treatment. During the interview, Fungai said the following (interview conducted on 03/12/2012):

> *"They thought I was lying that I was on AZT. They told me when you are on AZT you do not take ARVs. They gave me AZT until I gave birth and after that they refused to change for me"* [sic].

Below is an observations done at Joubert Park Clinic, where Fungai reports that she was treated badly:

> *I was at the clinic at 8:30 am. When I got there the clinic was full and people were waiting for their turn to be assisted to get ART sitting on the chairs. I asked the clinic manager if I could attend the workshop that was running with patients on ART. When I was permitted to go in, the sister who was there was having a workshop with patients on ART on how they could live healthy on ART. Most patients were speaking in Zulu and the sister was responding happily. There was a certain man who was a cross-border who could not speak Zulu, who responded to a question he was asked in English, and he responded wrongly as he had not heard the question properly. The sister ignored the man and just looked at the man and continued to speak in Zulu. At that moment, there was a significant communication barrier, as the man could not understand and the sister continued to speak in Zulu*

> *while at the same time frowning.* (Field notes observation, 08/01/2013).

One of the male nurse participants from the same clinic said that HIV positive cross-border migrants on ART experience negative treatment from the healthcare providers, which prevents some from treatment continuity. While the majority of the participants are managing to negotiate continued access and continuity of ART and have not heard any negative experiences with the healthcare providers, there is a minority who are being treated badly. This confirms previous studies that have been done which show that cross-border migrants were not denied treatment, and that they were being shouted at by the healthcare providers (Moyo, 2010; Pophiwa, 2009). However, while this is the case, it cannot undermine the relationships that are taking place between the participants and the healthcare providers, as it is supported by the majority of the participants, especially those from AS Clinic.

HIV positive cross-border accessing treatment in the Johannesburg city negotiate confidentiality and trust among the people that they confide in, and the ones that they disclosed to are mostly family and friends. Below is an account of what Jeremy, a male participant from Mozambique, said during the interview (AS interview conducted on 15/01/2013):

> *"The people that I trust are not many. The people that I trust are those that I grew up with since I was a baby and we have been through a lot together and I have seen them standing by my side even in times of trouble so that makes me to trust them because I know they can help me. They have also faced problems and some of them are also HIV positive and they are also on ARVs so they are the ones who told me first about it and that made me to trust them to be able to also share my status with them and to be able to tell them that I am on ARVs"* [sic].

Likewise, Garikayi a male participant from Malawi (AS interview conducted on 13/12/2012) said,

> *"The way I built trust is because with all my other friends they have other closer friends who are positive so it was easier for me to trust them because they had told me first."*

Confidentiality negotiated in the lives of the participants is also taken on by the ARVs, as some of the participants believe there is stigma associated with HIV and ARVs. Below is an account of what Evans, a male participant from Malawi, said during the interview (AS interview done on 14/01/2013):

> *"My status was kept as secret in the family and we never told people about it"* [sic].

When it comes to dealing with problems at home, especially in the event that someone is HIV positive, most HIV positive cross-border migrants come from families in which they sit down as a family and discuss about, as well as negotiate secrecy. Jeremy, a male participant from Mozambique, (AS interview conducted on 15/01/2013) said:

> *"When someone is HIV positive like me, I told my girlfriend first then I asked her to go and get tested and then when she was found that she is HIV positive then we told the family about it. The family did not have any problem with it they just told us that they will support us and that we should take care of each other and should not separate so that we will not pass the virus to other people"* [sic].

Among some of the participants who selectively told family members, confidentiality is negotiated with those people in which they confided. One of the male participants, Edwin from Tanzania stated that (JP interview conducted on 11/01/2012):

> *"We kept it as a secret and we don't share it with other people outside the family because we believe that other people should not know about it since it is a family problem. At home we are divided in to two groups so my brother in Pretoria knows that the other two are not supposed to know about it"* [sic].

Belonging

There were certain participants who had a sense of belonging, both in the city of Johannesburg as well as back home. Some of the participants felt that home was both in the city of Johannesburg as well as at home in their countries of origins. Zoro, a female participant from Zimbabwe after talking about how she also has a sense of belonging back home said (JP interview conducted on 03/12/2012):

> *"For me it's because I am being treated as a South Africans... so that's how I define my belonging. They also don't call me as a Zimbabwean and it makes me feel that I am part of them"* [sic].

What Zoro said about belonging both in countries of origins and in the Johannesburg city was also shared by some of the participants. Some felt that they belonged in Johannesburg rather than back home in their countries of origin. Some of them said this because they did not visit home more often. While the minority reported this because their family networks were in Johannesburg and they felt if they go back home to countries of origins they will not get support. Below is an account of what Charles, a male participant from Lesotho, said (AS interview conducted on 14/01/2013):

> *"I feel like I belong here, of course I come from Lesotho and sometimes I think of what is happening at home and how others are but I am fine here and I feel that my home is here"* [sic].

Edwin, a male participant from Tanzania (Interview done on 11/01/2013) and Garikayi, a male participant from Malawi, also shared the same sentiments about the concept of home and belonging, stating that they felt that their belonging was in the city of Johannesburg, since this is where they were getting support in terms of treatment and friends.

Warner (1994) has written that there should be a focus between the time that has elapsed and memory of what refuges can remember about home when talking about country of origin and their return to it, as well as what they hope for if they return, in comparison to actual experiences. The same concept applies even to the HIV positive cross border migrants on

ART, since some of them felt they no longer belonged in their countries of origins because of the time that had elapsed.

When it comes to the issue of belonging, the majority of the nurses spoke about the support groups they once had earlier on, and hence some of them spoke about the sense of belonging that the HIV positive cross-border migrants are finding from the equal treatment they are getting from the nurses. This social connection and sharing of geographical connections with citizens as well as being treated equal is the one believed to be making them to have a sense of belonging. This confirms the study done by (Miller, 2009), who said that belonging can be put into three stages, which are social connections with other people, historical connections, which are about sharing history and that of sharing geographical connections. In this sense the nurses defined belonging in terms of geographical connections. They further agreed that this sense of belonging was helping patients to stay on treatment. One of the male nurses, Kelvin, said the following during the interview (interview conducted on 13/12/2012):

> *"… treating them the same gives them that sense of belonging"* [sic].

To support what Kelvin said, Eddie, one of the male nurse participants, said (interview conducted on 29/11/2012) that the support group they had helped them to have a sense of belonging because it was run by cross-border migrants themselves.

In terms of what they anticipate when they return home, all the participants agreed that they anticipated continuation of treatment and Fungai, a female participant who was not on treatment, said she anticipated that when she goes back home she will be able to recommence ART. Below is a recount of what Ratidzo, a female participant from Zimbabwe, said during the interview (JP interview conducted on 05/12/2012):

> *"Not much … I only need to get a letter then I will get my medication as usual"* [sic].

In support of what Ratidzo said, Evans, a male participant said the following (JP interview conducted on 14/01/2013):

> *"I think if I go home I will be able to get my treatment and to be free there"* [sic].

What Evans and Ratidzo said during the interview was also shared by the majority of the participants. When asked about how they define belonging, participants had different definitions, mostly associated with their relations with the communities in which they reside in the city of Johannesburg, as well as about how they access their treatment. During the interview (conducted on 11/01/2013) Edwin, a male participant from Tanzania, said the following:

> *"Belonging is to be able to get help in a place. As for me I get my help here and therefore I feel that I belong here in Johannesburg"* [sic].

Closely related to what Edwin said, Evans a male participant from Malawi said the following during the interview (interview conducted on 14/01/2013):

> *"…belonging is to be free in a country and not being harassed by the police"* [sic].

Weak support networks

However, Charles, a male participant from Lesotho, is not getting support from his social network. Below is an account of what he said during the interview (interview conducted on 14/01/2013):

> *"However, with my wife, she is one person who never gives me support, she laughs at me a lot about my status"* [sic].

Participants shared different views about their sense of belonging and what they think of home. Some participants said they belonged back home and they did not have any sense of belonging in the city of Johannesburg. Some of them had experienced xenophobic sentiments in the communities they now live. Closely related to this, Miller (2009) said there is no agreed upon definition of belonging. They had been given names such as '*Makwerekwere'*[16]. When it comes to whether belonging makes them to want to stay in Johannesburg or to go to

[16] Is a word used to refer to foreigners.

countries of origins participants had different views. Those who felt they belonged home had plans to go back home, those who felt they belonged in Johannesburg wanted to stay in Johannesburg and those who felt did not belong anywhere felt that they would prefer to stay in Johannesburg for livelihoods. Below is a recount of what Ratidzo, a female participant from Zimbabwe said (JP interview conducted on 05/12/2012):

> *"If people where not calling foreigners 'amakwerekwere', I would feel like I belong, I hate that word and it makes me see that I am an outsider"* [sic].

Closely related to what Ratidzo said, Fungai a female participant from Zimbabwe (interview conducted on 03/12/2012) noted:

> *"I just see that I am a Zimbabwean, foreigner. They call me 'Kwerekwere'. I feel at home when I am in Zimbabwe. I know if I go home, I will start treatment there"* [sic].

One of the participants did not have a sense of belonging either in Johannesburg or back home in her country of origin. This is because she survived with her two children and did not have any close relative back home while she did not have any close relative in Johannesburg. Below is what she said (interview conducted on 05/12/2012):

> *"I don't know which one is exactly my home. When I go home I will have to start again, as I did not leave anything behind and in Johannesburg I don't know anyone"* [sic].

Belonging was shaped by the support networks that one has in a certain place and lack of social networks led to the migrants to feel that they did not belong in that place as seen in Sarue's case.

4.3.5 PERCEPTIONS OF CROSS-BORDER MIGRANTS ON ART BY BOTH THE HIV POSITIVE CROSS-BORDER MIGRANTS AND THE HEALTH CARE PROVIDERS

These perceptions were both about the perceptions of self as people on ART, perceptions of ART as well as how they see themselves as people on ART. It was also about the perceptions of the nurses towards the HIV positive cross-border migrants on ART. In all the interviews with the participants, they had the same perceptions about ART. They agreed that ART made them feel good and feel stronger in their bodies.

Strength in ART

During the interview with Zoro, a female participant from Zimbabwe (AS interview conducted on 03/12/2012) she said:

> *"I see ARVs as good because during the time that they were not being found a lot of people died, but now the ARVs treat me every illness"* [sic].

Closely related to the above, Dorothy, a forty year old female participant from Zimbabwe had the following to say (JP interview conducted on 13/12/2012):

> *"Ever since I started taking my tablets I can see that my life is getting better I can see that my health has improved and I feel much better"* [sic].

The perceptions that Zoro and Dorothy shared about ART are the same perceptions that the majority of the participants on ART shared. This confirms a study done by Gilbert and Walker (2009) in which the participants of their study saw ARVs as lifesaving.

Positive and negative perception of self

There were different perceptions of self between participants. Mostly, the different views were between men and women, on how they see themselves as people on ART. While all

men did not see a difference in the way they were before they were on ART and after they were on ART, women had different perceptions. Most women saw a difference. Below is a recount of what Garikayi from Malawi said during the interview, a view that was shared by the majority of the male participants (AS interview conducted on 13/12/2012):

> *"I just see myself as a normal person like I was before I was on ARVs, there is no difference"* [sic].

With women, being on ART was associated with being HIV positive. Some women saw it as a burden, while other women saw a change in their body shapes, and this change had been caused by being HIV positive. A female participant Dorothy from Zimbabwe said (JP interview conducted on 13/12/2012):

> *"The life that I had I never thought that on a daily basis I would take tablets to survive"* [sic].

Ratidzo shared the same views as those shared by Dorothy, hence Sarue, a female participant from Zimbabwe, had a different perception of herself as a person on ART (JP Interview done on 05/12/2012):

> *"I always tell myself that looking* forward [to] *the future as a new person is over… because after I was HIV positive I look like a grandmother and people will be calling me grandmother yet you would see that there are other people who are older than me some who are as old as my mother they look young and people will be calling them aunt or mother"* [sic].

Life with hope on ART

The majority of the participants, however, saw their life as life with hope on ART. Below is what one of the male participants, Evans from Malawi, said during the interview (interview conducted on 14/01/2013):

> *"… as long as I get treatment I see myself having a brighter future"* [sic].

Evans shared the sentiments of the majority of the participants about life on ART during the interview, except for one male participant, Eddie from Tanzania, who said that he was scared that he might die even though he is on ART (JP Interview done on 11/01/2013). One of the female participants who stopped treatment because she was being treated harshly by the health care providers had a different perception on her life. Fungai, a female participant from Zimbabwe said the following during the interview (interview conducted on 03/12/2012):

> *"I am no longer concerned, whatever happens, happens. I will take anything, as long as I am still able to walk"* [sic].

When at home in the midst of families, in the midst of friends or even in the midst of other people in their home communities, the majority of the participants agreed that they did not see any difference between them and those people. They pointed out that they just felt normal like any other human beings. Below is an account of what Dorothy a female participant from Zimbabwe said during the interview (JP interview conducted on 13/12/2012) said:

> *"When I am at home in the midst of the family… I don't worry myself that much I just take it that I am just like all the other people even though I am HIV positive"* [sic].

There were different perceptions that the nurses had about HIV positive cross-border on ART who are accessing ART in their clinics.

Compliant to ART

HIV positive cross-border migrants on ART at Joubert Park Clinic and Albert Street Clinic are said to be compliant by most of the nurses. Gladys, a female nurse (interview conducted 28/11/2012) said:

> *"The ones that are on ART have seen that ART works wonders in their lives and they are compliant"* [sic].

In support of what Gladys said, Bev from a different clinic said the following (interview conducted on 11/12/2012) and the majority shared the same sentiments:

> *"Cross-border migrants on ART do not take ART for granted …"* [sic].

Fear of accessing healthcare because of lack of documentation and the Nomadic nature of cross-border migrants

Some nurses perceived that HIV positive cross border migrants in the city of Johannesburg face the challenge of not having documents. This challenge is mostly seen at the hospital level, though it's not a problem at the clinic level. Some of the nurses said that HIV positive cross-border migrants face problems when they are referred to the hospital when they are sick with an illness that requires hospital intervention, because they will be asked to provide Identity Documents so as to capture them in the system. According to some of the nurses, in the event that these HIV positive cross-border migrants don't produce these documents they will not be helped. Below is a recount of what Talent, one of the female nurses, said during her interview (28/11/2012):

> *"I understand in a hospital they want them to produce an ID so that they capture them in the system ... it becomes a problem sometimes if they are too ill and they are referred to the hospital. Sometimes they never reach to the hospital because they are scared"* [sic].

Gladys, from a different clinic, confirms what Talent said, by saying the following (interview conducted on 28/11/2012). However, none of the participants confirmed what Gladys said:

> *"The challenge they face is when they do not have documents they will spread the rumours among themselves that when they go to the health centres they want them to have documents and this hinders some of them to have access because they are scared"* [sic].

Nurses assumed that lack of documents has an impact of access to ART and healthcare because cross-border migrants who do not have documents are scared to access healthcare because of fear of being refused health care.

Nurses perceive that HIV positive cross-border migrants on ART are nomadic. However, when they come to the clinics for help the clinics help them to get more treatment but they tend to lose their treatment most of the time as they move from place to place. However, none of the participants reported facing this challenge. Below is a recount of what Talent, a female nurse participant, said (28/11/2012):

> *"...because of their nomadic nature, today they are in this building tomorrow they are in another they tend to lose those tablets"* [sic].

They reported that because they tend to move more often they lose their medication.

Getting treatment from more than one clinic in and across the borders

Some nurses said that HIV positive cross-border migrants get treatment from different clinics in the inner-city of Johannesburg using the same name. In addition to this, they said they send some people to their countries of origin who get treatment for them. The nurses said this is for reasons of having more treatment, so that they can have more to keep them going while others said they might be selling the treatment to those who would have lost theirs. Below is a recount of what Talent said, as shared by other nurses (interview conducted on 28/11/2012):

> *"They go to the clinics around the inner-city Johannesburg and get treatment using the same name. They also have people who are documented whom they pay to bring back treatment for them from home and they end up having more than the required treatment"* [sic].

Kelvin, a female nurse participant said the following during the interview (interview conducted on 13/12/2012):

> *"Some of them come to this clinic and they go to another clinic just to get more treatment"* [sic].

However, none of the participants of this study confirmed what the nurses had said in terms of getting treatment from more than one clinic.

The frustations of health care workers

One of the male nurse participants recited that HIV positive cross-border migrants frustrate him as they make a lot of complaints which make him to be angry. Below is a recount of what Kelvin said during the interview (interview conducted on 13/12/2012):

> *"The problem is that most of them do not understand because most of the complaints from the department of health come from them. They complain a lot about the services and it really frustrates me"* [sic].

Contrary to what Kelvin said, Bev from the same clinic had the following to say about HIV positive cross-border migrants on ART (interview conducted on 11/12/2012):

> *"HIV positive cross-border migrants on ART are very respectful"* [sic].

Others believed that HIV positive cross border migrants on ART are a special group because of the challenges they are facing. One of the male nurse participants Eddie (interview conducted on 29/11/2012) said:

> *"I see them as people who are in need who are a special group of people, they have the stress of crossing the borders, some illegally some legal and when they get here they need that special treatment so that it doesn't get worse for them so I value them as vulnerable people"* [sic].

To support what Eddie said below is a recount of what Kelvin from a different clinic said (interview conducted on 13/12/2012):

> *"In their countries they are poor that is why they come all the way from their countries to get treatment in the city of Johannesburg"* [sic].

The perceptions shared by Kelvin are different from the perceptions shared by Bev from the same clinic, as she said they do not come from their countries every month for treatment. She stated (interview conducted on 11/12/2012):

> *"...so far I haven't had someone who stays in Zimbabwe and just coming and travelling every month to come and get treatment..."* [sic].

These perceptions are the perceptions that some studies found in which cross-border migrants were believed to be travelling for treatment (Vearey, cited in Segatti & Landau, 2011). Closely related to this, the majority of participants tested HIV positive and started accessing treatment when they were in the city of Johannesburg, since only two of the participants reported coming to Johannesburg when they were already on treatment. Moreover, all of the participants in this study reported coming to the city of Johannesburg due to poverty and not to access treatment. Some of the studies have shown that migrants do not travel for treatment but for economic livelihoods and they seek treatment once they arrive, showing that they would have fallen sick while in the host place (Sargent & Larchanche, 2011).

4.3.6. POLICY ISSUES IN RELATION TO CROSS-BORDER MIGRANTS

This theme was about knowledge on the part of the healthcare providers of migration policy. From all the interviews, only one nurse, Eddie from Zimbabwe, had knowledge about the migration policy. Among the four South African nurses, Talent had a slight idea about the migration policy but tended to confuse it with the Health policy. Below is a recount of what Eddie (interview conducted on 29/11/2012) said when he was asked if he understood the health policy before explaining what he understood about it:

> *"I understand it and all the changes that have taken place on the migration policy"* [sic].

Talent, who had some knowledge about it, said the following during the interview (interview conducted on 28/11/2012):

> *"Migration policy I don't have too much understanding about it but I know that as migrants there are certain rights that they have like the right to health care is number one on top though you might not have rights on certain things"* [sic].

The majority of the nurses said they did not know anything about the migration policy. An example is what Kelvin one of the male participants said (interview conducted on 13/12/2012):

> *"I don't want to talk about it because I don't understand it"* [sic].

The fact that the nurses of this study did not know about the migration policy confirms the study that Pursell (2004) did. Though Pursell (2004) looked at the health policy and not at the migration policy in her study, she found that among the 12 doctors that were interviewed, only one doctor from Congo knew that refugees with refugee documents are entitled to access treatment. However, what is different is that in my study even without knowledge of the specific migration policy, none of the nurses have ever turned a patient away for being a cross-border migrant. They reported that they just treat them without asking for Identity Documents because they said that the department of health told them that they should not deny cross-border migrants treatment. This shows that the policieswere being implemented among the health workers in this study, even though there were specific details about the migration policy that the nurses were not aware of.

4.4. Conclusion

In conclusion, this chapter has shown the results of the treatment experiences of the HIV positive cross border migrants on ART in the city of Johannesburg. The results showed that HIV positive cross-border migrants make sure that they go to the clinics to get their treatment every month, negotiating with nurses to come on a flexible day, maintaining old residential addresses, getting treatment at home, asking for more treatment when going home temporarily, as well as taking their medication on time. The results also showed that HIV positive cross-border migrants are not part of any support groups, and that treatment seeking does not lead to new forms of social networking in the city. While some participants did not have any sense of belonging in the city of Johannesburg, there are others who had a sense of belonging in both Johannesburg and their countries of origin, while some of them did not have any sense of belonging in their countries of origin.

CHAPTER FIVE:

CONCLUSION AND RECOMENDATIONS

This chapter summarises the main points of the research and shows how the study informs the treatment experiences of HIV positive cross-border migrants in the city of Johannesburg in relation to access, treatment, continuity and social networks.

The aim of this study was to explore what HIV positive cross-border migrants on ART in the city of Johannesburg do to access and to continue with ART, given the challenges that cross-border migrants face when in Johannesburg as well as understanding the social networks in their lives, and examining how they help them to negotiate continued access and continuity of ART. Cross-border migrants are facing challenges that are common to other migrants as seen in other previous studies (Vearey, 2008; Moyo, 2010, Landau & Freemantle, 2010), however these challenges are not preventing them to negotiate continued access and continuity of ART.

When it comes to answering the empirical question of this research participants reported going to the clinic every month to get treatment, asking for more treatment when going home temporarily, eating healthily, taking medication on time, going home and coming back before the next due date of treatment collection, maintaining old residential addresses as well as making use of transfer letters to negotiate continued access and continuity of treatment.

The literature reviewed for this study showed that there is a gap which this study seeks to cover by doing this research. The access evaluation framework was important for this study, as it looks at access as more than access to services, but also looking at affordability and acceptability for both patients and healthcare providers. While this is the case, it was important in helping me to understand the issues of access and continuity of ART for cross-border migrants from the patients as well as the healthcare providers. This framework helped in unpacking the relationship that took place between the participants and the healthcare providers and how this helped them to negotiate continued access and continuity of ART.

The social network theory was important for this study in order to understand the social networks that exist for the cross-border migrants on ART. This theory was also important in helping to explore issues of openness, confidentiality and trust which could be best understood by the use of social network theory. The results for this study show that none of the participants of this study were part of a support group and that the family network was the central network for the HIV positive cross-border migrant, which helped them to continue accessing ART. The biosociality concept adopted by Rabinow (cited in Whyte, 2009), was not taking place among the migrants in this study and the study supports the findings of Landau and Madhavan (2011), when he talks about homogeneity social network based on thick trust. The theoretical frameworks were helpful in discussions and engaging with issues of access and continuity of ART and the issues of support networks among cross-border migrants.

The methodology selected for this study was suitable in exploring the issues of access and continuity, which could be best, understood through qualitative interviews, which could allow participants to tell their stories more freely. The sampling strategy for this study has been outlined, along with the details of the targeted participants for this study. It was important to do this study at JP Clinic and AS Clinic as these clinics are primary health clinics which are run by the City of Johannesburg. While services are free, ART is free and cross-border migrants are allowed to access without documentation. There was thus a likelihood of finding relevant participants from these clinics.

Although there was no time to develop the study's full potential, most importantly, the study did not include the internal migrants who could be facing the same situations as the cross-border migrants. This ought to be seen as a fruitful area for further research. Moreover refugees were also not included in this study, yet regardless of their immigration status, they could also be facing the same experiences as the other cross-border migrants. There is a need to move away from the strong emphasis on the causal relationship between support groups and continuity of ART as family networks are important in facilitating continued access. There is a need to engage health care providers in communication skills so as to facilitate effective access of ART for cross-border migrants.

References

Adepoju, A. (2006). "Internal and International Migration within Africa" in Kok, P., Gelderblom, D., Oucho, J., & van Zyl J. (Eds.), *Migration in South and Southern Africa*: *Dynamics and Determinants* (26-46). Pretoria: Human Sciences Research Council.

Barbour, R. (2001). Checklist for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal, 322*(5), 1115-1117.

Berk, M. L., Schur, C. L., Dunbar, J. L., Bozzette, S., & Shapiro, M. (2003). Short report: Migration among persons living with HIV. *Social Science & Medicine., 57*, 1091-1097.

Berger, P. (2008). Immigrants in Johannesburg: Estimating numbers and assessing impacts. *CENTRE FOR DEVELOPMENT AND ENTERPRISE,* 1-9.

Biehl, J. (2004). The Activist State. *Global Pharmaceuticals, AIDS, and Citizenship in Brazil: The AIDS Model, 22*(3), 105-132.

Biehl, J. (2008). Drugs for all: The future of global AIDS treatment. *Medical Anthropology, 27*(2), 99-105.

Braun, V., & Clarke, V. (2006): Using thematic analysis in psychology: *Qualitative Research in Psychology*, 3(2), 77-101 available on line at http://dx.doi.org/10.1191/1478088706qp063oa Retrieved 08 April 2013.

Bygrave, H., Kranzer, K., Hilderbrand, K., Whittall, J., Jouquet, G., Goemaere, E., ... & Ford, N. (2010). Trends in loss to follow-up among migrant workers on antiretroviral therapy in a community cohort in Lesotho. *PloS ONE, 5*(10), 5 April-1-5.

Bischofberger, I. (2008). HIV-infected Sub-Saharan migrants in Switzerland: Advancing cross-cultural health assessment. *Journal of the Association of Nurses in AIDS Care., 19*(5), 357-367.

Cassidy, R., & Leach, M. (2009). AIDS, citizenship and global funding: A Gambian case study. *Citizenship DRC, Institute of Development Studies, 2009*(325), 07 March 2013-1-33.

City of Johannesburg. (2013). Migrant's help desk. Retrieved 07 Feb 2013. http://www.joburg.org.za/index.php?option=com_content&do_pdf=1&id=2180&limitstart=1

Creswell, J. W. (1994). Research Designs: *Qualitative & Quantitative Approaches*. Thousand Oaks, California: SAGE Publications.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet, 374*(9692), 08 March 2013-817-834. doi: http://dx.doi.org/10.1016/S0140-6736(09)60951-X

Davies, M., Boulle, A., Fakir, T., Nuttall, J., & Eley, B. (2008). Adherence to Antiretroviral Therapy in young children in Cape Town, South Africa, measured by medication return and caregivers self-report: *a prospective cohort study* 8(34) Retrieved 15 October 2012.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The SAGE handbook of qualitative research.* (4th Ed.). Thousand Oaks, California: SAGE.

Director for Social and Human Development and Special Programs. (2009). *Policy framework for population mobility and communicable diseases in the SADC region.* (Southern African Development Community No. 1). Gaborone, Botswana: SADC Secretariat.

Fennely, K. (2005). Healthy generations: 'the healthy migrant' effect. *Martenal & Child Health Program, 5*(3), 1-12.

Forced Migration review. (2010). HIV/AIDS, security and conflict: Making the connections, 3-31.

Gilbert, L. & Walker, L. (2009). "They (ARVs) are my life, without them I'm nothing"-experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa. *Health & Place., 15,* 1123-1129.

Grupta, R. K., Jordan, M. R., Sultan, B. J., Hill, A., Javis, D. H. A., Gregson, J., …Bertagnolio, S. (2012). Global trends in antiretroviral resistance in treatment-naive

individuals with HIV after rollout of antiretroviral treatment in resource-limited settings: a global collaborative study and meta-regression analysis. *Lancet, 380*, 1250-1258.

Gushulak, B. D., & MacPherson, D. W. (2006). The basic principles of migration health: Population mobility and gaps in disease prevalence. *Emerging Themes in Epidemiology*, 3 (3), 1-11.

Hammami, N., Nostlinger, C., Hoeree, T., Lefevre, P., Jonckheer, T., & Kolsteren, P. (2004). Integrating adherence to highly active antiretroviral therapy into children's daily lives: A qualitative study. *Paediatrics Official Journal Of The American Academy Of Paediatrics*, *114*(5), 590-597.

Hawley, C. (2008). Refugees flee South Africa attacks. *"Stu" Escaped from Zimbabwe in January, Crossing the Border for the Sanctuary of South Africa*, 1-3.

Human Rights Watch. (2009a). Discrimination, Denial, & Deportation: *Human Rights Abuse Affecting Migrants Living with HIV*. New York, USA. www.google.com Retrieved 15 October 2012.

Human Rights Watch. (2009b). Returned to Risk: *Deportation of HIV-positive Migrants*. New York, USA. www.google.com Retrieved 15 October 2012

International Organization for Migration. (2010). Migration and Health in South Africa: *A review of the current situation and recommendations for achieving the World Health Assembly Resolution on the Health of Migrants*. Pretoria, South Africa.

Johnson, L. F. (2012). Access to antiretroviral treatment in South Africa, 2004-2011. *Southern African Journal of HIV Medicine, 13*(1), 23 May 2012.

Jones, P. S. (2012). Mind the gap: Access to ARV medication, rights and the politics of scale in South Africa. *Social Science & Medicine, 74*, 28-35.

Kleinert, S., & Horton, R. (2009). South Africa's health: Departing for a better future? *The Lancet, 374*(9692), 08 March 2013-5-11. doi: 10.1016/50140-6736(09)61306-4 http://ac.els-cdn.com/S0140673609613064/1-s2.0-S0140673609613064-

main.pdf?_tid=c858300a-8702-11e2-8ed0-00000aab0f6c&acdnat=1362645859_b1f7fac24bc284f66f56eea24d495b52

Landau, L. B., & Freemantle, I. (2010). Tactical cosmopolitanism and idioms of belonging: Insertion and self-exclusion in Johannesburg. *Journal of Ethnic and Migration Studies, 36*(3), 375-390.

Lewthwaite, P., & Wilkins, E. (2009). Natural history of HIV/AIDS. *Natural History and Clinical Features, 33*(6), 1-5.

Lima, V., Fernandes, K., Rachlis, B., Druyts, E., Montaner, J., & Hoggy, R. (2009). Migration adversely affects antiretroviral adherence in a population-based cohort of HIV/AIDS patients. *National Institute of Health, 68*(6), 1044-1049.

Lippman, S. A., Kerrigan, D., Chinaglia, M., & Diaz, J. (2007). Chaos, co-existence, and the potential for collective action: HIV related vulnerability in Brazil's international borders. *Social Science & Medicine, 64*, 2464-2475.

Mack, N., Woodsong, C., MacQueen, K. M., Guest, G., & Namey, E. (2005). *Family health international qualitative research methods: A data collector's field guide.* North Carolina, USA: USAID.

Madhavan, S., & Landau, L. B. (2011). 'Bridges to nowhere: Hosts, migrants, and the chimera of social capital in three African cities'. *Population and Development Review, 7*(3), 473-497.

Martin, S. F. (2001). 'Global migration trends and asylum', new issues in refugee research. *Working Paper*, 11/01/2013.

Mcintyre, D. I., Thiede, M., & Birch, S. (2009). Access evaluation framework. http://www.readcube.com/articles/10.1186/1471-2458-10-137 10 February 2013-1.

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*(2), 179-193.

McCarthy, K., Chersich, M. F., Vearey, J., Meyer-Rath, G., Jaffer, A., Simpwalo, S., & Venter, W. D. F. (2009). Good treatment outcomes among foreigners receiving

antiretroviral therapy in Johannesburg, South Africa. *International Journal of STD & AIDS, 20,* 858-862.

Merriam, S. B., & Associates. (2002). *Qualitative research in practice: Examples for discussion and analysis.* San Francisco, CA: JOSSEY-BASS.

Miller, D. (2005). "Immigration: *The Case for Limits," in Contemporary Debates in Applied Ethics,* A. Cohen and C. Wellman (eds.), Malden, MA: Blackwell Publishing, pp. 193-206.

Miller, L. (2009). Belonging to a Country: a philosophical Anthropology. *Journal of Australian Studies*, 27(76) 215-223.

Mogensen, H. O. (2010). New Hopes and New Dilemmas: Disclosure and Recognition in the Time of Antiretroviral Treatment in Dilger, H., & Luig, U. (Eds.), *Morality, Hope and Grief: Anthropologies of AIDS in Africa* (61-79). New York, USA: Berghahn Books.

Moyo, K. (2010). *Street level interface: The interaction between health personnel and migrant patients at an inner city public health facility in Johannesburg.* (Unpublished Master's thesis). University of the Witwatersrand, Johannesburg: South Africa.

MSF-SA Association. (2012). Medecins sans frontiers: *MSF Projects in South Africa.,* 1, http://www.msf.org.za/about-msf/doctors-without-borders-south-africa Retrieved 21 February 2013.

Muanamoha, R. C., Maharaj, B., & Preston-Whyte, E. (2010). Social networks and undocumented Mozambican migration to South Africa. *Geoforum., 41,* 885-896.

Nelson, L., & Hiemstra, N. (2008). Social and Cultural Geography. *Latino immigrants and the renegotiation of place and belonging in small town America*, 9 (3)319-342.

Nguyen, V. K. (2005). Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship. In A. Ong & S. Collier (Eds.), *Global Assemblages: Technology, Politics and Ethics as Anthropological Problems* (124-144). Oxford: Blackwell.

NOAACSC. (2009). Social Network Analysis. Social Science Methods for Marine Protected Areas Managers, 1. Retrieved 12 February 2013. http://www.hd.gov/HDdotGov/detail.jsp?ContentID=345

Osterberg, L., & Blaschke, T. (2005). Drug therapy. *Adherence to Medication, 97*(1), 353-487.

Patel, R. (2009). *Barriers and facilitators to antiretroviral therapy adherence: A patient and health-care provider perspective.* (Unpublished Master's Thesis.). University of the Witwatersrand, Johannesburg: South Africa.

Patton, M. (1990). The nature of qualitative inquiry. In *qualitative evaluation and research methods.* (9-34). London: Sage.

Pophiwa, N. (2009). *Healthy migrants or health migrants? Accounting for the health care utilization patterns of Zimbabwean migrants living in South Africa.* (Unpublished Masters in Forced Migration). University of the Witwatersrand, Johannesburg: South Africa.

Pursell, R. (2004). Accessing health services at Johannesburg's clinics and hospitals. In forced migrants in the new Johannesburg: Towards a Local Government Response. Migration paper series No. 8., 93-98.

Republic of South Africa. Refugees Act, 1998. Act No. 9 of 1998. Government Gazette. Pretoria, South Africa: Government Printers. Retrieved April 5, 2012 from http://www.bing.com/search?q=Refugees+Act%2C+1998&form=HPNTDF&pc=HPNTDF&src=IE-SearchBox

Republic of South Africa. Immigration Amendment Act, 2004. Act No. 19 of 2004. Government Gazette. Pretoria, South Africa: Government Printers. Retrieved May 20, 2012, from http://www.bing.com/search?q=Immigration+Ammendment+Act%2C+2004.+Act+No.+19+of+2004.&form=HPNTDF&pc=HPNTDF&src=IE-SearchBox

Republic of South Africa. (2004). National Health Act, 2003. Act No. 61 of 2003. Government Gazette. Pretoria, South Africa: Government Printers. Retrieved April 12,

2012, from http://www.bing.com/search?q=National+Health+Act%2C+2003&form=HPNTDF&pc=HPNTDF&src=IE-SearchBox

Republic of South Africa. Immigration Amendment Act, 2011. Act No. 13 of 2011. Government Gazette. Pretoria, South Africa: Government Printers. Retrieved 5 February, 2013, http://www.mm3admin.co.za/documents/docmanager/2D5ED792-878C-4371-9575-8281A96BBB26/00017893.pdf

Robins, S., & von Lieres, B. (2004). Remaking citizenship, unmaking marginalization: The Treatment Action Campaign in post-apartheid South Africa. *Canadian Journal of African Studies, 38*(3), 575-586.

Segatti, A., & Landau, L. B. (Eds.). (2011). *Contemporary migration to South Africa: A regional development issue*. The World Bank: Washington DC: World Bank and AFD.

Sargent, C., & Larchanche, S. (2011). Transnational migration and global health. *The Production and Management of Risk, Illness, and Access to Care, 40*(1), 345-361.

Soskolne, V., & Shtarkshall, R. A. (2002). Migration and HIV prevention programmes: Linking structural factors, culture, and individual behaviour- an Israel experience. *Social Science & Medicine., 55*, 1297-1307.

Spiegel, P. B., & Alia, N. (2003). Inclusion of refugees in HIV/AIDS programmes reduces the spread of pandemic among refugee populations and host countries. *UNHCR, HIV/AIDS and Refugees: Lessons Learned* 21-23.

Statistics South Africa. Mid-year population estimates 2011: *Statistical Release P0302U.S.C.* 18 (2012). http://www.statssa.gov.za/publications/P0302/P03022011.pdf

Statistics South Africa. (2012). Census 2011: *Provinces at glance* Report Number 03-01-43, (1-84) http://www.statssa.gov.za/publications/03-01-43.pdf

Stein, J., Lewin, S., & Fairall, L. (2007). Hope is the pillar of the universe: Health-care providers' experiences of delivering antiretroviral therapy in primary health-care clinics in the Free State province of South Africa. *Social Science & Medicine, 64*, 954-964.

Terre-Blanche, M., & Durrheim, K. (2006). 'Histories of the Present; Social Science Research in Context' in: Terre Blanche, M, Durrheim K and Painter, D. (Eds) *Research in Practice: Applied Methods for the Social Sciences*, Cape Town: UCT Press: 1-17

Tzatha, A., & Schepers, J. (2009). The limitations of Social Network Analysis. *Journal of Network Theory, 4* (2), 1 Retrieved 05 February 2013. http://www.networktheory.nl/2009/limitations-of-sna/47/the-limitations-of-social-network-analysis.html

UNHCR. (2010). *Support to antiretroviral therapy adherence amongst urban refugees in Kuala Lumpur, Malaysia.* (Field Brief). http://www.unhcr.org/4cd406089.html Retrieved 16 February 2012.

UNAIDS. (1999). Sexual behavioural Change for HIV: *Where have theories taken us*? Geneva, Switzerland. www.googlescholar.com Retrieved 15 October 2012.

UNAIDS. (2009). *South Africa country situation.* (National Response). http://dspace.itg.be/handle/10390/1298 Retrieved 18 August 2012 Retrieved 17 July 2012.

UNAIDS (2011). In 2011 there were 1.7 Million AIDS-related deaths lower than the 2-3 million in 2005. http://www.unaids.org/en/dataanalysis/ Retrieved 15 June 2012.

UNAIDS. (2012). *Together we will end AIDS*, WHO Library Cataloguing-in-Publication Data. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/20120718_togetherwewillendaids_en.pdf Retrieved 15/10/2012.

Vadiee, M. (2011). The quest for multi-sectoral HIV/AIDS prevention in Central and Eastern Europe and why it matters. *HIV & AIDS Review, 10*, 99-104.

Vearey, J. (2008). Migration, access to ART, and survivalist livelihood strategies in Johannesburg. *African Journal of AIDS Research, 7*(3), 361-374.

Vearey, J. (2011). Global public health. *Learning from HIV: Exploring Migration and Health in South Africa*, 5 April 2012, 1-13.

Vearey, J. (2011). Chapter 5: Migration and health in South Africa: implications for development. In: Segatti, A. and Landau, L. (Eds) Contemporary Migration to South Africa: *A Regional Development Issue*. World Bank and AFD. The World Bank: Washington DC

Vearey, J., Palmary, I., Thomas, L., Nunez, L., & Drimie, S. (2010). Urban health in Johannesburg: The importance of place in understanding intra-urban inequalities in a context of migration and HIV. *Health & Place., 16*(1), 694-702.

Vearey, J. & Wilhelm-Solomon, M. (2011). Migration issue brief #9. *Deportation and Public Health: Concerns around the Ending of the Zimbabwean Documentation Process*, 1-15.

Vervoort, S. C. J. M., Borleffs, J. C. C., Hoepelman, A. I. M., & Grypdonck, M. H. F. (2007). Adherence in antiretroviral therapy: *A Review of Qualitative Studies, 21*(3), 271-281.

Vissman, A. T. et al. (2011). Applying the theory of planned behaviour to explore HAART adherence among HIV-positive immigrant Latinos: Elicitation interview results. *Patient Education and Counselling, 85*, 454-460

Warner, D. (1994). Voluntary repatriation and the meaning of return to home: A critique of liberal mathematics. *Journal of Refugee Studies, 7*(2/3), 160-174.

Webber, G. E. A. (2010). Life in the big city: The multiple vulnerabilities of migrant Cambodian garment factory workers to HIV. *Women's Studies International Forum., 33*, 159-169.

Whyte, S. R. (2009). Medical Anthropology Quarterly. *Health Identities and Subjectivities: The Ethnographic Challenge, 23*(1), 6-15.

Whyte, S. R., Whyte, M. A., & and Kyaddondo, D. (2006). *Health Workers Entangled: Confidentiality and Certification,* 80-101. Retrieved 18 April 2012.

World Health Organisation. (2008). *SIXTY-FIRST WORLD HEALTH ASSEMBLY.* (Resolutions and Decisions Annexes No. 1). Geneva: Switzerland.

APPENDICES

Appendix A: Information Sheet and Consent Form

Study title: Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks.

Name of the principal researcher: Roseline Hwati

Department/research group address:

African Centre for Migration Studies, Wits University, 1 Jan Smuts Avenue, Braamfontein, Johannesburg

Telephone: (011) 717 4033/ 7174092

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Greeting: Hello! My name is ***Roseline Hwati,*** Masters Student in African Centre for Migration & Society at Witwatersrand University. I am conducting a research project that is exploring the treatment experiences of HIV positive cross-border migrants in Johannesburg: access, treatment continuity and support networks at Joubert Park and Albert Street clinics as well as support groups in Johannesburg. The research is being undertaken as part of my Master's degree in migration studies.

Exclusion and inclusion criteria: The reason why I am approaching you is that I have identified you as an HIV positive cross-border migrant or health professional (nurse, doctor counsellor) working with HIV positive cross-border migrants. I would like to inform you that only HIV positive cross-border migrants on Antiretroviral Therapy (ART) who have been accessing treatment for six months in Johannesburg (who started here or back home in their countries of origin) and staff/health providers (Nurse, counsellor and doctor) of over 18 years and who have been receiving/providing antiretroviral therapy in Joubert park, Albert street clinics and support groups in Johannesburg and have been working for more than 3 months are eligible to participate in this research project.

Invitation to participate: I would like to invite you to participate in this study as it will help us to explore what HIV positive cross-border migrants do to stay on ART as well as how they form support networks and how they belong.

What is involved in the study: Should you decide to participate in this project research, your participation will include the following: An interview session that will take a maximum of 60 minutes. I would like to have your permission (attached consent forms) to record the interview as I do not want lose any of its details. The tapes will be kept for 2 years after the publication or for 6 years if there is no publication of results. More so I will also ask you if there are other people in the same situation as you are who will be willing to participate in this study so that I can ask them. We will make use of participant specific number as an identifier in which I will use a number specific to you so that the information you provide will not be traced back to you and for anonymity purposes. In this study I am looking to do interviews with 10-15 participants who are HIV positive cross-border migrants on ART from Africa but currently living in Johannesburg as well as the staff at the clinics or support groups. We will use a questionnaire that I have made specifically for this research with different questions about what you do to stay on HIV treatment, support networks and how this shape your sense of belonging and notion of home.

Immigration Status: In the event that you do not have Identity documents I assure you that I it will be treated with confidentiality and I will not report you to the police or any official who works in that department.

Risks: There are very few risks in participating in this study. I will ask you some personal questions about your experiences of staying on antiretroviral treatment, forming of social networks as well as feelings of belonging. You may experience some embarrassments in discussing some of the topics in the interview or you might feel stressed after talking to me. But, you may find it helpful to talk about these issues with me. For this reason if any of the topics discussed in the interview/ upset you, I can refer you to (Gaudence and Marivic) counselors at the Centre for the study of Violence and Reconciliation that you can talk to. Their number is 011 403 5102/3. If for any reason you are uncomfortable you can skip a question or choose to stop the interview at any time.

Benefits: There is no direct benefit to your participation in this study. But, this research will help us to understand the experiences of what HIV positive cross-border migrants do to stay on antiretroviral therapy in Johannesburg city in order to develop/or improve ways on staying

on ART when it comes to different HIV positive cross-border migrants.

Payment: No payment is provided to participant. Light refreshment will be provided for the participants during the interviews as well as reimbursement for transport if you use transport to come to do the interview. The fixed amount for transport is R30.

Participation is voluntary: If I should come to any question you do not want to answer, just let me know and I will go on to the next question or you can stop the interview at any time. It will not affect you in any way.

Confidentiality: **If you give consent, you will not be identified by name in the final reporting of results, you will remain anonymous and all your information will remain confidential. The information that you share with me may be written up in research reports. We will NOT use any of your personal details and it will not be possible to identify you personally in any of the research reports. We want to help HIV positive cross-border migrants to stay on ARVs so we have no intention of violating confidentiality.**

Contact details of Human Research Ethics Committee (HREC) administrator and Chair – for ethics issues inquiries. Contact**: Prof Peter Cleaton-Jones** 011-717-1234 Fax: 011-717-1265 Email anisa.keshav@wits.ac.za

Contact details of the research project's supervisor- for reporting of study related adverse events. Matthew@migration.org.za: 27 (0)833076102 jovearey@gmail.com: 27 (0)11 717 4041

Contact details of researcher: – for further information contact me: 073 1494 561 email roselinehwati@yahoo.com

Researcher: please read through this carefully with the participant:

- I agree to participate in this research project.
- I have read/been read this consent form and the information it contains and had the opportunity to ask questions about them.

I agree that my responses will be used for research on condition my privacy is respected, subject to the following:

- I understand that the experiences of everyone interviewed here will be put together, so that I will not be personally identifiable and I understand that the cohort group maybe identifiable in the final report.
- I understand that I am under no obligation to take part in this project.
- I understand I have the right to withdraw from this project at any stage.

- **<u>FOR WRITTEN CONSENT ONLY - PARTICIPANT</u>**:

PARTICIPANT:

…… ……

Printed Name of Participant Date Signature/Mark/Thumbprint

Appendix B: Information Sheet and Consent Form

For logged verbal consent only – participant

Study title: Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks.

Name of the principal researcher: Roseline Hwati

Department/research group address:

African Centre for Migration Studies, Wits University, 1 Jan Smuts Avenue, Braamfontein, Johannesburg

Telephone: (011) 717 4033/ 7174092

.....

Greeting: Hello! My name is ***Roseline Hwati,*** Masters Student in African Centre for Migration & Society at Witwatersrand University. I am conducting a research project that is exploring the treatment experiences of HIV positive cross-border migrants in Johannesburg: access, treatment continuity and support networks at Joubert Park and Albert Street clinics as well as support groups in Johannesburg. The research is being undertaken as part of my Master's degree in migration studies.

Exclusion and inclusion criteria: The reason why I am approaching you is that I have identified you as an HIV positive cross-border migrant or health professional (nurse, doctor counsellor) working with HIV positive cross-border migrants. I would like to inform you that only HIV positive cross-border migrants on Antiretroviral Therapy (ART) who have been accessing treatment for six months in Johannesburg (who started here or back home in their countries of origin) and staff/health providers (Nurse, counsellor and doctor) of over 18 years and who have been receiving/providing antiretroviral therapy in Joubert park, Albert street clinics and support groups in Johannesburg and have been working for more than 3 months are eligible to participate in this research project.

Invitation to participate: I would like to invite you to participate in this study as it will help us to explore what HIV positive cross-border migrants do to stay on ART as well as how they form support networks and how they belong.

What is involved in the study: Should you decide to participate in this project research, your participation will include the following: An interview session that will take a maximum of 60 minutes. I would like to have your permission (attached consent forms) to record the interview as I do not want lose any of its details. The tapes will be kept for 2 years after the publication or for 6 years if there is no publication of results. More so I will also ask you if there are other people in the same situation as you are who will be willing to participate in this study so that I can ask them. We will make use of participant specific number as an identifier in which I will use a number specific to you so that the information you provide will not be traced back to you and for anonymity purposes. In this study I am looking to do interviews with 10-15 participants who are HIV positive cross-border migrants on ART from Africa but currently living in Johannesburg as well as the staff at the clinics or support groups. We will use a questionnaire that I have made specifically for this research with different questions about what you do to stay on HIV treatment, support networks and how this shape your sense of belonging and notion of home.

Immigration Status: In the event that you do not have Identity documents I assure you that I it will be treated with confidentiality and I will not report you to the police or any official who works in that department.

Risks: There are very few risks in participating in this study. I will ask you some personal questions about your experiences of staying on antiretroviral treatment, forming of social networks as well as feelings of belonging. You may experience some embarrassments in discussing some of the topics in the interview or you might feel stressed after talking to me. But, you may find it helpful to talk about these issues with me. For this reason if any of the topics discussed in the interview/ upset you, I can refer you to (Gaudence and Marivic) counselors at the Centre for the study of Violence and Reconciliation that you can talk to. Their number is 011 403 5102/3. If for any reason you are uncomfortable you can skip a question or choose to stop the interview at any time.

Benefits: There is no direct benefit to your participation in this study. But, this research will help us to understand the experiences of what HIV positive cross-border migrants do to stay on antiretroviral therapy in Johannesburg city in order to develop/or improve ways on staying on ART when it comes to different HIV positive cross-border migrants.

Payment: No payment is provided to participant. Light refreshment will be provided for the participants during the interviews as well as reimbursement for transport if you use transport

to come to do the interview. The fixed amount for transport is R30.

Participation is voluntary: If I should come to any question you do not want to answer, just let me know and I will go on to the next question or you can stop the interview at any time. It will not affect you in any way.

Confidentiality: **If you give consent, you will not be identified by name in the final reporting of results, you will remain anonymous and all your information will remain confidential. The information that you share with me may be written up in research reports. We will NOT use any of your personal details and it will not be possible to identify you personally in any of the research reports. We want to help HIV positive cross-border migrants to stay on ARVs so we have no intention of violating confidentiality.**

Contact details of Human Research Ethics Committee (HREC) administrator and Chair – for ethics issues inquiries. Contact**: Prof Peter Cleaton-Jones** 011-717-1234 Fax: 011-717-1265 Email anisa.keshav@wits.ac.za

Contact details of the research project's supervisor- for reporting of study related adverse events. Matthew@migration.org.za: 27 (0)833076102 jovearey@gmail.com: 27 (0)11 717 4041

Contact details of researcher: – for further information contact me: 073 1494 561 email roselinehwati@yahoo.com

Researcher: please read through this carefully with the participant:

- I agree to participate in this research project.
- I have read/been read this consent form and the information it contains and had the opportunity to ask questions about them.

I agree that my responses will be used for research on condition my privacy is respected, subject to the following:

- I understand that the experiences of everyone interviewed here will be put together, so that I will not be personally identifiable and I understand that the cohort group maybe identifiable in the final report.
- I understand that I am under no obligation to take part in this project.
- I understand I have the right to withdraw from this project at any stage.

- **FOR LOGGED VERBAL CONSENT ONLY PARTICIPANT**

Indicate by ticking the appropriate box with an X

YES	NO

Witness one

....

Printed Name of Witness Date Signature/Mark/Thumbprint

Witness two

....

Printed Name of Witness Date Signature/Mark/Thumbprint

Appendix C: Audio-Taping: Consent Form

I give my consent to be audio taped during the interviews. I have read the Participant Information Sheet and understand that my identity will be kept confidential. The researcher has explained to me that the tapes will be typed up and used only for the purposes of the study: "**Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks".** I understand that after the research the tapes will be kept for 2 years after publication or for 6 years if there is no publication of results. I also understand that I am free to withdraw this consent at any time.

PARTICIPANT:

.....

Printed Name of Participant Date Signature/Mark/Thumbprint

Appendix D: Audio-Taping: Consent Form

For Logged Verbal Consent only Participant

I give my consent to be audio taped during the interviews. I have read the Participant Information Sheet and understand that my identity will be kept confidential. The researcher has explained to me that the tapes will be typed up and used only for the purposes of the study: "**Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks".** I understand that after the research the tapes will be kept for 2 years after publication or for 6 years if there is no publication of results. I also understand that I am free to withdraw this consent at any time.

Indicate by ticking the appropriate box with an X

YES	NO

Witness one

....

Printed Name of Witness Date Signature/Mark/Thumbprint

Witness two

....

Printed Name of Witness Date Signature/Mark/Thumbprint

Appendix E: Interview Schedule for patients

Cross-border migrants receiving antiretroviral treatment

Title of Study: Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks.

Study Number: TBA

Principal Investigator: MA Student/ Roseline Hwati, Wits University

Phone number: 0027 773 1494 561

Email Address: roselinehwati@yahoo.com

Sponsor/funder: N/A

Hello! My name is ***Roseline Hwati*** and I am conducting a research project on exploring the experiences of what cross-border migrants do so that they can stay on their HIV treatment, the support networks that they have and how this shapes their sense of belonging.

I would like to invite you to take part in this study as it will help us to explore the experiences of how cross-border migrants stay on HIV treatment in Johannesburg. I would like to ask you some questions and I would like you to answer based on your experience as ***a cross-border migrant*** in this clinic or support group *and the ways you use to continue with HIV treatment in Johannesburg*.

- South Africa has experienced a large number of cross border migrants than other countries in Africa.

Section 1: Identity

- Where do you live? How long have you been in Johannesburg?
- How old are you?
- What country are you from (*home country)*?
- What made you to come to South Africa? (*Probe for how they came to South Africa and ended up in Johannesburg)*
- What is your marital status?
- What level of education have you completed?
- Do you have any children? If yes, how many children do you have?
- Are you here with your family (wife/husband and children)?
- Have you been staying at a specific place here in Johannesburg for a long time? (*Probe for how long they have been staying at that place*
- For how long have you been on treatment?
- Where did you start accessing treatment?
- When did you start getting ART in Johannesburg?

Section 2: staying on HIV treatment (ART)

- What do you as a cross-border migrant within Johannesburg who is on ARVs do to access and to stay on treatment?
- If you travel home temporarily what do you do to access treatment and stay on treatment? (*Probe for the reminders they use to take their medication*)
- Are you part of a support group in Johannesburg and what kind of help are you getting? (*probe for any other social networks they have, how they formed them and the help they are getting*)
- What challenges are you facing as a cross-border migrant on ART and how do you overcome these challenges? (*Probe for what services they seek to overcome these challenges*)

Section 3: **Social support networks**

- Does belonging to a certain group help you to continue with your treatment? *(Probe for in what way this belonging to a group help them to continue with their treatment*).

- What perceptions do you form of yourself as a person on ARVs when you are in the city of Johannesburg or back home in the midst of family and friends? (*Probe for how they think of themselves and their lives as people on ARV's and how different it is now than before they were on ART*).

- How do you negotiate trust and secrecy? (*Probe for with whom and how do they decide on who they negotiate with especially on them being on ART*).

Section 4: belonging and the concept of home.

- How does what you do to stay on HIV treatment influence what you think of home and belonging? (*Probe for if they think of moving home forever, what they think and anticipate if they return home and what they anticipate if they are to stay in Johannesburg*)

- If you move back home forever how do you intend to stay on treatment? (*Probe for what ways they will use so that they can stay on treatment*)

- Do you know if there are some networks that exist at home that can help you to stay on treatment? (*Probe for what networks exists and the services that are being offered there and if they think they can access more networks in their home village*).

- **Thank you for answering our questions**
- **Is there anything you would like to ask me**

Appendix F: Interview Schedule for staff

Title of Study: Treatment Experiences of HIV positive temporary cross-border migrants in Johannesburg: access, treatment continuity and support networks.

Study Number: TBA

Principal Investigator: MA Student/ Roseline Hwati, Wits University

Phone number: 0027 773 1494 561

Email Address: roselinehwati@yahoo.com

Sponsor/funder: N/A

Hello! My name is ***Roseline Hwati*** and I am conducting a research project on exploring the experiences of what cross-border migrants do so that they can stay on their HIV treatment, the support networks that they have and how this shapes their sense of belonging.

I would like to invite you to take part in this study as it will help us to explore the experiences of how cross-border migrants stay on HIV treatment in Johannesburg. I would like to ask you some questions and I would like you to answer based on your experience of working with *cross-border migrants* in this clinic *and the ways they use to access and to continue with HIV*

treatment in Johannesburg. South Africa has experienced a large number of cross border migrants than other countries in Africa.

Section 1: Identity

- Where do you live? How long have you been in Johannesburg?
- How old are you?
- What country are you from (*home country)*?
- What made you to come to South Africa? (*If non South African, Probe for how they came to South Africa and ended up in Johannesburg)*
- What is your marital status?
- Do you have colleagues who are not South Africans? (probe about how they met and how they interact with them when it comes to cross-border migrants on ART)
- What level of education have you completed?
- Are you here with your family (wife/husband and children)?

Section 2: staying on HIV treatment (ART)

- What do cross-border migrants do to access and to stay on HIV treatment?
- What perceptions of cross-border migrants do you have? (*probe about what led to those perceptions*).
- Are there specific challenges that cross-border migrants experience that the citizens do not experience when it comes to ways they use to stay on treatment? (*Probe about what is making them to face those challenges*).
- How do you understand the migration policy? (*probe about how they interpret the policy)*
- Have you ever turned people away for being a cross-border migrant? (probe about how it started and what made them to decide on the basis of cross-border migrant).
- Have you ever had any experiences of drug resistance with cross-border migrants (*probe about how they deal with the drug resistance when it is on cross-border and if it is different from how they deal with the citizens*).

Section 3: **Social support networks**

- How do you assist cross-border migrants to access support networks and are they accepted? (*Probe about what they do if they are accepted differently from the citizens*).

- Do you have any support groups specifically for cross-border migrants? (probe about how the support groups for cross-border migrants started and how it is going).

Section 4: belonging and the concept of home.

- Do you think having cross-border migrants in support groups make them to have a sense of belonging? (*probe about what is making him or her to say that*)

- **Thank you for answering our questions**
- **Is there anything you would like to ask me?**

Appendix G: Gauteng department of health approval letter

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Ms Sue le Roux
Tel: (011) 355 3583
20 July 2012

To: Chair of the Ethics Committee

REQUEST FOR PERMISION TO CONDUCT A RESEARCH STUDY IN CITY OF JOHANNESBURG HEALTH FACILITIES BY ROSELINE HWATI

The Gauteng Department of Health (GDH) received a request for permission to conduct a research study in City of Johannesburg health facilities from Roseline Hwati. The study is entitled "negotiating HIV treatment continuity after migration: exploring the experiences of HIV-positive cross-border migrants in the Johannesburg City". The department has completed a preliminary review of the proposal; however, the proposal has not been reviewed and endorsed for research ethics adherence.

Kindly review this proposal and provide ethical clearance before we can grant researcher permission to proceed with the study. GDH has not been accredited by NHREC as an ethics committee and therefore has no power to provide ethical clearance.

Once the research study proposal is cleared for ethics by your committee, we will then provide a formal approval to Roseline Hwati for this research study to proceed at the City of Johannesburg health facilities.

Yours sincerely
SUE LE ROUX

DIRECTOR: POLICY, PLANNING AND RESEARCH
DATE: 20/07/2012

1

Appendix H: City of Johannesburg approval letter

Joburg

a world class African city

ENQUIRIES
Tel
Fax
4th Floor
Metro Centre
Braamfontein
Fax

6 December 2012

Dear Ms. Hwati

APPROVAL TO CONDUCT RESEARCH WITHIN HEALTH IN THE CITY OF JOHANNESBURG

Permission has been granted to you to conduct research in the Health Department within the City of Johannesburg.

Topic: **Treatment Experiences of HIV+ Cross Border Migrants In Johannesburg: Staying on Treatment and Support Networks**

Please contact the following person(s) before you commence with your project and to gain access to the clinics:

Regional Health Manager: Region F: Mr. Oupa Montsioa
Tel. No.: 011 681 8130/082 467 9423

Should you have any queries please do not hesitate to contact our department.

We look forward to your Final Research Report.

Thank you

DR. R. BISMILLA
Executive Director
City of Johannesburg
Health Department

Appendix I: Medical ethics clearance form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Roseline Hwati

CLEARANCE CERTIFICATE **M121032**

PROJECT Treatment of Experiences of HIV Positive Cross-Broder Migrants in Johannesburg: Staying on Treatment, Support Networks and Belonging

INVESTIGATORS Ms Roseline Hwati.

DEPARTMENT African Centre for Migration & Society

DATE CONSIDERED 26/10/2012

DECISION OF THE COMMITTEE* Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 14/11/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Jo Veary

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix J: Department of health financial directive

DEPARTMENT OF HEALTH
DEPARTEMENT VAN GESONDHEID
Private Bag X828
PRETORIA, 0001
Republic of South Africa

UMNYANGO WEZEMPILO
LEFAPHA LA MAPHELO
Privaatsak X828
PRETORIA, 0001
Republiek van Suid-Afrika

Faks/Fax : (012) 312-0759
Telefoon/Telephone : (012) 312-0550
Navrae/Enquiry : Ms. U Le Roux/ x0550
Verw/Reference : BI 4/29 REFUG/ASYL 8 2007

APPROVED

REVENUE DIRECTIVE- REFUGEES/ ASYLUM SEEKERS WITH OR WITHOUT A PERMIT

To: PROVINCIAL HEALTH REVENUE MANAGERS
HIV/AIDS DIRECTORATES

19TH SEPTEMBER 2007

Dear All

HOSPITAL FEES: ASSESSMENT OF REFUGEE / ASYLUM-SEEKERS (with or without a permit)

Preamble

REFUGEE ACT, Act No. 130 of 1998 (Chapter 5; Section27, (g))

RIGHTS AND OBLIGATIONS OF REFUGEES (Protection and general rights of refugees)
27. A refugee-
(g) Is entitled to the same basic health services and basic primary education which the inhabitants of the Republic receive from time to time.

To avoid contravening patients rights, as precepts to the Constitution (section 27 (3)) and the Refugee Act: **Act No. 130 of 1998 (Chapter 5; Section27, (g))**

1. **Where refugee status have been determined or asylum seekers with or without a permit:**

1.1. Basic Health Care:

1.1.1 Refugees / asylum seekers **with or without a** permit that do access public health care shall be assessed according to the current MEANS test. (as specified in the Annexure H).

Join the Partnership Against AIDS – Our Actions Count

1.2. Anti-retroviral treatment (ART)

1.2.1 Refugees / asylum seekers **with or without a** permit that do access public health care, shall be exempted from paying for ART services irrespective of the site or level of institution where these services are rendered. ***(Please refer to the ART directive: BI/429/ART dated the 20th April 2007).***

2. Full paying patients:

2.1 The following full-paying patients are excluded from free services (basic Health Care and ART) irrespective of the level of care where the service is being rendered:

2.1.1. Refugees / asylum seekers whose income **exceeds** the prevailing means test shall be levied at the full paying UPFS.

2.1.2. Externally funded patients, including members of medical schemes registered in terms of the Medical Schemes Act, 1998 (ACT No. 131 of 1998).

2.1.3. Externally funded patients whose medical schemes **are not recognised** within the RSA scheme pool shall be charged as full paying patients (Self Funded), unless prior arrangements have been made.

2.1.4. Patients treated on account of other state departments, e.g. Compensation Commissioner (COID), SA Police Services, Department of Correctional Services.

2.1.5. Patients treated in state facilities by their **private medical practitioner.**

NB: The execution of this directive is with immediate effect.

Your co-operation would be appreciated.

MR. FG MULLER

CHIEF FINANCIAL OFFICER (CFO) (NDOH)

APPROVED

Join the Partnership Against AIDS – Our Actions Count